INTO THE MYSTIC

Bereaved parents, love and spontaneous creativity

Greg Roberts BSW Hons

Submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

Deakin University

June, 2015
DEAKIN UNIVERSITY
CANDIDATE DECLARATION

I certify the following about the thesis entitled (10 word maximum)

Into the Mystic: Bereaved Parents, Love and Spontaneous Creativity

submitted for the degree of  - Doctor of Philosophy

a. I am the creator of all or part of the whole work(s) (including content and layout) and that where reference is made to the work of others, due acknowledgment is given.

b. The work(s) are not in any way a violation or infringement of any copyright, trademark, patent, or other rights whatsoever of any person.

c. That if the work(s) have been commissioned, sponsored or supported by any organisation, I have fulfilled all of the obligations required by such contract or agreement.

I also certify that any material in the thesis which has been accepted for a degree or diploma by any university or institution is identified in the text.

'I certify that I am the student named below and that the information provided in the form is correct'

Full Name: Greg Roberts

Signed: [Signature Redacted by Library]

Date: 30th June 2015
Acknowledgements

Heartfelt thanks to Deborah, Carol, Kate, Craig, Tracey, Philip, Jasper, Judy and their children and families for sharing your stories with me so that I (alongside you) could research this topic. Your generosity and patience throughout the process is humbling for me. My hope is that this thesis is now another part of your story and a connection to your children.

To Jeanette, Madeleine and Dylan, this thesis could only happen because you are part of my life and I thank you from the depths of my being for creating a space and place for this project that has been part of our lives for so long. Your support, inspiration, challenges and love have sustained me and allowed me to do what I do.

Sincere appreciation to all of the organisations and their staff who helped distribute notices about my research to bereaved parents and who supported the idea of what I was hoping to achieve. To all the bereaved parents who contacted me or talked with me about this research project – you have contributed much to the final thesis and encouraged me to go on.

For my friends, colleagues, writers, teachers, students and fellow travelers who over the time I’ve been working on this research have offered conversation, questions, support and insights that have shaped me and my writing of the thesis – many thanks to you all.

This thesis has required the supportive and critical supervision of several people over the eight years and I am very thankful for each piece of guidance and support offered. There were many challenges and changes, but all were necessary and are valued. My thanks to Dr Heather D’T Cruz, Dr Anna McGarvey and Dr Struan Jacobs for guiding and shaping the first few years of work. My gratitude and appreciation to Professor Bob Pease and Dr Selma Macfarlane for supporting me through difficult times and guiding me through to completion and submission of the thesis.

To dear Madeleine, the little girl who taught me to love more, fear less and create.
# Table of Contents

Acknowledgements ......................................................................................... 2
Abstract ........................................................................................................... 8
An introduction: .............................................................................................. 10
The researcher, the writer and the topic .................................................. 10
Part 1 – Sailing into the mystic .................................................................. 13
  Chapter One – Reasons and writing .................................................. 13
    Research beyond the self and towards others ....................................... 13
    A perspective on my self: A journey, a quilt and a thesis .................... 15
    Sign posts for the reader: A thesis as a patchwork quilt .................... 17
    Being a bricoleur and craftsperson ....................................................... 18
    A design for the quilt: How the overall thesis looks ......................... 20
    What is this quilt about? Levels of curiosity and approaching the topic ... 23
    Centrality of stories .................................................................................. 26
    Point of departure: an alternative reading of the thesis .................... 28

Chapter Two - My experience .................................................................. 29
  Morning and mourning ........................................................................... 32
  Considering the experience of having a child die ................................. 33
  An experience that most parents are not prepared for ....................... 35
  Considerations for professionals and researchers in working with
  bereaved parents ......................................................................................... 38

Chapter Three – Moving towards the phenomena ............................... 42
  Introduction to the stories of bereaved parents .................................. 42
  Life Moves On: Grief, survival and transformation. Mish Cooray’s story .... 42
  The constant gardener. Wendy Whitely’s story .................................... 43
  Finding participants .................................................................................... 44
  Point of Departure: an alternative reading of the thesis .................... 47

The interviews .................................................................................................. 49
A final poetic listening and representation ............................................. 53
Personal Perspective ...................................................................................... 54

Part 2 – In the heart of the mystic ............................................................ 55

Chapter Four - Finding ways to connect .............................................. 55
  The quilt-maker and the solid powerful something: A short methods
  fable ............................................................................................................ 55
  Stories of love, death, loss, longing: Finding a place for love ................ 57
  About the co-constructed stories ......................................................... 58

Chapter Five - Deepest feelings find a path through creativity – Deborah’s story ..................................................... 61
Chapter Ten - Steffie’s Gift – Philip’s story.........................145
  Introduction - 2009.................................................................145
  The scene of the conversation - Later in 2009 – Greg’s perspective 145
  The conversation - Philip’s story........................................146
  A dream into reality.............................................................148
  More than memories...........................................................151
  A place of connection..........................................................152
  Changing direction..............................................................153
  2014 – Philip’s reflection after reading the story .......................157
  January 2015 – Greg’s creative synthesis of Philip’s story........160

Chapter Eleven - Trees by the river – Jasper’s story..........164
  Introduction - 2009.................................................................164
  The scene of the conversation - Later in 2009 – Greg’s perspective 165
  The conversation – Jasper’s story.........................................166
  Changing horror into a place to be together..........................167
  Breaking the silence.............................................................168
  Familiar but very different..................................................169
  A connection in nature........................................................171
  2015 – Jasper’s reflection after reading the story .......................172
  January 2015 – Greg’s creative synthesis of Jasper’s story.......174

Chapter Twelve - Making some good come of it – Judy’s story..........................................................181
  Introduction - 2009.................................................................181
  The scene of the conversation - Later in 2009 – Greg’s perspective 183
  The conversation - Judy’s story.............................................184
  The pieces coming together..................................................186
  Something to hold and carry...............................................187
  Hand to heart.................................................................187
  It doesn’t end.........................................................................190
  2014 – Judy’s reflection after reading story.............................191
  January 2015 - Greg’s creative synthesis of Judy’s Story........193

Part 3 – The mystic and meaning.................................197

Chapter Thirteen – Epistemology.................................198
  Approaching the research design.....................................198
  Finding a background for the quilt.................................200
Existentialism .......................................................... 200
Personal perspective on existential concepts ...................... 202
Phenomenology .......................................................... 203
Postmodernism ................................................................ 205
Personal perspective: Taoism .............................................. 207
Situating the research in a qualitative paradigm .................... 209

Chapter Fourteen – Methodology leading to methods........... 211
Interpretive Interactionism: A starting point ....................... 211
Heuristic phenomenology ............................................... 211
Autoethnography .......................................................... 212
Hybrid-creative methodology .......................................... 213
A pleated text .................................................................. 214
Arts-based and participatory methods .................................. 214
Heuristic phenomenology that is creatively hybridised ........... 216

Point of Return – Alternative reading of thesis .................... 218

Chapter Fifteen - Methods............................................... 219
Finding the phenomena: Identifying with the focus of the enquiry and my initial engagement with the research ....................... 219
Engagement with participants ............................................ 220
Self-dialogue and immersion in the phenomena and experience .............................................................................. 221
Moving into the interviews ................................................ 222
The interviews .................................................................... 223
Incubation ......................................................................... 224
The listening guide ........................................................... 225
Finding the plotline ............................................................ 226
I poems .............................................................................. 227
The elements of life: A personal perspective ....................... 229
Drawing on elemental theory .............................................. 229
An elemental grief scale .................................................... 231
Elements become voices to be heard: Merging of methods ...................................................................................... 233
Tacit knowing, focusing, indwelling and intuition in an effort to illuminate and explicate the phenomena ...................... 235
Focusing ............................................................................ 237
Bringing the pieces together to form stories with verisimilitude ........................................................................... 240
Co-constructed narratives ............................................... 241
Participatory research ....................................................... 243
Creative synthesis: Creating an essence of each person’s story – poetic knowing .......................................................... 244

Point of Return – Alternative reading of thesis .................... 247

Chapter Sixteen – Bringing the stories to the literature........ 248
Blending the emergent understandings from the research with existing understandings in the field ........................................... 248
Grief: Pondered and theorised .......................................... 248
Ideas that attempt to explain grief and bereavement ............ 249
Abstract

Parents commonly experience a child’s death as a time of agonizing despair, intense loneliness, confusion, guilt, bitterness and significant changes to psycho-biological functioning (Raphael 2006; Stebbins & Batrouney 2007; Dyregrov & Dyregrov 2008). After the death of a child, parents not only need to re-negotiate a changed relationship to that child (Klass, Silverman & Nickman 1996), but also struggle to find ways to express feelings of love for the child (Jeffreys 2011). Parents are left to find ways to continue to love the child without him or her being physically present (Walter 1996) amid fear that their connection to the child will be lost.

Much attention in the field of bereavement counselling is given to helping people learn to live with their loss (Worden 2002; Dyregrov & Dyregrov 2008; Attig 2011). What then of learning to live with a deep love for a child who has died, when the love itself has not gone? There is a need to also understand how we can, potentially, facilitate (or inadvertently stifle) the spontaneous and often intuitive processes, which may lead to a functioning, lovingly expressed relationship between a parent and a dead child (Howarth 2000).

Drawing on existential, narrative and arts-based theoretical concepts, this thesis explores the phenomena of bereaved parents’ spontaneous creativity in relationship to a child who has died. Using heuristic phenomenology as a key methodological referent alongside arts-based and participatory methods, the research engages a multi-faceted dialogue between the researcher, eight bereaved parents and the reader in order to bring an open-ended and multi-layered understanding to the phenomena.

The research offers the inter-subjective understanding that the spontaneous creative activities of these bereaved parents appear to have been born from intense feelings of love for the child leading to intuitive experimentation (Heaton 2002) around ‘doing’ something in relationship with the child while expressing love for the child in a tangible and living way. The research shows that key features of these activities are
that they become personally held, reliable, symbolic ways of expressing feelings of love and connection to the deceased child. In a broader sense, the research indicates that many responses to death and loss are in fact expressions of love and care, seeking a reliable pathway towards what is absent, alongside expressions of fear seeking a pathway towards safety when life, as it once was, has dramatically changed. The learnings from this research suggest that those who support or engage with bereaved parents turn their attention to expressions of love and fear in the face of grief and loss in order to move beyond ideas of simply alleviating distress and discomfort.
An introduction:

The researcher, the writer and the topic

Grief can be messy, surprising, confusing, deeply personal, upsetting, debilitating, transformative and mystical. Grief is experienced in widely varying ways by different people. Grief is multi-faceted and multi-dimensional (Attig 2011). This thesis is a creative process where I bring my own facets of experience relating to grief/life and apply this to researching and writing about bereaved parents’ experiences of spontaneous creativity following the death of a child. Through my engagement with eight bereaved parents who participated in the research process with me, I also incorporate the facets of their experience. I imagine those who read this thesis will likewise bring their multi-faceted experiences to the reading.

I’m Greg, a man in my early fifties living in rural Victoria, Australia. I am the father of a daughter (who died) and a son. My partner and I also experienced three pregnancies that ended too early. Over the past eighteen years, I have worked in a range of roles within the health and community services sector. Prior to that, I worked as a massage therapist and for the first fifteen years of my working life I was a potter, immersed in arts, crafts and Eastern philosophies. I have also practiced and taught Tai Chi for over thirty years, continually learning about the body and awareness of self.

My paid employment for the past fourteen years has been as a grief and loss counsellor and educator with an honours degree in social work that is combined with the study and application of existential philosophy. I have been engaged with the writing of this thesis on a part-time basis over an eight year period. I have an interest in exploring and understanding more about the grief experiences for people who have had a child die as well as the grief experience for any person. I find myself constantly reflecting on the ways in which researchers, academics, social workers, psychologists, therapists and counsellors engage with and offer support to people who are grieving.
Through experience in my work as a bereavement counsellor, and from anecdotes in articles, books and personal stories, I noticed that bereaved parents often engaged in doing a range of things after the death of a child, be it writing, artwork, construction, music, gardening or lifestyle changes, to name just a few. I viewed these things as being creative in the sense that they bring something new into existence. I noticed that many of these activities or processes are less likely to come from pre-planned cognitive thought patterns or suggestions from other people. Very often, the activities appeared to emerge as spontaneous individual responses in each parent following the death of their child. I heard some parents describe this spontaneous response as being driven by intuition, yearning or just an internally held knowing, that came from their relationship to the child who had died.

The more I encountered this phenomena, the more I felt a growing awareness of how very important these spontaneously driven activities were in assisting families to make sense or meaning out of the experience of having a child die, regardless of whether that child was an infant, teenager or adult child. I became interested in exploring and clarifying the significance of these moments or processes within the context of grief following the death of a child through the writing of a thesis. For both professional and personal reasons, I sought a deeper, richer, more personally held, knowledge and understanding that relates to bereaved parents’ experiences of what I think of as spontaneous creativity that brings something new into existence through the relationship between a parent and a child who has died. This thesis seeks to provide an in-depth exploration and understanding of these experiences.

I am passionate about the topic and it would be a falsehood for me to research and write in a dispassionate way. I have strong leanings towards existentialism, phenomenology, post-modernism and arts-based processes and this will be apparent throughout. I have embraced the idea of the thesis being a ‘messy text’ marked by its open-endedness, incompleteness and my uncertainty about how and if, it will draw to a close (Marcus 1994; Heaton 2002). The reader is invited to bring their individual understanding to the topic, participate in and experience the research, while reading it
(Marcus 1994 p567). The artist in me wants to engage the reader in the topic in varied ways and so I hope that some of what is presented, and read, moves beyond the intellect to embrace emotions, physicality, spirituality and awareness of environmental and social experiences.

I have included aspects of my story and experiences because I see myself as a ‘text’ that I need to review and reflect upon (Ellis & Bochner 2000). While I see my own experience as part of the research process, I also hope that this will allow the reader to see some of what has influenced my thinking and position in relation to the topic.

Speaking in a more direct way, I would like to invite you, as the reader, to approach this piece of work as you would a performance, a piece of art, music or a sculpture, while also considering the scholarly aspects of what is essentially a creative-knowledge-building project. To this end the contents pages are deliberately detailed so that the thesis can be navigated in a non-linear way, allowing the choice to move between sections and chapters freely. There are some sign-posts in the text in bold type titled ‘Points of departure’ and these provide suggestions for an alternative sequence for reading the thesis with an indication of what might make this useful to some readers. You are encouraged to circle around what I’ve written, look at it from different angles, focus on specific areas, ignore others, take second glances at what I present and consider what it means to you, rather than just accept my interpretations. I respectfully invite your participation in exploring the topic with myself and the participants – who as co-researchers contributed so much to what you will read.
Part 1 – Sailing into the mystic

Chapter One – Reasons and writing

Research beyond the self and towards others

The experience of having a child die and then living with their absence brings a particular form of grief and like other forms of grief it is uniquely felt, experienced and thought about by each individual (Wheeler 2001). Therefore, any description of experiences associated with the death of a child will be quite personal, subjective and dependent on the overall life experiences of the person offering the description. It is supported in the current literature relevant to the death of a child that the presentation and sharing of individual and subjective experiences in storied or other forms, can resonate with, make connections to, or assist in attempts to understand the experiences of bereaved parents (Stroebe, Schut & Finkenauer 2013). In order to introduce the reader to these ideas, I have explored relevant literature in the following chapter. The inter-subjective understanding that emerges from engaging with the stories of bereaved parents can be helpful in supporting others with similar experiences (what might be termed the application of subjectively acquired collective understanding). Private and individual experiences and descriptions of them, can broaden and deepen the public and collective understandings of human experience life experiences, such as the death of a child. Therefore individual and subjective stories have a relationship to public and collective knowledge building (Denzin 1989).

My research offers expression, reflection, engagement with and exploration of the inter-subjective and individual experiences of bereaved parents, including myself, who have engaged in spontaneous activities after the death of a child. In doing this, what is shared may resonate with and expand the collective and public
understandings of what bereaved parents do after the death of a child, including what these spontaneous activities mean for them as they live with their grief.

Through exploring this topic, ideas have emerged that can enhance and expand upon the way in which support options are offered to child-bereaved parents with particular regard for including the deceased child as part of the parent’s ongoing life. Understanding more about spontaneous creative activities and the place they hold within grief and bereavement, in this case after the death of a child, can add to the ways in which people approach grief and bereavement exposing wider options for the building of resilience in child-bereaved families and perhaps other forms of bereavement (Ritchie 2003, 2007). The research engages with a spectrum of human experiences within differing contexts around the death of a child and hopes to contribute to a broadening of knowledge and the way research is conducted in this particular topic area.

I wanted to write and research in a way that highlights inter-subjectivity, or movement between the subjective and the collective, while producing a thesis that had a sense of congruence with the topic itself. In doing this, I grappled with the many possible ways to present a thesis of this nature. From the beginning, words and concepts like spontaneous, emergent, creative, intuitive, subjective, relationship, exploratory, unknown, individual, mystical and non-linear, all came through for me as very important. While exploring these concepts, I became strongly drawn to heuristic phenomenology (Moustakas 1990) as well as emergent and contemporary methods of writing and presenting research (Hesse-Biber & Leavy 2006; Taylor & Wallace 2007; Liamputtong & Rumbold 2008; Ellingson 2009; Denzin & Lincoln 2011; Chilton & Leavy 2014). These referents offered ideas and methods that could accommodate and allow for the presence of the concepts mentioned above in a way that I felt comfortable with.

I have adopted and adapted ideas from these research methods and so the writing style and presentation is a little less linear than what might be found in a more
traditional thesis. As I progressed with exploring the emergent, contemporary methods of conducting, writing and presenting research I found they complimented the existential, phenomenological and arts-informed approaches that I had been drawn to. Putting them together as a hybrid methodology had a high level of congruence with my experiences of the subject matter and would allow a multifaceted view of the phenomena (Ellingson 2009). With subject matter that felt free flowing, non-linear and subjective, I found myself increasingly feeling a sense of incongruence, stagnance and stricture when I considered more structured and positivist approaches to thesis writing. I don’t assume that structured and more positivist approaches are not useful, but for me they feel less congruent with this particular topic.

The epistemology and methodology for the thesis, which is explored more fully in part three, have a relationship with an existential and phenomenological understanding of life that underpins my own personal and professional way of being in the world. I see a particular congruence between my worldview as a person, the way in which I am choosing to do the research and the topic itself. Death, grief and bereavement, particularly in relation to the death of a child, are said to create an ‘existential crisis’ for people (Raphael 2006; Stebbins & Batrouney 2007; Stroebe, Schut & Finkenauer 2013) and so bringing my own existential worldview to meet the existential themes inherent in the topic, brings a sense of honesty, verisimilitude and plausibility to the research (Taylor & Wallace 2007).

**A perspective on my self: A journey, a quilt and a thesis**

December 21st 2014.

Driving on a narrow country road, from the wide expanses of the western plains in south-west Victoria (Australia) into the more densely treed bush-land and hills of the central highlands, Greg is thinking about the writing of his thesis. It’s coming into the last months of bringing everything together and he wants it to form some sort of cohesive whole. Many thoughts whirl around his mind, based on past ideas he’s had with flickers of expectations from others about what is required of a thesis. But
today, it’s like something is just sitting there within himself, indistinct, yet feeling
significant. He recognises the need to create a space for this something to present
itself. Drawing on the embodied knowledge of Tai Chi and mindfulness and bringing
in a more recent discovery related to the art of focusing (Gendlin 1981), he pauses his
racing thoughts through bringing awareness to his body and the road ahead. He
notices his breathing and keeps attention on his immediate surroundings. Greg feels
his body and mind settle. So then he waits.

A sensation pushes up from his gut and it seems to speak to his waiting brain. The
something he feels bubbles up to form words – ‘Life is made up of pieces’. The
words seem calm yet forceful and wanting to be heard. Something inside Greg says:
“Get this down and pay attention”. He knows not to ignore these moments. He pulls
over and switches on the voice recorder of his mobile phone and records those words.
“Life is made up of pieces”. He sits and lets feelings wash over him……….?option…….

More sensations, images and words flow forward. He speaks them into the recorder,
capturing the words as they arrive –

“Life is never completely whole, we are made up of pieces. We are often trying to
keep those pieces together. It’s like a large patchwork quilt.”

Greg’s time travels within himself to an experience of just over eight years ago with a
group of bereaved parents. He can picture the tiny church hall in a small country
town. Bereaved parents arriving with their individual patches made of cloth. Each
patch has pictures, writing, beads, trinkets and hand-sewn decorations that express
something about a child who has died and what that child symbolises to that parent
and in some cases the whole family. They have all come together to spend an
afternoon to consider how to put all these patches together so that they form a quilt.
When finished, the quilt will be displayed for public viewing. As a bereavement
counsellor to most of these parents, Greg recalls being active in supporting the idea
of a memorial quilt for rural bereaved parents. At the time, the other bereaved
parents insisted that he too should create a patch for this quilt. And so he did.
Greg’s thoughts come back to the present moment. Sitting in his car, with a voice recorder turned on, he sits, reconnects to the thoughts and feelings of ‘Life is made up of pieces’ and ‘It’s a bit like a large patchwork quilt’. With some time set aside and space made, more feelings and words bubble upwards and out of his mouth to be captured on the voice recorder – ‘We experience these pieces of life through all our senses and they become part of ourselves, forming part of who we are and how we see the world.

Hmmm…… Greg thinks of a patchwork quilt and thinks of all the years working on his thesis - ‘There are so many pieces to try and piece together’. He remembers the idea of being a bricoleur. A bricoleur uses what falls to hand and whatever they can find, in order to create a montage, piece of art, essay, jazz music or a quilt. (Denzin & Lincoln 2011). Working like a craftsperson, diverse and interesting materials and ideas are used to produce a depiction, a representation or a patchwork quilt that says something about a research question (Taylor & Wallace 2007; Denzin & Lincoln 2011).

As he sits by the roadside letting these thoughts and experiences wash over him, it becomes obvious……. This is the metaphor that he can articulate his thesis with – A patchwork quilt with himself as the bricoleur or craftsperson, working with participants who contribute their own handwork of personal stories, for the main motif on the quilt. The metaphor has been used before, by other qualitative researchers (Ellingson 2009; Denzin & Lincoln 2011) but that’s OK and kind of comforting – like a quilt!

**Sign posts for the reader: A thesis as a patchwork quilt**

When people are grieving, it’s helpful for them to be offered information about the landscape they are entering, such as having knowledge about common responses to death and loss, what they might expect, what can be helpful and so on (Dyregrov & Dyregrov 2008). Guiding ideas, signposts and maps can be useful when you are navigating something different. It seems important to give some signposts and
information to the reader of my thesis, offering some sense of what it is being presented on the page and where to look for more information if there is uncertainty about what is being presented. I can see the possibility of questions arising for the reader about the intention behind how the content is pieced together. For instance, in these first few paragraphs, a shifting between first person and third person voice—used, to create depth, breadth, sense of time and a connection to spontaneity (Richardson 1992). Part of me would like to just let the reader explore and follow their own way of engaging with my thesis because this seems consistent with the ideas of spontaneity and emergent experiences. But I’ve accepted that this might be disconcerting for some people and it could be confusing and distract from the content. So I want to give some guidance while leaving a sense of openness to the text and how it is engaged with.

I want to follow on from the idea of using the metaphor of the thesis as a patchwork quilt. Through this metaphor, I see myself as the craftsperson creating the quilt, placing the different patches that are on the quilt, exploring the positioning of the patches and what is needed around them. As with any quilt, there is also attention to the material from which it is made, as this is both underneath and around the patches holding them in place and framing them (Ellingson 2009).

**Being a bricoleur and craftsperson**

Drawing on the ideas of Denzin and Lincoln (2008 b p. 5), I see myself as an interpretive bricoleur, using “a pieced together set of representations that are fitted to the specifics of a complex situation”. In line with this concept, I have needed “to invent or piece together new tools and techniques” and my “choices regarding which interpretive practices to employ were not necessarily made in advance” (Denzin & Lincoln 2008 b p. 5). Much like a craftsperson working with raw materials to make a quilt, the process of writing has been an emergent construction that has developed over time based on what has presented itself, what has come to mind and what has come to hand while engaging with the topic (Weintein & Weinstein 1991). A bricoleur creates what is termed a bricolage (Kincheloe, McLaren & Steinberg 2011).
where the researcher works with, reflects, respects and presents some of the complexity of the living world which is constantly changing. In this piece of research the bricolage is symbolised through the metaphor of a quilt.

In creating a quilt (or bricolage) as a bricoleur, I am taking on the role of methodological negotiator, bringing flexible and elastic ways of working with the experiences of others in order to piece together a final representation that reflects and respects the complex and highly individual lived experiences that are being shared. Each part of this quilt is pieced together with an awareness that each aspect of the quilt, including the whole finished quilt, has a relationship to the topic itself being designed to illustrate something about the topic (Ellingson 2009). My intention is to invite the reader to consider various aspects of the phenomena I am exploring through not only reading the thesis, but also through emotional engagement with both the content and the style of writing/presentation, which deliberately moves and shifts in an attempt to both ‘show and tell’ (Ellis, Adams & Bochner 2011) about the experiences of grief and spontaneous creativity.

In order to move closer to the experiences described by the participants, I spent a lot of time immersed in their stories and made efforts to keep in touch with them as I started to craft together their words with my sense of the story they had told me. Several participants made their own changes and additions to the final drafts of their own stories in keeping with the participatory nature of the thesis. Through use of phenomenological and existential referents, my idea was to move closer to the essence of the phenomena being explored through attention to individual experiences of bereaved parents and the inter-subjective meanings held and emerging for them (Moran & Mooney 2002).

Because the writing of the thesis has been a collaborative process, it felt important to consider the potential readability for those that might be interested, such as parents affected by the death of a child, particularly the participants. I also was aware of needing to focus on producing a thesis that is relevant and useful as a piece of
research for practicing professionals and other researchers. Patricia Leavy (2014) suggests that it is imperative for dissertations and research to move beyond academic scholarship into the realm of public scholarship, calling for them to be written in a way that has higher levels of accessibility and readability for any person who may have an interest in the particular research topic. For these reasons, I’ve decided to write in a more personal style, addressing the reader in a more direct way, seeking to avoid a sense of detachment from the material and encouraging a sense of being part of a conversation about a topic that is full of personally understood experiences and meanings.

I feel it is important to encourage a closer and dialogical engagement with these human experiences of grief after the death of a child and the spontaneous creative activities that bereaved parents engage in, because I have noticed that a significant amount of the existing literature is written in a more detached and less dialogical style. Once again, using the metaphor of the quilt, I would like the quilt to be picked up, looked at, touched and experienced, rather than it be something that simply hangs on a wall and looked at from a detached perspective (Ellingson 2009; Leavy 2014). By using the metaphor of a crafts-person making a patchwork quilt, I have chosen to integrate “different voices, different perspectives, points of view and angles of vision”, creating a space and invitation for “give and take between myself, the participants and the reader”, encouraging greater engagement with the material (Denzin & Lincoln 2008 b p. 7). In seeing the thesis as a quilt, I want the quilt to be interesting, engaging and connected to the reality of life.

A design for the quilt: How the overall thesis looks
I want to move into talking about the design and structure of this thesis - the placement of patches on this patchwork quilt. The final design emerged in the last six months of writing as I continued to experiment with the placement of materials that had been collected over the course of the research. There are three parts, somewhat like a quilt that is divided into three fields, each with a different background colour. Like this –
The centrally placed patch of part two gives primacy to the phenomena being explored. The co-constructed stories of the bereaved parents who participated in the research are located here - a deliberate placement of this rich material at the centre, or heart of the thesis. This large central patch on the quilt is made up of eight different sized and individual patches, representing the eight different stories of the participants. A little like this:

Around and through this central patch of participant stories, will be my own hand-stitching. The metaphor of hand-stitching represents my influence and role as the interviewer and researcher, including how I worked with and crafted the participant stories. I have also stitched into and around the participant stories my perspective of relating to the participant stories and my own sense of meaning and significance in relation to the things participants describe – at a personal, professional and research
level. Stitched into this section are eight patches of poetic writing that are my own creative synthesis of what emerged as significant to me within each participant story.

The thesis is collaboratively co-constructed, with the participant stories influencing much of what is written. Polkinghorne (1988) and Denzin and Lincoln (2008 b) suggest that all narratives are co-constructed or pieced together from our interactions with others and from our-‘selves’ who retain and bring forth previous life experiences to be co-constructed with our current experiences. Therefore, none of the patches in this quilt are entirely of my own construction nor entirely the construction of the parent who told the story in an interview and through other interactions. These patches contain materials from bereaved parents that are co-constructed through my engagement with them to form a sense of a whole story that relates to the topic. In part three there is further exploration of the concept of co-constructed narratives and the collaborative, participatory approach applied in the methodology.

Around the central patch of part two is part one and part three. Part one is intended to frame, draw attention to and sit in relationship to the larger central patch. Placed here is the introduction with an outline of the structure (some of which you have already read and are reading now), some pointers to my approach for the thesis, my research questions, some examples of the phenomena I am exploring, material from the current grief, trauma and bereavement literature that relates specifically to parents experiences of the death of a child and finally a brief outline of how I recruited and engaged with the participants. This material will be engaged with in a way that moves towards the central focus of the participant stories.

The third part will elaborate on the process of doing the research itself and include the epistemology, methodology, methods and a consideration of current literature in the general field of grief, bereavement in order to highlight what has emerged from the research against current thinking in the field. I will then consider my own theory building that has occurred over the course of the research in relation to the topic. Then I will conclude with my emergent meanings and understandings gained through
the research process and consider implications of these along with consideration of potential areas for future research.

In bringing together this quilt I am also aware of the relational aspect of the research project where I connect with the participants to build knowledge around the phenomena being explored in order to share and reflect on this with others in the world. I’ve come to realise that the research process is an endless interaction or relationship between four important areas. I offer the following diagram to show the inter-related aspects of the quilt, which are present in each part of the thesis.

![Diagram of quilt demonstrating inter-related aspects of research process]

**What is this quilt about? Levels of curiosity and approaching the topic**

I knew that I wanted to explore this topic in detail and then decided to do this through writing a thesis (make my patchwork quilt) about the topic. I had people ask me: “What are your research questions?” Early on, I found that difficult to articulate in any succinct form. I felt I just wanted to explore the topic and see what came forward. Then some time into the research, before I interviewed participants, it emerged for me with more clarity what it was that I was curious about in relation to the topic. So below are what have become my questions that have sat with me and kept me curious while I worked on my patchwork quilt. These questions were held in mind while I was interviewing participants and although I may not have asked these
specific questions my prompts and responses while talking with participants held a sense of what I was curious about.

**Primary question:**
What is the personally held significance of spontaneous creative activity in relationship to a child who has died and in what ways are these creative activities experienced as significant, over time, in allowing bereaved family members to grieve and maintain a symbolic connection with their deceased child?

**Other questions:**
- How do these activities influence the grieving process of bereaved parents in making sense of or finding meaning in, the experience of having a child die?
- What are the implications of this thesis for researchers, professionals or others who have contact with or support/assist parents after the death of a child?
- How can the subjective-intersubjective knowledge of these activities and experiences, generated through this research, inform future research and practice in the field of grief, bereavement and trauma?

Having found the questions that kept me curious, I wanted to engage with these questions in a way that highlighted bereaved parents’ experiences of the phenomena (spontaneous creativity after the death of a child). My sense was that this would offer a greater depth of understanding about the phenomena itself and bring forward any associated meanings for bereaved parents. As I began my research, I couldn’t articulate this very well, but I felt it was important that I use knowledge from lived experience in order to understand the topic. Re-connecting to units of philosophy taken as an undergraduate and then engaging in courses on the theory and practice of existential phenomenology, a door opened onto a way of knowing that fitted what I had simply felt was an important part of the methodology for my research.
Emerging from the ideas of Husserl (1859 -1938), phenomenology is an approach that focuses on the experience and observance of phenomenon as a means to elucidate the subject into consciousness. An added dimension presented itself with my discovery of heuristic phenomenology (Moustakas 1990). The heuristic phenomenological stance requires the questioning of what we have and what we think we know in order to emerge with something different, much as the artist, craftsperson or bricoleur takes a subject or materials and fashions it in order to emerge with something different or new (Moustakas 1990).

I made a conscious decision to not place large amounts of theoretical ideas before the presentation of the stories and phenomena. I did this in response to the existential idea of experiencing before objectifying. This then relates to the lived experience of spontaneous creative activity following the death of a child where bereaved parents often engage in these activities prior to understanding what this might mean for them. There is then another parallel with the research process that has led me from the experiences themselves to understanding what some of these experiences might mean. In an effort to have the thesis resonate with and reflect the subject matter itself I have structured and written the thesis in a way that invites the reader to consider the lived experience of grief, bereavement and spontaneous creativity following the death of a child before engaging in material that may tend toward building expectations or objectification around the topic. In this way, the thesis has an overall aesthetic quality that in itself says something about the experiences that are talked about.

With respect to the experience of grief, which is not a linear experience, this thesis does not always follow a linear path. The literature review for example is presented in different ways in different parts of the thesis, which for me reflects the experience of grief where some individuals might engage with information early in their grief only to return to that information at a later time looking for something different from a position of a changed perspective. In part one I explore the literature relating to grief and the death of a child in order to consider the experiences of parents who have had a child die before moving into the stories of the participants in part two. Then in
part three I consider the literature relating to grief and bereavement in general in order to consider the broader context of my own theory building as it has emerged from my engagement with the experiences and stories of the participants.

The structural choice of placing my own story and the stories of participants before significant amounts of theory, methodology and methods came because I wanted the reader to simply experience the stories as they are presented, inviting a potentially spontaneous and creative engagement with the stories themselves. These stories represent my experience of and engagement with, both the topic and the participants. I have worked to respect and maintain a sense of the individual voices in the stories, while also using creative prose and poetry to capture a sense of collective experiences.

**Centrality of stories**
It seemed clear to me that the medium which carried the phenomena I’m exploring (the experiences of bereaved parents and their spontaneous creativity after the death of a child) was stories. It is through stories that I came to know of the phenomena and it is through stories that I have been able to sit within and engage with the phenomena. Finally, it is through stories that I seek to understand more about the phenomena, consider my questions about the phenomena and share my re-searching of this with others, such as readers of this thesis. Arthur Bochner and Nicholas Riggs (2014 p2) state that:

“The human condition is largely a narrative condition. Storytelling is the means by which we represent our experiences to ourselves and to others; it is how we communicate and make sense of our lives; it is how we fill our lives with meaning. To study persons is to study beings existing in narrative and socially constituted by stories. From bedtime stories to life reviews—across the span of our lives—we listen to stories and tell stories of our own.”

I find Thomas Attig’s (2011) ideas, theory building and approach to the topic of grief and bereavement enlightening and relevant to my thesis, with his idea of stories being
a central focus for understanding human experiences related to grief and loss. Much of Thomas Attig’s (2011) work is focused on understanding the lived experience of those who are bereaved and how their individual stories can provide us with greater insights into the nature of grief and bereavement in general. Attig suggests that while many of the theorists in the field of grief and bereavement have provided useful information about the nature of grief and loss, many theorists have ignored the individual stories and lived experiences of those who are living with grief.

Because grief and bereavement is acknowledged as such an individual experience, Attig (2011 p. 6) suggests that the stories and experiences of the bereaved are the “heart of the matter” in researching and understanding grief and bereavement more fully. Attig suggests that generalized theories and models around grief are only useful when and if they speak to or resonate with individuals and their life stories when living with grief. Attig calls for an approach that reflects, provides insight into and helps us understand the stories and lived experiences of the bereaved. So obviously, it was preferable to have bereaved parents as participants work with me on the research and offer their stories of their lived experiences as a source of knowledge and as a pathway to understanding more about what they experienced and did after their child or children had died. I bring together the stories of the participants along with my own experiences and stories as a way to explore the phenomena and re-search the topic.

The stories presented in this research are a form of artful enquiry applying literary, dramatic, and poetic forms of writing in order to create the effect of reality, a convincing likeness of life as it was sensed, felt, and lived. I’m less concerned with knowing and more concerned with living; less focused on control and more on care; less driven to reach immutable truths and more driven by opening dialogues among different points of view. I avoid covering life experiences with disembodied concepts and theories, instead maintaining a focus on finding ways to personify lived experience (Bochner and Riggs 2014).
The above serves as a connection to the next chapter which engages more with stories relating to the topic. This next chapter begins with some of my story as a bereaved parent describing my engagement in spontaneous creativity after the death of my daughter. Following this I consider the experiences of being a bereaved parent as depicted in the current literature, before turning attention to how I invited, met and worked with the bereaved parents who became participants in the research.

**Point of departure: an alternative reading of the thesis**

There are theoretical and methodological ideas mentioned here in part one which are given a more detailed consideration in part three. I understand that some readers might find it beneficial to understand more about the theoretical ideas that informed how I approached the topic and the writing of the thesis before continuing on. These readers could now jump ahead to Chapter Thirteen, where the epistemology and methodology is located. I would then suggest a return this point to continue reading chapters two and three. Otherwise I suggest simply reading on.

**Inspirational Music**

When I first began this research project I was inspired by many things. One of those things was music. Before continuing with reading the thesis I would like to invite the reader to paste the following link into a web browser, then watch and listen to this YouTube clip of the song ‘Into the Mystic’ by Van Morrison (1970). Obviously this song inspired the naming of my thesis, but here it also serves as an emotional link to the beginning of chapter two.

[https://www.youtube.com/watch?v=s_Pn4OF2kte](https://www.youtube.com/watch?v=s_Pn4OF2kte)
Chapter Two - My experience

Between land, water and sky

The beach. I want to go to the beach.
It's a cloudy day
Wind is cold

The beach. I walk along the beach
The tide coming in
Waves are creeping

The beach. I take a stick and write on the beach
Merry Christmas
Love you Maddy

The beach. I walk away from the beach
My heart is empty
Sadness sits heavily

Between land, water and sky (Another Voice)

I want to go
Cloudy, cold wind

I walk along
Tide, coming, creeping

I take a stick
Merry Christmas Maddy

I walk away
Heart empty, sits heavily

I’m called later
Take the camera
Don’t know why

Sun setting, clouds low

I go over

I notice the sand
Writing gone, light

streaming

Rays of light streaming
This photo was taken on the first Christmas after my daughter Madeleine died. My partner and I had written messages to her in the sand earlier in the day. Later in the day, I had a strong urge to return alone to the beach and to take my camera as a last minute thought while walking out the door. This scene greeted me as I came over the sand dunes. My heart soared briefly and I felt connected to her. I took the camera, focused and pressed the button.

Click!

Nineteen years later I’m sitting in a quaint timber lined room in an old cottage in the countryside, piecing together what is the final draft of my thesis. The dual-voiced poem prior to the photo emerged from within me spontaneously and claimed a place at the beginning of chapter one. In the writing of the poem and placing of the photo, I realise it was in these moments that my re-search really began and continues.

The photo captures a moment in time, meaningful and experienced deeply by the person who pressed the button on the camera, but the meaning cannot ever be fully
grasped by anyone else. However, words, description, poetry and image, when brought together, can take us closer to the experience of the ‘other’ if we are curious to know about it. Between the person who offers the words, description, image and poetry and the person who reads, comprehends, views and hears, a different experience and a place for new knowledge emerges (Liamputtong & Rumbold 2008). Meanings can unfold and a different level of understanding is made possible in the sharing of an individual experience. This is the fabric my thesis is made of – stories told through words, description, poetry and images, with a hope that the reader is curious.

Like the experience depicted in the photo and poem, both early on and over time, I experienced urges and drives to do things following the death of my daughter. I would find myself doing things without any rational understanding until after I had done them, but there was always a sense of connection to her and an urge or drive to do something. Even now writing this thesis, I'm aware that there is a relationship to my daughter and her death in being engaged in this project, but I didn't set out to write the thesis in direct response to my daughter’s death; certainly not in any planned way.

Another early example of the type of spontaneous urges I have followed, was the writing of a piece of poetry only days after her death. The following short piece of writing gives expression to aspects of that experience and was written in the first two years of embarking on my PhD studies, while reflecting on the topic and beginning my research before I engaged the participants. I felt this piece belonged in the thesis, but it only became clear that it belonged towards the beginning of the thesis as I entered the final years of completing my research. I’ve called this piece ‘Morning and Mourning’ which for me reflects both a beginning and an end. I include it here to give more detail to the phenomena being explored in this thesis, from a personal perspective.
**Morning and mourning**

On the morning of July 31st 1995 I experienced the most profound sense of love I have ever experienced, an overpowering sense of being connected to something beyond myself as an individual. Nothing I can do or say would assist another human being to understand what I felt or experienced that morning and I have never quite felt it in the same way since, only glimpses that I always seem to relate back to that very moment. My daughter Madeleine had been born only an hour before. My partner, nurses and midwife had left the room and Madeleine and I were alone for a short while. I held her and looked into her tiny face and a profound sense of love washed over me. It was incredibly powerful and I have never forgotten that moment. I suspect I never will. I would love to feel it again, just as it was with Madeleine in that moment, but can’t be sure that I will ever experience much more than an echo of it. My love for my son, born after Madeleine, is equally powerful, but also very different and unique to him.

Twenty-five days after this incredible feeling, I sit and cradle Madeleine while she is dying. I experience another strong sense of love for her alongside profound sadness and I became lost in those last moments of her being physically present in this world. I’m overwhelmed with sadness and love, as I say goodbye to her. Now, more than nineteen years later, I wonder if Madeleine left our human existence and somehow become a part of the powerful ‘something’ that I experienced an hour after her birth as I held her? I think “yes” because there have been times since where I felt I brushed against that ‘something’ and immediately felt her presence.

Just days after Madeleine died, I felt compelled to write a poem for and about her (Appendix a). I’m not a writer of poetry usually, but the urge to write was undeniable. It came strongly and I felt driven by something. As I wrote the poem, the emotions connected to love and sadness came flooding in and the words just came to me and flowed out of me onto the page. In the aftermath, for a while, I felt better, calmer and somehow connected to her. As I write this paragraph or revisit this piece of writing, the feelings are similar. The words spill out onto the page and the
emotions came forward again, I feel a sense of connection to Madeleine and feel closer to her in some way. It feels spontaneous and intuitive.

**Considering the experience of having a child die**

Within the story I’ve just shared, the grief associated with the death of my daughter is quite apparent and while my research has a focus on the experiences of spontaneous creativity for bereaved parents, it’s obvious that these experiences are only occurring because a child has died. So I feel it is important to spend some time exploring how the death of a child is talked about by other writers and researchers. This knowledge allows a level of sensitisation to an important aspect of the topic and an awareness of what might be the current assumptions and theorising about the experience of having a child die.

Bereaved parents may adjust to the death of a child over time but never really get over it (Arnold & Gemma 2008). I would concur with this idea and I know many bereaved parents, including the research participants, who would agree. To highlight the magnitude of the grief experience for parents, there is also evidence that both mothers and fathers of a child who has died have a higher risk of mortality (Murphy 2008; Rostila, Saarela, & Kawachi 2012).

It is clear that the death of an infant, child or young person, brings trauma and grief that is felt and shared by extended family, friends and the community around them. The experience affects most, if not all aspects, of an individual’s and a family’s lives (Gilbert 1997) and results in a “psychological upheaval for parents” (Janoff-Bulman 1992). Robert Neimeyer (2006) suggests that due to this psychological upheaval, a search for meaning becomes particularly intense after a death or loss and that particular events, such as the death of a child, raise profound issues regarding the significance of life itself. The life narrative and self-narrative of bereaved parents is profoundly shaken by a child’s death, much like a seismic event that changes a landscape forever (Neimeyer 2011). J Shep Jeffreys (2011 p. 150) reminds us that:
“from a biological point of view, a parent is the physical agent whose function is to send the genes from earlier generations into the future and this intertwines the parent and child in a very special relationship. When a child dies, a sense of the generational continuity is cut off”.

The search for meaning resulting from the existential crisis that occurs after the death of a child is a crucial aspect for parents and their ongoing lives (Talbot 1996–1997). Research indicates that the search for meaning, or lack of finding it, is a greater contributor to distress than factors such as the cause of the child’s death, passage of time and gender of the parent (Keesee, Currier & Neimeyer 2008).

In their book focused on the death of a child, Arnold and Gemma (1983 pp. 26-27) provide perhaps an appropriate summary of the varied issues that impact on both families and parents:

“Death of a child member becomes an important identifying piece of information about the family. It is woven into its history and into the everyday operation of member’s lives. The child who has died continues to be a family member after death. Parents are forever parents of a dead child as well as surviving children. The dead child lives in memory. The family grieves for him/her and remembers him/her with little comfort and support from the society around them. The family of a child who dies, lives without that child’s physical presence and actual contributions but with memories, wishes, dreams and hopes. The death of a child member affects individual members and the whole family system. There may be resultant alteration in family structure and in members’ roles. The strengths and values of the family may be questioned as members turn to or away from the family for support and comfort.”

Many bereaved family members I have spoken with find there are often times when they feel that the death of their child is an ‘unspeakable’ life event. Perhaps this is because in modern western society death is not a topic that is comfortably spoken about (Sutherland. 1997). I also often see a level of discomfort amongst professionals and academics when the topic of child death is raised. Stewart and
Dent (1994) note that the death of a child is not something expected or common in western society today and that this means some professionals are likely to have little experience or expertise in the area.

**An experience that most parents are not prepared for**

When I meet or talk with bereaved families, it becomes clear that the death of an infant or child is something that parents or family members do not usually anticipate, it is an abnormal event in this sense. Family members and parents in particular, will experience the death of a child as a time of agonizing despair, intense loneliness, confusion, guilt, bitterness and often a re-examination of personal beliefs (Arnold & Gemma 1983; Peppers & Knapp 1985; Jeffreys 2011). There is evidence that the death of a child brings with it both grief and trauma reactions amongst family members (Bride & Mazza 1997; Stebbins & Batrouney 2007). The way in which some of the participants in my research describe their experience of the death of their child or children illustrates the traumatic aspect of having a child die.

Comparative and longitudinal studies provide evidence that the death of a child leaves family members with a grief that is more intense and prolonged than other losses (Sanders 1980; Rubin & Malkinson 2002; Raphael 2006; Stebbins & Batrouney 2007; Arnold & Gemma 2008; Stroebe, Schut & Finkenauer 2013). This is likely to be due to the added aspect of trauma within the grief experience, where the experience of the child’s death becomes deeply embedded within the thought processes of the parent. It is also because parents don’t expect their children to die before them. It seems out of order with the nature of life. A bereaved parent’s expectations of the world are turned upside down as they feel forced through a ‘crack in the universe’ that they never thought existed (Jeffreys 2011 p. 153).

“Each of us lives and each will die. We are born; we enjoy the careless days of childhood, the maladies of old age; and then we die. At least, these are the general expectations that most human beings hold. Death is viewed as a phenomenon of old age.”

(Peppers & Knapp 1985 p. 21).
The death of a child is generally considered a ‘traumatic death’ regardless of the cause, with high levels of complexity in grief reactions amongst parents (Figley, Bridge, & Mazza, 1997, Aho, Tarkka, Astedt-Kurki, Sorvari, & Kaunonen 2011). Trauma can be defined as ‘a normal reaction to an abnormal life event or situation’ and many in our western culture would consider the death of a child as an abnormal life event. Kay Talbot, a psychotherapist and researcher, is a bereaved parent who has written about the experience of having a child die. In the prologue to one of her books, Talbot (2002 p. xxvii) has this to say:

“In those first years after Leah’s death I experienced the intense and varied emotions that accompany acute grief, as well as physical symptoms, such as chest pains and insomnia. I went to counselling, took anti-depressants and sleeping pills, and despite the warnings of my psychiatrist, I used alcohol to numb the pain. My nights were filled with images of Leah’s funeral and death.”

Another researcher - Reiko Schwab (2012), summarizes his view on the death of a child this way:

“The death of a child, regardless of age, is one of the worst possible losses adults can experience. Grief over a child’s death is particularly severe compared to the loss of a spouse, parent, or sibling. The parent-child bond is uniquely strong and enduring. Children are extensions of parents; they hold parents' dreams, aspirations, and hopes for the future and promise the continuity of parents' life after their death. They define parents' sense of self and give meaning and a sense of purpose to their lives. When a child dies, parents feel mortally wounded; it is as though part of them is torn away by force. The family also loses its wholeness. A child's death is perceived as untimely at any age because parents are "supposed to" die before children. Moreover, miscarriage, stillbirth, and death in childhood and adolescence are often sudden and unexpected and in some cases violent, which traumatizes survivors.”

As with other traumatic losses, bereaved parents often describe a type of re-living events relating to their child’s death, repeatedly, over time. Bereaved parents can be
incapacitated by unrelieved stress, finding they have become fixated on certain aspects of the child’s death and some parents may experience significant grief until they die (Talbot 2002).

Certainly, my daughter’s death felt traumatic for me. Having had such a profound experience of parental love for her after her birth, it was traumatic to look on as my baby daughter was subjected to invasive medical procedures. Often my partner and I were unable to comfort her when she cried, either because of the procedure itself or because of the wires and tubes connected to her tiny body; we felt distressed and powerless. I vividly remember the day that I carried her in my arms to the operating theatre, rather than have her wheeled there by someone else, and felt an overwhelming urge to protect her and take her away from that place (the hospital). The thought of her unconscious and alone amongst surgeons and nurses, while they cut into her skin and operated on her heart, felt unbearable. I wanted to hold her close and run from that place. I wanted to flee from what felt like a threat to her life. The physical and emotional memory of these events spring forward in me vividly and powerfully even now.

For parents who have a child die, the meanings, hopes, dreams and purposes associated with the child often leave a painful ‘existential vacuum’ due to the child’s physical absence (Frankl, 1978) and the grief of bereaved parents is complex (Jeffreys 2011). Art Peterson is a bereaved parent, quoted by Therese Rando (1986 p. 489), who suggests that from his own experience “there is no expert to make this pain go away”. This indicates the importance of helping bereaved parents to find their own way in grief. The research within this thesis gives attention to the role that spontaneous creativity might have in bereaved parents finding their own way with their grief, whilst grappling with making sense of life in what can feel like an existential vacuum.
Considerations for professionals and researchers in working with bereaved parents

Arnold and Gemma (1983 p. 127) suggest that professionals are “responsible and accountable for exploring their own beliefs about death, loss, bereavement; about children, families, parenting; about children dying and about their need to help”, because the essence of contact with bereaved families is the “therapeutic use of self” (Arnold & Gemma 1983 p. 124) rather than a focus on just alleviating distress and emotional pain. Jeffreys (2011) reiterates this idea, saying that care providers must have a commitment to self and be attuned to stored personal loss material and understand their own limitations. He goes on to say that anyone engaging with the bereaved needs to adopt a stance of being an ‘exquisite witness’ where we “observe more than act, listen more than talk and follow more than lead” (Jeffreys 2011 p. 26).

It is true that for many bereaved parents, they do not wish to have their grief changed or diminished by professional intervention, instead wishing for someone to be with them offering care and respect as they grieve. In fact, as Robert Kastenbaum (2001) states: “Parents may not wish to relinquish their grief, for the pain is part of the precious memory that keeps a connection with the deceased child”. In the stories of the research participants, I can see that some of the pain and grief contributes to these parents engaging in the spontaneous creative activities which they talk about. This then keeps the precious memory and connection to the child active and alive for the parent. It seems to me that the love held for the child turns to distress and grief when the child dies and then perhaps what follows is a struggle to reclaim the love that is held for the child, through the creative activities, that spontaneously present themselves amongst the grief and pain.

There has been, and at times continues to be, a focus in traditional grief theories that inform many modern health and welfare systems on making things ‘better’ or trying to ‘resolve’ grief. In the case of the death of a child, professionals cannot necessarily accomplish these results and need to accept this as a reality (Arnold & Gemma 1983 p. 127). I and others who have researched in this field, suggest that formal training
and study has a limitations as far as influencing a professional’s ability to fully understand or have knowledge of the pain and reactions of another person in these circumstances (Arnold & Gemma 1983 p. 124). In short we can’t ever assume to know or understand another person’s grief experience.

Therese Rando (1986 p. 489) quotes bereaved parent Art Peterson, who indicates that many professionals have been taught to remain detached in order to maintain credibility and avoid involvement with a client’s circumstances. Peterson goes on to suggest that it is most often professionals who maintain this detachment that provide inadequate or damaging forms of support for bereaved parents, through attempts to appear infallible in a situation where it is inappropriate and foolhardy. Often undervalued in this field, is the ability to draw upon lived experience and reflect on our personal reactions, beliefs and knowledge and this is often acknowledged as a flaw in much research and theory building around grief and loss (Attig 1996; Klass, Silverman & Nickman 1996; Neimeyer 2000; Wolfelt 2006).

In recent times, Alan Wolfelt (2006) has advocated for the use of what he calls a ‘companioning’ model of working with bereaved individuals and families. This is quite similar I feel to J. Shep Jeffreys (2011) idea of being an exquisite witness, as mentioned above. Wolfelt (2006) describes the idea of companioning as learning to be present to another person’s pain, without focusing on taking away that pain, it is about honouring the spirit rather than focusing on the intellect, listening with the heart more than the head and respecting disorder and confusion, without attempting to impose order and logic. Interestingly, Wolfelt suggests that working with the bereaved is about curiosity rather than expertise. This is certainly something I have been mindful of in working with the research participants and in writing the thesis.

Robert Neimeyer is a researcher and practitioner who adopts a constructivist/narrative approach that highlights the ways in which people reconstruct meaning in their lives following a significant loss or death, while facing the challenges of grief. Neimeyer (2000) rejects many of the implicit assumptions found
in what might be termed ‘traditional grief theories’ and proposes a number of criteria for research and development of theory relating to grief. My summary of the criteria suggested by Neimeyer (2000) is as follows:

- The personal and individual reality of death or loss for each person needs to be revealed, instead of assuming that death holds a universal significance for people regardless of their historical, cultural, familial or personal contexts.
- People need to be seen as being active in dealing with grief and bereavement, rather than being passive reactors or simply being swept along by the grief process. (Neimeyer quotes Thomas Attig on this concept – “Bereavement may be a choiceless event, but the grieving experience, when understood as an active coping process, is permeated by choice” (Attig 2011 pp32-33)).
- Theories and research should be richly descriptive in elucidating the personal meanings of loss without subtly prescribing what constitutes so called ‘normal’ grieving.
- Theories and research need to attend to and illuminate the passionately held meanings that shape the emotional, behavioural and somatic responses to grief and bereavement.
- There is a need to describe how a person’s world is forever transformed by loss rather than suggesting recovery will lead to some ‘pre-morbid’ state of normality.
- While maintaining a focus on the highly individual aspects and experiences of grief, there is consideration of how these individual qualities merge into the larger social and family contexts of the grief and bereavement experience.

I have found these criteria useful and relevant to my research, with the emphasis on individual experiences and personally held meanings informing my methodology, methods and my overall approach to writing the thesis. Neimeyer’s criteria lends itself well to engaging with the stories of bereaved parents in a way that emphasises the highly individual nature of experiences associated with grief and the personally held meanings that can emerge for people as they find ways to live a changed life after a loss or a death. Neimeyer’s criteria also align neatly for me with the
existential and phenomenological referents I apply in the methodology. It was important for me to hold all of these ideas in mind as I engaged with the stories of the bereaved parents who were my co-researchers.
Chapter Three – Moving towards the phenomena

Introduction to the stories of bereaved parents

What follows are two examples of people responding to spontaneous and creative urges after a child has died. One example is from a sister and the other is from a mother towards her daughter (and to some extent a deceased partner also). I wanted to offer these to re-engage with the phenomena being explored before starting to talk about the participants in the research. These two brief stories were also used as part of my very early engagement with the participants in order to give them a sense of what the research was about. In some ways, these stories sourced from existing materials form a link between my own ideas and experiences and the experiences of other people.

Life Moves On: Grief, survival and transformation. Mish Cooray’s story.

Mish Cooray was an artist when her sister Laxmi, died in a boating accident (Cooray 2001). While Mish and her family initially felt “thrown off balance” by the grief and trauma, Mish continued her creative work to varying degrees. Mish noticed and documented, in writing, poetry and artwork, how the death of her sister and the subsequent grief changed her perceptions and influenced her creative output. Initially, Mish was advised to read about grief, but could not find a book that connected with what she was looking for. Mish felt she was “living and breathing
grief day and night” and simply felt a need to find something that was more “philosophic, inspirational and uplifting” that would allow her to see that there was perhaps “light at the end of the tunnel”, but could not find any such book (Cooray 2001).

Years later, Mish brought together her artwork, poems and writing that she had created over the time after Laxmi’s death. The artwork, poems and writing were created as Mish grappled with and sought to make meaning of her sister’s death. As an artist, this was perhaps a natural form of expression for Mish. The final result was the creation of the book which brought together these creative expressions and emerged from Mish’s early felt need to find inspiration and meaning within the grief. This also serves to keep Mish’s relationship with Laxmi tangible and meaningful. Mish has created something which allows herself and others to connect with Laxmi’s presence and place within the living world, even though she is no longer living or physically present.

**The constant gardener. Wendy Whitely’s story**

Wendy Whitely spontaneously began cleaning up a piece of derelict railway land in Lavender Bay (near Sydney), after the death of her husband Brett in 1992 (Hawley 2006). Gradually, it began to take the form of a garden and Wendy recalls that she “could lose herself in doing something physical” and she didn’t ask anyone’s permission and didn’t have any “grand plan”. When Wendy’s daughter, Arkie, died in 2001, Wendy’s distress and grief intensified and she threw herself into the ‘garden’ with greater devotion and a ferocious energy. Wendy says she can “sense her with me as I dig away, so a lot of the time I’d feel I was doing this for Arkie”
(Hawley 2006). Wendy goes on to say that she “misses Arkie like crazy”, but has also learnt that “pain passes, anger passes and doing something physical helps, so you’re exhausted at the end of the day” (Ibid). Wendy also suggests that being “outside in the sunshine” helped her. “Seeing it was a beautiful day”. “Living in the day, don’t waste it sitting in a dark room feeling sorry for yourself”. “There’s a helluva lot on offer out there”. Barry Pearce, a curator at the NSW Art Gallery, commented recently, after walking through the garden that “it’s a great act of love”.

I was grateful to come across these two stories early in my research process as they capture the type of spontaneity, urge to do something and creativity that can be present after a child has died. The stories also show how this can be present alongside deep grief. What was missing for me was a deeper understanding of the context of these experiences along with a curiosity about how these ideas or creative activities might be a part of a bereaved parent’s life over time. There was the feeling for me, on reading the above stories, of wanting to talk directly with Mish and Wendy in order to have a more nuanced sense of what was being expressed. This confirmed for me the plan to interview bereaved parents and talk with them about the spontaneous creative things they had done since the death of their child or children and to do this over a longer period of time, to capture a sense of significance of these things in the ongoing life of the parents.

Following on from this I want to now move towards the stories of the research participants themselves. I feel it’s appropriate here to offer some information about how I came to meet and engage with the participants in the research, before coming to the stories that you will read in part two. As with the making of a patchwork quilt, there needs to be some stitching that holds the patch of part two onto the background of part one. The following is my stitching between these two parts.

**Finding participants**

To start the process of recruiting participants and to ensure I worked with participants ethically around a sensitive topic, I needed to seek ethics approval from Deakin
University where I was enrolled as a PhD candidate. Over a period of months, in consultation with my supervisors, I developed a process that would allow me to engage and work with the participants in an ethical way (Appendix e). I then sent out a call for participants, viewing them as potential co-researchers given the participatory nature of the research. I did not see these bereaved parents as simply potential sources of data, but rather they were to be active participants who would offer their own understandings to the research process.

There were many questions for me about how to recruit participants for this exploratory research in a way that as clearly as possible articulated the phenomena I wanted to explore. It was important for possible participants to understand what I was interested in and invite them to share their experiences of this, within their own lives. I knew that I wanted to focus on the phenomena of bereaved parents doing things after the death of their child. I wanted to pay attention to things done that were not directed by others and seemed to be more intuitive in nature. I also felt that there was the element of creativity involved, but understood that for some parents they may not think of what they had done as creative. My working title in the beginning was ‘Emotions, intuition and creativity after the death of a child’.

The information I had gathered during an initial review of the literature relating to bereaved parents was used as the basis for engaging with and including people in the research. So this was the basis of information used in the creation of notices that were placed in newsletters of organisations who offered support to bereaved parents, inviting bereaved parents to become participants in my research.

Participants were initially recruited through a self-selection process achieved through inviting interested family members to participate via notices placed in newsletters and journals of the following organizations – SIDS & Kids, The Compassionate Friends, Stillbirth And Neonatal Death Support (SANDS), Australian Centre for Grief and Bereavement, Very Special Kids, Bonnie Babes Foundation, and Road Trauma Support Team Victoria. These organizations were asked to distribute the notice amongst any relevant professional networks. There is therefore an assumption
that participants were primarily clients of these organisations. Where this was not the case, every effort was made to ensure the participants had access to appropriate support if required. The aim was to have a minimum of four participants and a maximum of eight participants.

What struck me after I had put out a call for participants, was that I had a quicker and larger volume of responses than I had anticipated. I only needed around eight participants, because of the detailed and personal nature of the research, but within a month I had twenty people asking if they could take part and by the end of two months I had over twenty-five people. Nearly all of the responses from those that replied to the newsletter notices were saying that they were very interested in my research topic and that they had things that they had done in relationship to their child that they wanted to share if they could. Many commented that they felt this was an important topic to research and understand better.

In discussion with my supervisor, it seemed the only way to manage the large number of potential participants was to take the participants who were the first to get in touch and to work my way through these, in order of contact, to get a variety of ages of the children who had died and some variety in the participants being male and female. Obviously I had to explain to participants as I went through this process, what I was doing and the reasons for wanting a variety of circumstances. I wanted a variety of different circumstances so that I could get some sense as to whether the age of the child made a difference to the things people did. Having a mix of male and female participants was for a similar reason. Could there be a difference in the things people did based on whether they were fathers or mothers? In keeping with a phenomenological approach, the sampling was purposive in order to obtain the relevant information about the phenomena I am studying, in this case, allowing something new to come into existence (spontaneous creativity) in relationship to a child who has died. There is a focus on the experience of the phenomena itself more so than the experience of having a child die and this was a key aspect of ethical considerations (Davey 1999).
Point of Departure: an alternative reading of the thesis

For those readers that would prefer a more detailed explication of my engagement with participants and how I worked with their stories (before reading the stories presented in part two), I would suggest moving to Chapter Fifteen which covers my methods in detail. The reader could then return to the remainder of this chapter before moving into part two of the thesis. However, I invite the reader to continue on, knowing that further detail will be found later in the thesis.

As a bereaved parent myself, I could sense that the other bereaved parents were eager to share their stories of their child and the ways that, as parents, they had done things that allowed them to stay connected to their child. In short, there seemed to be a passion about wanting to share these stories, not just with me, but with others through being part of the research. So it was a difficult time working through the participants and telling many of them that I already had enough people and would keep them on a list in case some people changed their minds. I would have liked to include everyone, but it would have been impossible for me to manage all of the stories in a thesis of this size, using the style of research that I wanted to use. I feel the need to honour the fact that in some way, all of those parents who got in touch with me contributed to the research by showing just how powerful the feeling is of wanting to share something of their child’s place in their lives, with other people.

Once I had my group of participants, there was then the process of telling them more about my topic and having them tell me more about their child or children and the things they had done in relationship to that child or children. I didn’t want to interfere too much with how each person offered their stories and descriptions, so I only gave the brief examples I’ve shared here – the stories of Mish Cooray and Wendy Whitely.

I offered brief one hour information sessions through either a small group setting or individually on the phone. What unfolded was that I ran one small group session in a capital city for three people and then all other information sessions were done on the
phone. This gave a chance for me to talk in person about what I was doing, give the plain language statement (Appendix b - emailed for phone participants) and answer questions. The participants were then invited to take away the plain language statement and complete it after reflecting on the session and having time to read about the research at their leisure. No-one declined to sign the plain language statement and within a few weeks we were ready to make a start.

To get started, I sent each participant an information sheet about doing the first step for the research (appendix c). This information sheet encouraged the participants to use their own way of expressing themselves and telling something of the things they had done since their child had died. I tried to avoid examples of what others had written about their experiences on this sheet, other than a suggestion about how they might give the basic information about their child, which I based on my own example. This allowed me to be a little transparent about my own situation and show a willingness to share a little of my story, while giving the participants room to express themselves in any way they wanted to.

Over a period of a month I received what I called these first steps of the research, mostly by email, but some information came through the regular mail. Because I had already had some contact with the participants to introduce the research and the process, I had some idea of the circumstances and some of the things that these parents had done since their child died. Most of the participants gave a brief background to their child and how they died and then gave information about the things they had done since the child died. Photographs came, showing the things that had been done. These first steps appear at the beginning of each story you will read in part two and are all in each person’s own words.

There was such diversity amongst the things that these parents had done since their child had died and they are certainly not just arts-based things. I had realised very early on that some people may not see these things as creative if you view creativity as having a link to the arts. However, the idea of using a term like ‘doing things’
didn’t seem to do justice to what I was seeing and hearing in these examples. By exploring the idea of creativity, I realised that creativity is the act of bringing something new into existence. This fitted quite well with the research topic and the examples from the bereaved parents – something new coming into existence in relationship to the death of their child. So right here is a point where something significant emerged from the research. The idea that parents were bringing something new into existence, following the death of their child and also in relationship to their child, indicates that parents were engaged in a living, changing interaction with the child who had died, through things that they were doing since the death of their child.

A child dies
A relationship remains
Something new is born
A living, changing interaction
Things are done
Love and connection endure

The interviews
I arranged to meet each of the eight participants and conduct an interview so we could talk further about the examples of things they had done since their child had died. Participants seemed welcoming of the opportunity to talk more about what they had done. I know from the literature, that many bereaved parents like to have the opportunity to talk about the child who has died, because there are often limited opportunities to do this in their day to day life (Klass 1999). With each interview, I opened with a question of the following nature: “What part do the things you have done (in relation to your child) and the creative process, play in your life and what do these things mean to you?”

I met around half of the participants in their family home and the other half met me at an agreed venue and this was generally because of convenience of timing and location. While the willingness to talk about their child or children was very similar for all the participants, there was the difference of being in the family home, where a
parent would look towards or indicate placement of events and things within the house; for example, saying: “When you came in the front door you would have passed such and such, which is one of the things I have done in relationship to my child”. Reflecting on this, there is the sense that the child who has died still dwells within the house as part of the family, albeit in a different way to the living children. The parents I spoke to in other venues would talk about and describe their home environments in a similar way, but my own experience of that was different and less tangible in some ways.

After each interview an interesting swirl of emotions, thoughts and feelings would stay with me, lasting for some time. In each case, I had at least an hour of either driving or not needing to be anywhere else, so that I could allow these experiences to be present and stay with me, washing over me and around me. In most cases, the time I had was much longer than an hour and this allowed time for a walk or a chance to just sit and reflect. I would describe my mood at these times as a combination of deep melancholy blended with a type of peacefulness and calm.

I came away from the interviews with audio recordings of each story. My first task was to listen through each one, beginning the process of considering how I might present these very personal stories in written form, while seeking to understand more about the experiences and activities described by the participants. After listening to all of the interviews twice, I turned toward the task of transcribing the interviews, as I needed written material to work with. This involved listening some more to the interviews and typing them verbatim into a computer and saving them as files.

Here I was able to immerse myself in the stories, coming to know each participant’s story quite well. Each listening would transport me back to the interview itself, bringing forth the setting and the voice of the participant. As I typed and then read through the written words, I noted how the transcripts seemed to flatten out the spoken words. My sense of a narrative or conversation, that was clear to me sitting in the interview, became rather disjointed and unclear as a verbatim transcript
because the conversation moved and changed and returned and drifted around the topic.

I had initially considered that simply tidying up the transcript and taking out less relevant aspects would be best and give a sense of the person. Once I worked with transcribing the interviews, it became obvious this was not going to be the case and I felt something was missing. I started to ponder ways to try and capture more closely the voice of the participant in a way that felt closer to how I had experienced it as the interviewer. I needed to create a narrative that presented the participants’ experience as clearly as possible and captured some of a sense of who they and their child or children are. After a lot of searching and finding ideas that seemed close but not quite right to me, I decided to find my own way to present the participant and their child to the reader as humans with a particular voice that reflected my experience of the conversation with them in the interview. I used the following key referents to do this.

- Heuristic phenomenology (Moustakas 1990) – In particular the ideas of immersion and inter-subjectivity.

- The listening guide (Gilligan et al. 2006) – A voice-centred and relational method of working with narratives.

- Poetic (for me ‘Storied’) representation (Richardson 1992; Schwartzman 2002) – A method of fashioning transcripts into poetic or storied forms that have resonance to the interviewers experience of the interviewee.

- Presentational and participatory knowing (Seeley & Reason 2008) – The intuitive grasp of the significance of patterns as expressed in graphic, moving and verbal art forms.

(These are described in more detail in part three.)
Informed by these referents, I teased out each person’s interview transcript to get a sense of cognitions, emotions, spirituality, physicality and environmental/social elements. I then re-constructed or re-narrated their transcript (using the participant’s own words from the transcript) into a storied form that for me reflected the experience of the interview. I also aimed to maintain the style of voice that comes when one person is telling a story to another – in this case to get a sense of the participant telling their story to the reader. The metaphor that kept coming to my mind was that of piecing together a puzzle that could be put together in infinite ways, until I had a sense of it looking and feeling right in relation to that particular person. Therefore, the participant stories you will read are what I am referring to as co-constructed narratives. The stories are a reflection of my experience of the interview where I mostly listened, with some prompts of course, while the participant told their story. While re-narrating the stories, I also paid attention to a sense of timing of events, or temporality, as they were described by the participant. In addition, by blending in just a few of my own words from the interview, I included the context of moments where I (as the interviewer) had asked something that had prompted a certain response. For example I might ask “Did this change your experience of the grief?” and while the person may have responded with “Yes it did, it helped me a lot” what I eventually included in the final story would become “With regard to any changes in my experience of the grief I felt that this helped me a lot”.

Once I had completed these stories or narratives, they were returned to the participant for them to read and indicate whether they felt this reflected what they wished to express and resonated with their experience of the interview. Some participants made changes to the stories and I have not interfered with those changes. Some participants felt the narratives reflected their voice and story well and they simply made minor corrections to details. As a final participatory step I invited participants to write their own reflection on their story to include the significance of the things they talked about then (in the interview) and how these things are or are not, so much a part of their lives, now four to five years later. These reflections, some short, some longer and some not at all, are given space toward the end of each story.
A final poetic listening and representation

As a way to conclude each of the participant stories, I decided to create a poetic synthesis of the participant’s words and place this as a conclusion to each story. In part three I talk in more detail about the process of creating this poetic synthesis. The poems are offered to provide the reader with a sense of what I, as the researcher, experienced as significant in each story. Laurel Richardson (1992) describes the use of poetry in this context as emotionally preoccupying and able to open up unexpected places within the self, thus positioning the researcher as a knower/constructor of understanding and meaning. Laura Ellingson (2009) suggests that poetic forms of writing offer rich opportunities to highlight larger segments of the participant’s stories than might be possible with conventional reports. The poems I’ve written are intended to highlight what I see as significant segments of each participant’s story.

Each poem was created using only the participant’s words and these words were taken from what I saw and heard as significant parts of their story. I then grouped the words together and listened for how they might come together in a poetic way that would represent something about the story that had been told. There is no set length to the poems as some stories seemed to generate more longer poems than others, with the poems being in direct relationship to the story itself, rather than being separate pieces that are detached from the story. These poems are intended to be freely interpreted by the reader and I believe they say quite a lot about my experience and understanding of each story. I see these poems as a type of poetic coda (to borrow a musical term) that returns to the essences of each story, gives them emphasis and brings the story to a close. In a piece of music the coda (an Italian word meaning ‘tail’) returns to and gives emphasis to any themes from earlier on, in order to then draw the piece to a close (De Voto 2015).
Personal Perspective

Over eight years being with
The spontaneous things that bereaved parents do
After the death of a child.

Wondering often
Where will the research take me?
A sense of significant ideas emerging.

It’s intriguing
A research project
Within the life of the researcher
My being

Never far from the topic
It is part of me

With parts of others

I
You
We
They
Us
Part 2 – In the heart of the mystic

Chapter Four - Finding ways to connect

The quilt-maker and the solid powerful something: A short methods fable

The quilt-maker sends a message out into the community. He is looking for something very particular and precious to use as a material to make a quilt. The quilt will contain, hold and display what he is seeking. This particular precious something can only be found in certain places and is only available from a particular group of people. These are people who have experienced the joy and pride of being a parent and also the sadness and pain of having a child die. These parents continually search for and collect precious pieces of the experience of having their child in their lives. They bring those pieces together and with great reverence draw those pieces into themselves, into their physical bodies, into their emotional selves, into their thinking brains, into their spiritual auras and into all the spaces around them - between themselves, others and the world they live in. In a kind of slow alchemy, these pieces of experience rub against each other, melt into each other and join with each other to form something more solid and quite powerful. This solid powerful something, can keep a person alive when they fear they will perish and so it is a wondrous thing.

This wondrous thing is a perfect material for the quilt-maker who wants to make a quilt that will radiate this solid powerful something, so that he and others can experience its essence and understand its qualities. The quilt, once made, will contain and hold this solid, powerful, wondrous, something for others to see and experience.

Several people hear of the quilt-maker’s endeavour and support his wish to make a quilt that will radiate the solid powerful something into the world for others to see and experience. However, they question the quilt-maker over how they can ever give
this something to him in the form of a material that he could craft into the type of quilt that he talks about? The quilt-maker explains that this solid powerful something can only be given to him in the form of fine threads made of words, sentences and stories. He goes on to explain that from the threads of their words, sentences and stories he must work carefully to weave pieces of fabric that hold the essence of this wondrous, powerful something. To do this he tells them, he must place the threads of words, sentences and stories on his weaving loom, then gently weave pieces of fabric, while holding within himself a sense of the person who gave the words, sentences and story along with what he knows of their child who died. He concludes by saying that he believes that if he can achieve all this, then the fabric, made of words, sentences and stories, will be perfect for the creation of a unique patchwork quilt, with the pieces of fabric stitched together so that the quilt both holds and radiates the solid powerful something for others to experience. The quilt-maker assures them that they will not have to give away all of the solid powerful something from within themselves, but rather they will give a trace of it, a small piece of thread and this will be enough for his purposes.

Eight people eventually agree to meet, one at a time, with the quilt-maker so that he can gather the threads of their words, sentences and stories. Afterwards as he works at the weaving loom to weave the threads into pieces of fabric. He works gently and slowly with their words, sentences and stories at his loom for many days and nights. As he works he keeps in touch with the person whose threads he is weaving. He does this to check that he is not losing anything important in the process and to allow the person to assist in the process if they wish.

Working painstakingly over many years, the quilt-maker creates many pieces of fabric from the eight people and he slowly and carefully stitches these pieces of fabric together, forming a large patchwork quilt. The quilt holds and radiates the solid, powerful, wondrous, something and the quilt-maker frames the quilt for public viewing.
Stories of love, death, loss, longing: Finding a place for love.
This is the centre, or heart, of the research as it contains the stories from the participants in the research. Each story begins with an introduction that was written by the participant and sent to me before I interviewed them. As mentioned in part one, I provided each person with an information sheet regarding what I was looking for from them as an introduction (appendix c) and this included encouragement for them to write or present their information in any way they felt comfortable with.

The part that comes after the introduction is a co-constructed narrative and begins with my short reflection on arriving at the agreed meeting place to interview the participant. These narratives were constructed by myself using sentences, paragraphs and words taken directly from the interview transcript. I re-narrated the interview transcript into what feels like a coherent and congruent story. I did this by ‘focusing’ and ‘experiencing’ (Gendlin 1981 & 1997 – more explanation in part three) in relation to my contact with the participant and in relation to what was talked about in the interview. This allowed me to develop what felt like a more congruent narrative that felt like it captured a more conversational tone. This co-constructed narrative was given to the participant to read, after I had worked on it, so that they could confirm or adjust the coherence and congruence in relation to themselves. This is in keeping with the participatory nature of the research design. Some participants made changes and corrections that also became part of the narrative. As much as possible a collaborative approach was taken to ensure each participant felt comfortable with the final result. The complete interview transcript was used and the only things removed were aspects that were unrelated general conversation (“I’m going to a party after this” or “I imagine you are busy in your work at present”, etc), material that was problematic for privacy reasons and utterances that were not content related (repeated hmms, umms, yeps and Oks etc). There is more detail on how I worked in this way with the interview transcripts in the methods chapter in part three of the thesis for those that would like to read about this before continuing on.
There is a third part to each story, where participants were invited to include a short piece of writing covering how they currently view or experience the things they talked about when they were interviewed, which was over four years ago. Participants were invited to consider what’s similar, what’s different and what role do these things have in their life now. In my invitation I made it clear that the participant could choose whether or not to do this and some participants were happy to mostly let the story stand as it was. Where they are included these third parts to the stories are completely the work of the participant, with no adjustments by myself.

As I mentioned at the end of part one, each story has a conclusion in the form of a poetic synthesis that I wrote using the words from what I felt were significant parts of each participant’s story. These poems are my own brief synthesis of the content in each story that I felt had a relationship to the phenomena being explored.

My aim with these stories was to have them read in a reasonably consistent way, even though they are different sections written in different ways at different times over a seven year period. I have simply indicated at the beginning of each different part, the year that this was written. There are eight stories in total and I am presenting them as a collection of short stories. I give emphasis to the individuality of each participant by designating each story as a chapter in its own right. Some of the stories are shorter than others and hence some chapters are quite short. The style of expression in each will be different as this reflects how the participant spoke with me during the interview and the nature of each story reflects something of each participant. I have written the larger co-constructed part of each story in a way that has a sense of the participant addressing the reader to reflect the way the participant was addressing me when we did the interview. The interview is the basis of the content for the larger central part of each story.

**About the co-constructed stories**
This collection of eight short stories was created over a period of five years, the result of a collaborative effort between nine bereaved parents and their deceased children, with one parent (myself) taking the role of initiator, writer, researcher and narrator.
As reflected in the fable at the beginning of this section, the process of creating these short stories was mysterious, uncertain and driven by a feeling that there was something important that would be revealed in the telling, creating and presenting of the stories. For me as the researcher, many important things have been revealed during this process.

The telling, writing and creation of stories is an analytic and meaning seeking process in and of itself and so in the context of this thesis, these short stories are the presentation of what might be termed data and might also be seen as the presentation of my analysis of that data – to borrow from positivistic terminology. The creative synthesis of each story into poetry at the end of each story represents a more intensely focused meaning seeking and analytic enquiry, on my part, into the experience of each parent. While later in the thesis, in part three, I will summarise my own meaning making and knowledge building that has emerged from my engagement with both the phenomena and the stories of the participants, in this central section the stories and poetry are presented as a form of creative and holistic research in their own right. Each short story is both an act of creative and collaborative storytelling and a rigorous enquiry and investigation into the phenomena of spontaneous creative activity following the death of a child. Each story merges the experiences of the researcher and the participant, while foregrounding the voice of the participant as the person who has lived the experience.

In keeping with a primarily existential methodology, I have limited any interpretations or assumptions and have tried to just present my own sense of each story as it was told to me, while attempting to also capture a sense of each participant’s way of talking and expressing themselves. The stories are quite evocative and some have content with graphic details. Because of this and out of respect for each participant’s story as unique to them, I suggest that the reader take a pause between each story, to reflect on the content, before moving on to the next story. I am suggesting this also in relationship to self-care for the reader and in the spirit of the collaborative and reflective nature of this research. This is merely a
gentle suggestion and not at all a fixed directive towards the reading of these stories. I now invite the reader to listen to the eight participant stories.

As a brief summary, what you will read in each story is:

1) Early introductory material, written and sent to me by the participants,
2) My short introduction to the interview setting and then the co-constructed narrative (the larger section)
3) Follow up communication written by some participants five years after they had been interviewed and after they had read the co-constructed narratives I had created. This part was at the discretion of the participant after they had read the co-constructed narratives and made any adjustments or changes to this. Some participants wrote more and some wrote less or barely commented at all (the latter often because they were happy with the co-constructed narrative as it was).
4) A collection of poems that I have written, using the participants’ words, which concludes each story.
Chapter Five - Deepest feelings find a path through creativity – Deborah’s story

Introduction - 2009
On February 1st 2008, our first child and lovely girl was born into this world. To our great despair, however, she didn’t take a breath or open her eyes, and left us at that same time. For much of the latter part of my pregnancy, our girl was in a breech position, and despite my determined efforts to encourage her into a head-down position, she remained breech to the end.

My labour and birth progressed much faster than anticipated. Our girl was born feet-first to her shoulders with the help of ambulance officers at our home before we were transferred to hospital for her final birthing. To our relief, our obstetrician and doula were waiting for us on our arrival, and within moments our baby was born. The staff tried everything, but sadly, our girl had died at some point during transition.

The scene of the conversation - Later in 2009 – Greg’s perspective.
It’s a weekend and I have two interviews planned for today. I’ve agreed to meet Deborah at her husband’s parent’s house, which is about a two hour drive from my home and the closest of the two locations I have to go to. For this reason, I’m meeting Deborah first. Deborah heard about my research through a support organisation and although she lives in another state, she was keen to be part of the research and contacted me early on. Deborah and her husband have come to spend time with his parents and see other family in this state, before going home after the weekend. It’s a great opportunity to meet face to face from my perspective. I drive into the small rural town in the hills outside of the capital city. I call Deborah to check directions and after a short stop at a local park, I arrive at her husband’s parent’s house. Deborah greets me at the door, introduces me to her husband and his parents, then shows me through to a separate lounge area, where we can talk without interruption. We sit opposite each other on the lounge chairs and I place the voice recorder on the coffee table between us. She says that she does not want to use her
daughter’s name in the interview, which I am happy to agree to. Deborah talks openly about her story and the things she has done since her child died.

**The conversation - Deborah’s story**

I think right from the start I’ve had the need to do things creatively, right from planning the funeral. I had the need to express, in those fairly early stages, our deepest feelings. We went to a lot of effort with the funeral stationery; we had chosen beautiful stationery that had lovely, soft flowers on it. Arranging the layout was important and consuming. Few people would have seen it, but it was important to me to try and convey something poignant and meaningful which reflected the life I had carried. The pregnancy was a beautiful experience until she died at the end. You can’t ignore that whole journey over nine months. You can’t sum it up in that one terrible experience, so everything I do reflects the buoyancy I had prior to her dying.

It seemed to be just a moment in time for other people, but for us, what we did in that time was very important. Creativity played a big role. We had to get it (the funeral proceedings) right, so creativity has always been there I think. The creative activities that I do are a lot about the feeling; it’s quite difficult to explain. It’s important to me to have uniqueness about it, my approach I mean. I know a lot of people have experienced the loss of a child and you just can’t put all those people together and say it’s all going to be the same. It’s not like that. What I do reflects the uniqueness of our situation. So, for me it’s really important to do things myself; to create one-offs I guess; unique to us and to our situation. It sort of honors our baby girl.

Your ideas and the intensity of your feelings change over time. We are not quite two years down the track and already I’m thinking back to the initial intense period at the beginning of our loss, and the sense of numbness I had. That feeling starts to abate at some point, it changes a bit. I still get teary every now and then, but it’s not a daily kind of thing, or hourly! It does change.

**Looking for something solid amongst the fragile**

The chair I made from soap was about that fragile foundation. When I was pregnant I was never expecting in a million years that we could have the outcome that we did. In
this day and age of technology and progress, I just didn’t consider our baby could die. I had heard about having a child that was in a breech position and having practitioners routinely practicing caesarians, which just upset me because I wanted a natural birth, so I was doing everything I could to try and get the baby to be in the right (head-down) position. Even going through that and knowing that I was most probably facing the prospect of a caesarian, I still didn’t think that…it never crossed my mind that my baby could die. It never crossed my mind ever. Even when we went to ante-natal classes and I remember in one of the sessions, the midwife was talking about how many problems were associated with a breech baby, and if it gets stuck at the neck during birth, that is generally it. I was sitting there knowing my baby was in a breech position at that time and still not even thinking that that could happen to me. In my head I thought it was something that happened to other people.

And so the chair is more about that. The foundation which you expect: all the knowledge and understanding (of birth etc.) that you gather and grow to learn and inform yourself with, you expect it to be solid. And it’s not really, it’s fragile. There can be other factors that influence outcomes and that’s why the chair had to be made of a substance, like soap, that’s not permanent; to reflect that fragility and the unknown.

There is that sense of fragility and that is why I used the soap. The sturdiest part of the work (the chair) is something that is supposed to support weight, but if you were to sit on it, it would break. It’s the most fragile part. That conveys a real message about that whole tenuous kind of experience.

Whereas, the booties, which are made of silver, they are solid. My child is still a real being to me, even though she is not here and she always will be real to me and I’m solid in that. So, the relationship between the subject, the objects and the materials that I’ve chosen to use, is primary in conveying idea.

I had an exhibition in August, and presented the little chair and the booties. These objects probably showed the most direct relationship to my situation, and yet in presenting it to a general public, I didn’t talk about my situation. I talked very
generically about loss. This is just one way that people could relate to the subject, and if they see a little pair of booties, the impact of loss is always greater when you think of children and dying. As viewer, you make those sorts of connections between objects and ideas. No-one knew my story, specifically, because I didn’t put it out there as such, I just wanted to, you know, explore what I needed to in a way that made sense to me. A lot of the other things that I made were not as literal as this one image, so I feel the chair and booties most strongly and directly expressed what I was going through. Of all the pieces that I made, that work kind of summed it up. Others can relate to it as they want to, some people won’t get it, and some people might see something quite profound. Others just look at pretty objects and move on (laughs).

I’m a creative person generally and I don’t know if I wasn’t creative, whether I’d use techniques of creativity to express and explore. It’s hard because if you had your baby with you, your growing child with you, you’d probably do things with the child and you’d develop photo albums and all sorts of creative things that I imagine most people do with their living children. There is a void, an absence, and I have needed to try and fill in the gaps somehow. For me it’s just quite normal to use my creative outlets to try to do this.

**A place to visit**

My husband is not naturally creative, but he’s a wonderful gardener and he puts a lot of time and energy into various gardening pursuits. We were given a beautiful rose in a pot, sent up from Melbourne, from some of my friends, and he’s constructed a little space in our garden, and bought rose bushes and you know he really thinks about that sort of thing. So even though he’s not a big talker and hmm, he doesn’t go about things the way I do, he needs that space to be able to go back and re-visit experiences. Everyone will tell you men and women deal very differently with grief and women tend to talk more and go round in circles more and men tend to be a bit quieter and process things within themselves.

Perhaps it’s what he goes through to connect and to feel he’s not losing more than he has to. There’s a great lot to be said about the connection between parents and their child and I don’t think he can completely shut off. He’s been brought up in a family
where they don’t talk about hard stuff, you know? And yet he’s amazed me with how much he’s willing to give, in his way, to help himself and to be present in this dreadful situation.

We chose a little site in Canberra. My husband was very clear. We had our baby cremated and it was too much of a stretch for him to have her ashes in the house; so we have a little plot at the crematorium. It’s really lovely, mostly because he’s put a lot of love and care into what we wanted. Well we both did, and that’s a very special place that we visit. Weekly, every weekend, we’ll go down and it’s got two lovely rose bushes, which are coming into flower, and vases. It’s a really beautiful spot and that makes it easier, that we have somewhere lovely. It’s in a beautiful garden environment. There’s lots of birds and activity and it has that real peacefulness about it and it’s a space that we share together and that’s very important.

**Creation, connection and some peace**

For me though, I think the whole idea of doing things by hand, myself (and I’ve done a lot of things) is important. For close family members, I made a little photo album, with the photos, selected all the stationery and everything, all of that. It’s part of the uniqueness of the experience. To me it’s such an important experience in our lives that to go out and just buy (consumer) stuff, that other people would have as well, takes away from that personal link to the experience. For Justin’s parents who didn’t cope very well with the emotion and were struggling with things, I didn’t want to throw it in their face so I just gave them one image of our girl and one of Justin and me. If they wanted more photos they could always ask me. I had to think a little rationally about each individual situation (that is, how family members each respond to such difficult experiences; their limits), and decide what I should do creatively to meet the needs of others and show respect.

I think it’s valuable to me to be able to do things creatively because it makes me feel more at peace. Even though I may not be achieving a great deal, I am, within myself. Whatever you feel, this process is pretty normal, the sadness the being up and down; there are periods of time when I’m not thinking about the experience. For a long time, I wouldn’t let myself go back to the actual experience because it’s a very
painful place to be, but you know gradually, and I think through working creatively, I’ve been able to move between then and now. And re-visit certain emotions and not feel so overwhelmed by the experience. It’s been a real benefit to do things creatively.

There is a lot more freedom in creativity. When it’s just for me there is a lovely freedom and I don’t need to justify what I’m doing for myself, because it’s just meeting my needs and no-one else needs to understand that or even needs to see what I do for myself, you know so …. It’s more like… a feeling or instinct……an instinct. Yeah, yeah, for me I guess it’s more instinctive, it naturally is part of my work, and it’s that creative, instinctive way of expressing ideas. See that has a real, hmmm, I can relate to that in terms of the impact of that strong emotion that you feel, where you feel it so strongly that you are compelled to do something, like write a message or something and yet the very nature of it is impermanent. But I think rationality comes into it when I’m thinking of others, so like the making of photo albums. Each of the photo albums are a little bit different, my sister is very close to me and she wanted lots of photos, so every step of the way things are a balance between intuitive and rational.

I guess it’s that the process, whatever it is, just working through and devoting that energy to your child and you’re doing that through the process of creating something. If you get to the end of it and it seems that it still hasn’t changed anything, that’s OK. It’s tied to the absence, so that because even though you might come up with something that is amazing in terms of meaning it still doesn’t change what’s happened… You still have that, it doesn’t matter what you do it doesn’t change that you can’t fill that void.

I think these sorts of things, which, come from an instinctual, emotional base, are actually part of meaning seeking, of trying to re-find a new meaning. I think absolutely that’s the case, yep, very so. But for me it’s kind of short lived too. I can come up with something that expresses something that I feel has meaning and yet….I can’t explain this…. it doesn’t seem to have that longevity about it, I kind of then strive to find something else of greater meaning.
I have this constant thought of age; that she’d be twenty-one months now and I see other children who are roughly the same age and I kind of look at them and think: Oh, my little girl might have been doing things like that and I wonder what she would be up to, how different her personality would be. You know, you just go through that, but you can only really imagine, because you don’t have anything concrete to base it on. I look for the connections, I think that’s important, I don’t want her to just be a memory, it upsets me when, you know, others are so ready for you to move on, before you’re ready, so, the idea of moving on, I wonder - for others, does that mean forgetting the bad experience? And yet that may be all they have to remember their child by. It’s not so easy for me to just ignore that (the bad experience).

When we first lost her, each day that went by, it freaked me out because it was another day, further away from her and I remember, thinking a week and a half has gone by now and that’s further away from being with her. That upset me an awful lot, it was that distance, that was being forged as time went on and yet I knew that I needed that time in order to heal from that experience and even now I understand that time can be your enemy, but it’s also your savior; you kind of need it.

**Examples of creativity and related information**

*Creative Example 1: Collage entitled “past, present, future” Completed March 2009*

This collage was an activity I was asked to undertake at a *Bereavement Journeys Workshop* that I participated in earlier this year through ACT SIDS and Kids. The
counsellor running the workshop had provided the participants with a stack of magazines and asked each participant to construct a collage, over a number of hours, which responded to the notion of “past, present and future”. I understood this to mean in terms of my experience of child loss, not as a chronology of my life.

I was very focussed on conveying something of my experience and future direction through a narrative of symbols. Colour also helped me to arrange the ideas of past, present and future into some form of order.

The work is designed to be read diagonally from the bottom left of the collage to the top right. The warm red tones (bottom left) inferred “past”; the neutral tones in the middle portion of the collage (from top left to bottom right) represented “present” and the cool blue/green tones (top right) referred to the “future”.

I selected the red tones for “past” as this was a time of turbulent change. I wanted to convey the dynamic and rich nature of that time, beginning from before the tragic outcome of our girl’s birth, by using striking colour. Pregnancy is a time of great emotional and physical change. It involved for me a great deal of research and preparation. The motifs of books (for knowledge and understanding) and fruit and vegetables (for health) helped to convey this key time of preparing mind and body. The chair motifs talk about comfort, and the move beyond the confines of the “past”.

I selected the neutral tones of browns, beiges and yellows for their grounding qualities. I wanted to suggest something of a place for contemplation and almost rational thought. The past had been dominated by high emotion, and as I was coming to terms with our loss and thinking about the steps I needed to take forward, these earthy tones seemed to provide an impassive platform from where I could begin to consider my needs. The motifs evident in the neutral middle of the collage include coral and cave stalactites (referencing time, that is time to reflect and to prepare etc.), fresh food (again, referencing good health), and flower blooms and plant stems (suggesting growth). The wreath, which overlaps “past” and “present”, suggests how past experiences inform future directions. In this case, it tells of the death of our
child, but also of the strong unions and relationships that such a tragedy has brought about.

I used the cool blues and greens to elicit a sense of calm. Knowing that the future would be one of overcoming emotional obstacles – especially when contemplating having a second child - I wanted to suggest a place of calm that offered a sound and inviting space in which I could move into. This “future” is dominated by motifs of natural forms: plants, water lilies, dragonflies etc. These are things that occur naturally and rejuvenate purely. It talks also about a state of mind, as well as of nature occurring, as it should. The butterflies are recurring motifs, symbolising above all else, the notion of change.

Throughout the collage, I have woven and overlapped images to give a sense of my thinking process. It suggests confusion, uncertainty and moving forwards and backwards; the haphazard way we sometimes operate in order to get from one point to the next.

Creative Example 2: “Comfort and Pain” (soap chair and booties) 2009

Working as an artist, I have sought ways to express my loss through my art. This work (above) is one piece of a body of work that I completed a few months ago for a
small show in Canberra. The chair has been made from a transparent soap and the booties are made from sterling silver. The booties have not been polished or buffed to a high shine, but left as an unrefined whitened surface.

The next three paragraphs are excerpts from my artist’s statement:

My work touches on the sensitive nature of loss and uses a combination of enduring and impermanent materials to inform the relationship between idea and object. Soap is a gentle and somewhat soothing material whose cleansing properties allude to a certain comfort. Transparent in substance, it transforms empty space to that which is just visible. Apparent voids become tangible. Like loss, soap has a presence and a weight, yet the surface is unstable and manipulative, magnifying and distorting what lies beneath in alternative turns, and suggesting a false sense of foundation.

When combined with the lasting material of metal, soap tells of ‘time’, aligning its volatility and relative preciousness to passing moments before it wears down and disappears, leaving only memory in its wake. What remains after time has passed and the softer material has worn, is an artwork that is incomplete. It is a shadow of its fuller revealing, that reflects the tenuous struggle between loss and its abundance.

Detail of Booties
The making process is an important part of my creative exploration, as, in many ways, the laborious nature of my working practices mimics the journey of, and through, *loss*. Both occupations require an investment of time, emotional energy and due care. Both require the building of patience.

These booties are made of lamb motifs, and represent a loss of innocence. Each lamb has been cut out using a jeweller’s saw, refined through filing, and then soldered together. There are about six hundred lambs per bootie. The bootie is approximately 90mm long x 50mm wide x 50mm high.

**2014 – Deborah’s reflection after reading the story**

Having looked over this transcript, I feel as though I have just experienced a kind of time travel. It’s been a long while since I have had the time and space to concentrate on my emotion and experience of child loss, so intensely. On reflection, it almost seems indulgent that I was able to work through that difficult period with such focus and creative devotion. But I am so thankful I had that necessary space back then, to be able to do so.

We have had two further children since the interview in 2009; two girls, Polly, now 4 and a half, and Olive, 2. My life is full and busy with all sorts of activities associated with raising a family. And typically, that means time to do anything for myself, comes with limitation. I haven’t pursued my own creative work since having living children – not with any consistency anyway. Not in quite the same way either, or with the same motivation. The sentiments expressed in my earlier interview still resonate now. There is great truth to what I felt and what I still feel today. My time now is divided, however, and I don’t have the capacity just yet to pick up some of those creative ideas and explore them further, especially professionally.

I still think of my first-born every day. I had a peer supporter who lost her child quite a number of years before we became bereaved parents, and I remember her once telling me she didn’t, at that point, think about her dead child every day (she had two other, active boys on the cusp of being teenagers then). I wondered at that time whether I would reach the same point; whether there would be days when I just
didn’t think about my first child. That in itself fills me with sadness now, and maybe even a bit of guilt. My peer supporter’s point was that life takes on new forms and a different dynamic when living children are in the mix, and not to be hard on oneself if those living children demand much attention, over the one who is in heart and memory alone.

I have had a number of responses to my transcript. Firstly, it brought back some very vivid images in my head about the lead-up to the death of our first child. I don’t mind being taken back to that time, though it does bring sadness and stirs regret. This is one example:

On reading over my account of being in the ante-natal session, listening to, but possibly not really hearing (or wanting to hear?) what the midwife was saying about babies in breech positions, an image of her gesture sprung to mind. The midwife made a motion with her index finger at her neck, slicing from one side to the other, when she talked about a baby being born to its neck and then getting stuck: “…if a baby gets stuck, that’s pretty much it…slice…” That’s an enormously powerful image to have to hold onto in relation to the circumstances surrounding our baby’s death. I wish I could erase that image from my memory. I can’t remember what the midwife looked like exactly, but I can remember that gesture. I can be taken aback on reflection of events, but my feeling for my child is unchanged.

And secondly, the transcript reminds me of all that has changed within our family in the past several years.

We have brought Willa home. (And here, you may note I have made a personal development in being able to mention my first girl’s name without fear of having her identity taken away from me). Under two years ago, on her 5th birthday, we brought Willa’s ashes home. We had reached a point whereby we were ready and wanting to have her with us and our other children. Justin made a very beautiful house for the box that contains her ashes. We worked on the design together, but then he very lovingly constructed it over a fairly long period of time. It was a hard space for him to work in emotionally, but he wanted to, perhaps even needed to do it. I’m so very
proud of him. The house is a traditional shape with a peaked roof, made from marine-grade timber, suitable for outdoors. The front and rear sides each have three flower motif cut-outs, and a plain glass inner wall lining, purposely built to prevent weathering. It has been painted white. We placed the beautiful house in a special part of the garden, and have added some of the things that were dear to us from her original resting site.

Some of that space has been disturbed in recent times by our two newest members of the family: our puppies Archie and Rosie. They chew everything! So we have had to move Willa’s house indoors until which time, we can be certain the dogs won’t gnaw at the timber. It’s been interesting to me seeing how much distress this set of circumstances has brought Justin, and I am reminded not only how important and sacred this house is, but also how seldom Justin allows himself time for grief. Grief just clings. It’s not always overwhelming, but it’s fairly present.

I have included a picture of the house so you can see it, but it’s one of the very first photos I took of it in its garden location. So the space hasn’t been planted up with some of the small flowering shrubs we chose for the space, nor does it have many of the other features (bird baths, vase etc), we relocated from the original site.
Having Willa part of our family remains very important to us, to Justin and I. We do what we can to allow her space to be with us in whatever form it takes, because we love her so.

My time is mostly devoted to my living children: exploring the world; being creative; and engaging in different experiences. I have found it important and necessary to include Willa in our talks of “family” with Polly in particular, and in time, I will with Olive too. I don’t want the experience of Willa to be excluded from the knowledge of our living children. Little people have lots of questions, and they tend to be very direct. I try to find ways to explain Willa, our loss and how it all fits together through means other than my words, which seem inadequate at times. It can be a delicate exercise sometimes. Using some sort of creative tool is always helpful, even if I haven’t created that tool myself. Though I may not have the same amount of time to be actively working through a creative process to manage the ebb and flow of my own grief, I manage to find opportunities to help me take steps forward. I am drawn to texts about loss, not necessarily non-fiction either. I recently read a very engaging novel called *Lost and Found* by Brooke Davis, which carefully described feelings of loss that are common to me. That the author could articulate such sentiment of loss so accurately, connected with me, and made me feel less of an island. These days, taking steps forward also means finding ways to communicate and discuss tricky ideas with my children.

I have a picture book called *Someone Came Before You*, which simply and beautifully describes two loving parents whose first baby dies. It describes the anticipation of bringing a child into the world and then the sadness that immobilises those parents after the death of the baby. It suggests the healing nature of time and how time and love allows new beginnings, hence the birth of another child. Polly went through a period whereby she wanted to hear that story over and over. She identified with the living baby born at the end of the book, but had so many questions. I answered them honestly, but I’m uncertain how she processed it all. She was only about three at the time. It was difficult for her to appreciate something that she never knew truly existed, and I found my sadness transferred to her, which I
hadn’t intended or wanted. It was an emotional stretch for me, and one that was too
great for Justin. He read the book once or twice to Polly by request, but after a while,
I buried the book deep in her bookshelf. We needed some space from the reality of
that picture book, and relief for us all. It’s strange how emotion can be brought out.
Or maybe not so, given our profound loss. We will revisit that story again with the
children, in time.

We tend to get busy with life, and welcome the forgetting of deep, emotional pain as
a result. It emerges sometimes though, not just at those significant times, such as
birthdays, Christmas, Mother’s and Father’s Days, but more randomly. I am open to
whatever comes up. I hope in the years to come I will once again be able to devote
time to exploring loss, and associated feeling, creatively. I wonder how my thoughts
might have evolved by then – if at all.
January 2015 – Greg’s creative synthesis of Deborah’s story

A fragile foundation of life

Buoyant feelings connected to the child in utero

The poignancy and meaning of a beautiful pregnancy

Holding expectations for how life will be

On reflection, a fragile foundation of life

The things we think are solid can break and fall away

A child, a daughter has died

A painful experience that confronts and destabilises

Numbness and tears are an expression of deepest feelings

There is a void………………

An absence…………………..

A need to fill that gap………………..

Intense and unique feelings bring a need to be creative

An instinctive way of expressing ideas, thoughts, feelings

A response to strong emotions that compels

The things made speak for themselves

No need for explanation
Creativity brings movement between painful experiences, the death and how life is now

Time for re-visiting emotions, without feeling overwhelmed

Using creativity, invites a sense of freedom

Being creative, where things are done just for the self

No-one else has to understand

Being creative allows time within the self

Finding peace

A very solid knowing that this daughter is real and important
Chapter Six – Our first child – Carol’s story

Introduction - 2009
On a cold, sunny May 23rd 1983 our son, Lachlan James Quayle died after being put to bed for his morning nap. Lachlan is our first child and I am writing this 26 ½ years later. Lachlan was a healthy, chubby baby boy who was just beginning to sit up at 5 months and two days of age. Lachlan is our only son and has three younger sisters all now in their early twenties.

Significant things I have done to keep the memories alive

1. Garden, special tree or plants
2. Smocking sampler
3. Baby brooches
4. Cross stitch
5. Photo albums
6. Jewellery

Photo Albums

A collection of all photos available to me of Lachlan throughout his life and memorabilia of special significance collected since Lachlan’s death. The photos were removed from two old albums and collected together in chronological order in a decorative manner, including stickers, parts of the original albums (including pages and items of importance), journaling of the experience at the time of death, letters from State Coroner, SIDRF, Royal Children’s Hospital, name tags, Memorial Service booklets, cards at anniversary times and items created by his sisters. This album has been added to since main completion at the time of Lachlan’s 25th birthday. The books are both square, blue with a small bluebell decorated on front cover in silver. The books are heavy and each with approximately 20 double sided pages. The books
can be added to at any time and kept in a safe bag, easy to pick up and run in an emergency. Each page is covered with a plastic cover to prevent finger prints on photos or tearing of items if touched by children. The books can be accessed at any time.

Smocking sampler

In 1993 when Lachlan would have been 10 and after I had begun creating smocked dresses for my daughters, I decided to create a smocked ‘something’ for Lachlan. This is in the form of a piece of pale blue, polycotton material pleated into many small pleats gathered together and then stitched on with embroidery. The fabric has been imprinted with blue dots to help with pleating process but were not removed at the end of the task. The embroidery depicts the many ‘boy things’ we would have expected Lachlan to participate in and were chosen by all family members – a teddy, tent, cricket bat and ball, yacht, helicopter, horse (merry-go-round), puppy with the words “Memories forever Lachlan James Quayle 21st December 1982 23rd May 1983”

This has been framed with a mid-blue matte square around the outside of the smocking, narrow gold line framing the matte in a wooden frame in pale blue
wooden frame with inside gold edge. This has hung in lounge room since it was completed. The staff of the Australian Smocking magazine, provided the patterns free of charge when they found out the plan.

Baby brooches

In 1983, our family developed their links with SIDRF and in 1987 when undertaking Parent Support and Speaker Training, I found a small ‘FIMO” brooch at a craft stall. The brooch is about 2.5cms in length and of a baby wrapped in a blanket. I then purchased a number of similar brooches from the same stall keeping many for myself and giving away a couple to staff at SIDRF. They were similar in skin tone colour of pinkish beige but with different colours in the blanket, hair colour or in the case of the photo attached Australian colours and flowers. From that point until 2005, I wore these brooches on my collar/or outer clothing every day. Finally in 2005 when the last regular brooch was lost, I separated from the practice and found other jewellery to maintain my connection. The brooch is small, has a smiling face and is smooth but with character in the facial features, especially the smile. The hands are just poking over the blanket. There were many comments from my friends and colleagues as
soon as ‘Lachlan’ went missing – he was well known by everyone in the brooch. This photo is of the last remaining brooch that stays carefully secreted away in my jewellery case – just in case I should lose this one.

The scene of the conversation - Later in 2009 – Greg's perspective.
I’ve already interviewed another parent today as part of the research, so, after a break for lunch and a walk, I travel from a rural setting in the country, through to the city, then across town to the seaside suburbs. I roll down the windows on my car; it’s a warm day, and I take in the smell of the beach, which I love. I think to myself ‘even though it’s in the city, what a nice place to live’. I stop to check I can find the street I’m going to, get out stretch my legs a bit and then drive another ten minutes to arrive at Carol’s house. I knock on the door and a young woman opens it and invites me in, just as Carol is approaching from further in the house. Carol welcomes me warmly, we know of each other and have met through work-related connections, but don’t know each other really well. Carol takes me through to a large room at the back of the house and we pull up chairs to sit beside a large table. I place the voice recorder on the table beside us.
The conversation - Carol’s story.

We had an ordinary funeral two days after Lachlan died and then I remember standing outside when we had his ashes brought home and buried in the front garden. I remember standing there with Don, there was only the two of us and the minister, committing them to the ground, and saying to Don, “It won’t happen again, the next one is probably going to have Down Syndrome”. So it was like, yes it had shattered us, but it was also matter of fact. I was pretty matter of fact when he died, because I needed to be the one to contact people and tell people. I needed to tell the story, and that sort of stuff.

But also I think it was part of the nurse in me that wanted to be in control and to be in control was to know what was being said to people. They didn’t really know the truth, because I wasn’t even there when he died. My sister was looking after him and yes we were shattered. For me, family was the most important thing and that’s probably not how people would see it now (laughs) - now that they’re big and grown up and what have you. I wonder too whether, coming from a background of nursing, where it was always a nurturing role, that maybe makes a difference around what’s important in life. You know human caring has always been important in life for me. So I wonder if that is part of the reason why it wasn’t this huge change for me. It’s not to say that if I saw kids jumping around in cars without car seats or seatbelts, that I wouldn’t get really angry, because I certainly did. But in terms of any really dramatic change regarding my focus or things like that, I’d say no because these things always were a big focus for me.

I know that there was that element that families had always been paramount to me and in fact when I got pregnant I actually resigned and didn’t take maternity leave, I think in those days I could have taken maternity leave, but I decided that what I wanted to do was be home with my kids and look after my kids. So when he died, you know, we were absolutely shattered, but there was a part of the practical pragmatic part of me, and I suspect that it is the nursing part of me, that was aware that life isn’t forever and that kids do die. On top of that, and this is really bizarre, I had, when I did my paediatric training, I did three assignments, one on SIDS, one on
Whilms tumours and one on cystic fibrosis and we’ve had all three in our immediate family or close friendship network. It’s like, oh my god. So I still have notes from the late seventies of SIDS information from when I did my training. So I guess I was aware.

I think people in the community got to know, particularly where I was comfortable in talking about the ‘why’ which is probably further down the track from when I was working as a midwife. As a midwife and working in a hospital, I was very conscious of other mums and those mums not wanting to know that babies die, protecting them in the early days, but not so protective later on. I guess with the ‘reducing the risks’ message and my role at SIDS and Kids was about well actually “yeah you do need to know”.

I suppose as time went by and clearly now, is that feeling that perhaps I can create an example or be a role model that while life can from time be really painful, you can get on with life and find that space in your life to live with it. So I guess that was probably a significant thing and I guess beyond that I went on and had my three girls.

Keeping memories and the connection safe
It’s really interesting because if I think about it, in the early days after he died, there was no creative part to it. It was gathering photos and making sure that I had photos or anything of his that were all together and keeping them safe. One of the things I did with his photos was photocopy every single photo, actually up the road at SIDS & Kids and to put those photocopies in the bank in a safety deposit envelope, so that if anything happened, these were my back-up. This is just the thing you have at the time as a parent (laughs).

So we have all of his photos and at the time I kept them in a photo album, it’s traditionally how we kept photos, but there really wasn’t a story to it. So I guess it would have been, around his 21st birthday, I’d never ever written anything about him, never written anything up until that point, although I had done a lot of writing in my head, but had never put anything on paper. I remember I sat here, one night, with my mum and my sister and my sister said to me, I can’t believe that you can remember
back to your pregnancy, because I was actually, and this was maybe because he was my first pregnancy, actually able to recount right back to the very moment that I was told we were pregnant or that I shouldn’t get pregnant, (pause, laughs, “anyway”). So yeah, I had recounted the whole story, the whole story of what I could remember of the day that he died and I guess that was therapeutic, sitting down and having that story that’s there for the girls.

Then it was deciding how do I present that? Because for me it was really important to have the story down, but where do I put it in the photo album in a way that is not confronting to everybody who opens the photo album? So I found a way to put it in a little pocket that enables people to pull it out and have a read of it if they want to and for people to not do that if they don’t want to. I guess it’s from there that I’ve seen myself as doing more creative stuff around him.

There were challenges, one being the fact of cutting into a photo, because for me it was like, I don’t want to damage anything that I had of his, so actually cutting a photo was like (Ohhh – sighs an laughs uncomfortably). Of course unlike now with digital photos there was no going back, because while I have got some of the negatives, I don’t have all the negatives. Hence my anxiety about all this, like having stuff at the bank for safe keeping and what have you. But there were things that helped me with that. Like when I met Gerry, whom I’d known for years, and she started doing her ‘creative memories’ (scrapbooking), we had a conversation and I said to her when she first asked me about it, I said you know that would be really good for parents of, you know, babies who had died. And that was not the reason why she had actually invited me, it was just this is what she’s doing and probably hadn’t thought about it particularly and that is where she is today (doing work with bereaved parents). His photos have always been in photo albums always freely available for the kids to have a look at, always in the lounge room. And I suppose one of the things I did was I wanted them to tell the story, because they were just photos in an album, which is I guess just how they are kept, isn’t it? I think, look the connection was clearly there, but I think in most instances it was a pragmatic thing, a
task that I needed to do. Yeah, yep. I probably didn’t make a lot of sense of the ‘why’ until after the fact.

An album of life and keeping him close
As a consequence of that what I have is not just an album of his photos, but an album of his life (obviously in my mind), his life after his death, which is the way he stays with me. There are lots of things, like cards, anniversary cards, articles and newsletters, things that I got and things I have done that relate back to the fact that I would not have them or done them were it not for Lachlan, because life would have been very different. So, that’s a ‘live’ album I suppose which I guess I’ve shared with a number of people, even as a professional, where I can say to parents “it doesn’t have to stop” at the time that the death happens or that short period of time afterwards, that there are ways of keeping things alive. For me, you know, obviously at red nose day, things get added, things that I might have said, like I’ve spoken at red nose day a couple of times. So I keep those sorts of things, things that are significant and specifically around him, they just get added, including photos from when we had dinner on his birthday and things like that. So it’s ongoing, yeah.

As time went by after his death, apart from the photo album, there were probably things like the little brooch which became a really significant part of my life, his life and probably people around me as time went on. For me, it was a way of having him with me all the time and at the time I was working as a midwife so it was appropriate on a uniform. It was cute and it didn’t create a whole lot of conversation. I bought them as a link between me and two of the counselors (from SIDS & Kids). One was going over to Japan at the time and I had bought one to send over to her and it was just nice to have. I think in those days there was also a locket that I had at the time, but probably that was all I had. I’ve always had a locket, so there have been a variety of other things that have happened over time. For his 25th birthday I bought one of these (holds hand to jewelry) with his name on it. Jewelry has always been really important and I guess in some ways that is what the brooch was, but it was that continual link between him and me.
So he became, or the brooch became, significant (I think in the end I bought about half a dozen of them) and I’ve only got one left now because I kept losing them. In fact, the last one I lost was around his 23rd birthday and who knows where it went. But I guess out of that I made a lot of meaning, so I lost it and only had one left and people would notice and people would ask “where’s Lachlan”, not “where’s the brooch”, but where’s Lachlan. I guess in making meaning out of that, it’s like, well he’s twenty three, it’s time to leave home and now I have to find some other way of, ummm, I don’t know, having him with me.

Doing something for Lachlan
I guess it’s just part of that journey and I guess it’s stuff that just happens. It doesn’t really need a lot of thought. I mean thinking about the smock things, the sampler, there was a lot of thought went into it, but it was originally just from a feeling that I needed to do for him what I did for the girls. The thing that had always been important in our lives as a family was sewing. And so I’d learnt to smock for the girls when I was pregnant, actually with the second girl I think. So when I was approaching his tenth birthday I felt the need to create something, whatever that might be and I didn’t really know what it was, but I guess it was because I was making stuff for the girls, it was like this was never something I was able to do for him and so in fact what I’m talking about is the sampler that we’ve got that I gave the picture of to you of. It became a family thing because the girls were old enough then at 4, 6 and 8, and while I obviously did the sewing, everybody had input into what would be part of that sampler. So what would be the symbols that represented having a son in the house or having had a baby boy in the house or what he might be in the future. That input included obviously cricket and football, because that’s what his father would have wanted, and there was lots of conversation I suppose, while we were doing that, So that became equally important and it was one way of doing for him what I’d done for the girls, using those same skills. Now that hangs in the lounge room and there was a lot of thought that went into the framing, as there has been with lots of other things, because there are all sorts of things around the house, like cross-stitch. But there were lots of thoughts about where it should hang in the
house and all that sort of stuff. Yes it should be framed, yes of course it should be blue because he’s a boy. Yeah so I guess that’s all of what led me to that piece.

I think in the early days people would say to me, even when it had nothing to do with Lachlan, just sewing you know, they’d say you are incredibly creative and I’d go “no I’m not I follow a pattern” that’s not creative, I’m just doing what it tells me to do! Whereas I would say OK I can see the connection in the smocking sampler, because we designed it and it’s all ours and the same with the photo album, where there was a story to be told and it’s got more design to it. However now I would see that it doesn’t matter what you do it’s about creating and doing something around the person who has died.

I guess it’s interesting when people who don’t know you ask the questions about ‘well how do you come to be working in the area that you do?’ There’s always a bind about what do you disclose and what don’t you disclose. But that whole sense of then being able to reflect and know that I really do know what this was all about and why I’m here doing what I’m doing. I’ve got enough understanding to be able to support people and be realistic in an area that I’m obviously very passionate about.

A continuing part of life
So I guess for, me it’s very much about keeping him as a part of my life and giving me a space to be with him, from time to time. I guess as my life changes that will change, even over the next twelve months with changes to my connections to bereaved parents, it will change and probably be more important. At the moment, I have links with other bereaved parents because of my work doing stuff with bereaved parents. I’ve resigned from that role completely now. So next year I won’t be doing the support group. So it’s like another step and where is it going to fit in my life? Because it’s not like any easier; it’s going to be equally busy, you know? And sometimes being in a group like that even though you are the professional it still gives you a space to be thinking and know, well this is why I’m here. It’s the reason I’m here as part of my professional journey. I will always say that he has got a part in my decision making, I guess from the time when we really looked into SIDS, which was a couple of years after he died. So from there on when I first started
working at SIDS, most decisions, I know I wouldn’t be making them if it weren’t for him. Yeah, no it wasn’t planned, it certainly wasn’t. I mean I don’t think any step along the way was a plan. Even when I went from SIDS out into the community, it was over a couple of years and I was really angry at the way that people couldn’t understand why I would want to stay at SIDS. ‘Because there was real encouragement for me to move out of the organization and I understood it then and I understand it now. But I guess I felt like they didn’t understand where I was coming from. And those particular people were not bereaved parents, no that’s not true, one of them was, but she had lived all of her life as part of the organization, I mean for her it was her whole purpose in life. So I guess I was really cross.

So, when I went out into the community, I worked in welfare, but in fact I ended up working with bereaved parents, obviously because of my experience and expertise, but that’s just how it was. There just happened to be a number of families where there were bereaved parents in dire situations. So after many a conversation the manager would go, well it makes sense for Carol to do it. We’d try to move away from it and go “no other people need to do this as well”, but this child is already damaged enough or this parent is already damaged enough, maybe there is a close fit available here. And I guess it was opportunistic that the position came up at the Children’s Hospital. And while it was not the same it was still in the same vein where I always wanted to work, with children and families, so that didn’t change from when I first finished my training after nursing, but the content of that conversation changed over time. Yeah, so it’s not been planned you know?

I do wonder whether people, particularly when I started at the Children’s Hospital, whether people thought I was a bit altruistic. I know we did an article for The Age (newspaper) a couple of years after I started there and it went into the careers section. At the end of the interview there was the paediatrician and I and the publicity person. The journalist said to us have any of you had the experience? Remember this was going into the careers section of the paper for heaven’s sake! So the other staff just looked at me and of course there is part of me that’s thinks well of course I’ve had an experience, but I don’t know if I want to disclose this. So Jenny looked at me and I
said well yes I have and the journalist goes well tell me all about it. I said well, no, because it’s not relevant. There were two reasons – 1] because it’s not relevant and 2] I do not want to be seen by a group of professionals in an organization that is incredibly bureaucratic and hierarchical, and any other word that is associated with the more negative side of medicine, who would then see me as a crusader. And I am not a crusader. That’s not what I’m here for. Sure I’ll advocate for kids and parents, but I’m not here on a crusade. This is not a SIDS experience. If it was around SIDS, then maybe, but that wasn’t the case here. There were a number of people who knew about my story at the hospital, but it wasn’t something I was going to tell the specialists about and most certainly not publically. So I was aware enough that journalists go for the personal more than the professional, but I didn’t give away anything personal in that situation.

I think I’m probably a fairly practical person, a task-focused person. I mean I do a lot of reflective thinking from time to time, but I guess it hasn’t necessarily been around him. It’s just about him as part of the family. Him as part of the family, with the people that have died and wondering where they might be and how they might look after us. There’s sort of a sense for me that they are there. And they, like I said before, particularly Lachlan guides me from time to time. So I don’t know what that is? Spirituality? I don’t know. There are all with those connections to Lachlan, absolutely, yeah, yeah. I think it wasn’t until I lost the last little brooch, that I really started to realize that I had made a lot of meaning out of a lot of things that happened over time. When I changed jobs again recently it was like, you know, where is he? What am I doing and in fact again thinking about it and I remember consciously thinking about, you know, maybe he’s suggesting I’m just moving from kids to adults and that’s where he is now. He would be an adult himself. Then I think if anybody heard me talking like this, they would maybe think I’m absolutely off my rocker, you know? That’s just how it’s been. There’s a sense of Lachlan’s place in the family.

It’s not always been easy keeping him as a part of the family. A time when this was challenged was probably by the fact that Don’s parents really struggled to talk about him, to have his photo publicly displayed in the house. You know I remember taking
a neighbour to their place one day and she said to me “I can’t believe where the photo is”. You know and the photo was in the lounge room, but it was hidden behind the dining room table down the bottom of the shelf, quite tucked away. Now it’s not a little photo. Whereas you go to my mum and dad’s place and his photo is in the same place as all the other kids’ photos, now with grandkids etc.

I guess for me, there were two things; one was that one of our close friends, who was thirty when Lachlan died, was told by his mum that he was not the eldest child in his family. He had an older sister who died when he was a couple of days old and he’d not known about that. So I guess a couple of things came from that. One was there was no way on earth that Lachlan was not going to have a place in this family, or any chance that my subsequent kids were not going to know about him, regardless of whether other people liked it or not. His photo stayed in the lounge room where we expected to place our other children’s photos and it is still there. It creates a bit of a problem now because the other children want their baby photos taken down, but I have this dilemma, because if I take theirs down and leave his there, then there is this stark contrast. So I think they need to stay together. It’s also easier to just leave them there rather than making a lot of fuss about it (laughs).

**Making sense of his life**

I suppose there are times when I sit and think of how we’ve made meaning of this. What does it really mean for our family, for my god, for myself? I think a lot of it is more around a sense of, I suppose, pride more than spirituality. It’s certainly challenged my beliefs; no question it did challenge our religious background. It breaks the foundations and pulls apart what was important to you. Like all the things that were important in life, start to shift and change. I have to say it probably challenges my spirituality, I don’t know, around working in a Catholic organization, because that’s not my upbringing, never was our upbringing. So that in itself is a real issue and it’s not something that I’ve disclosed openly at work. so to get into the base around Catholicism and Catholic ethos and my own is all too hard, because I possibly think a whole range of things that don’t make sense to people.
I guess, you know, there was a time when, we got really, really angry with the church, because he had been baptized a few weeks before he died on Mother’s Day and I guess we probably had him baptized because of an expectation from Don’s family. And for us, while that was how we were brought up, it wasn’t that important to us. Yeah, and then of course when he died two weeks later, it was, woah, how, why, you know? We’d done the right thing, why did we do that, you told us we should, you know that sort of thing? That was then coupled with a change in minister at our local church and the person who did the baptism also did the funeral and had never done a funeral before for a baby, so he was only a young bloke. Then we thought of the minister that married us only eighteen months beforehand, we were really cross that we didn’t use him, so it’s all mixed up around that. It was sort of like they wanted to own us as a family and I suppose we sort of moved away from that because there was all this newness that happened down this way. We then had our subsequent daughter and still decided we wanted to get her baptized because that was ‘the right thing to do’. Then having this guy come to our house and asking why we hadn’t been to church and couldn’t understand why we hadn’t gone to church. For us it wasn’t about going to church because that wasn’t going to change anything that had happened, we didn’t think that it was going to make us better people or worse people.

So I guess from that sort of context as well, we felt we sort of did what the church required of us and he still died and then we didn’t get a lot of support I suppose from the church anyway. It made it really difficult. I do now feel challenged by a really strong faith in the workplace and that often gets me thinking and working in palliative care too and in the last ten years working with children dying, in particular means I do a lot of thinking I suppose about ‘where is he’? Where’s my dad, where’s everybody? Where’s my head in all of this and what happens? I don’t know that I’ve made any sense of that sort of thing.

It’s really about keeping his place in the family, even now having newer members of the family know about him and I guess as we grow older that becomes another layer of the grief, a challenge I suppose, because it’s not something I thought about, I think
we all think about things like when the kids get married, that’s something that he
never did or he didn’t get to go to school, you know, all those sorts of things. But in
fact that next step of saying to the kids if they bring a partner home, is where does he
sit in the family? How do we tell them? You know all that sort of stuff. Only one of
kids has got a partner at the moment and it seems like it’s fairly serious, but when we
first met him, he was at a local University studying science in the sleep laboratory,
where I had a lot to do with staff and it’s sort of like, - I remember the first lunch that
he came to and I’m sort of thinking I can’t say anything, because Megan will be just
devastated. You know she needs to tell him. So you know that’s sort of the next level
of things, because for me he is a really big part of our family. So the girls were used
to us going out for his (Lachlan’s birthday), we don’t go out for his anniversary date
anymore, but we do for his birthday. So I guess it’s up to them what they say to other
people. It’s sort of outside my area of responsibility, it’s a bit like a grandparent you
know? Because we had a grandparent along to one of our groups the other day and I
was sitting there thinking ‘what happens when my mum gets asked how many
grandchildren has she got? It’s like I can get really cross if she doesn’t acknowledge
him, but then that’s her responsibility not mine.

I look back think of a story I’ve told a few times and you met the eldest daughter
when you came in the door. When the kids were younger it was still quite raw and
the he was always part of the family and the kids always had this thing of showing
other people his photo when they came to the house. When my eldest daughter was
at Kindergarten, I remember this one day, when some of the kids came to play here
and one of the mums came to pick up one of them. She was standing there and
admiring the photos and Bronwyn, who would have been four, bounced into the room
with her friend and said “Oh that’s Lachlan and he’s dead!” For me it was like “oh
my goodness”. I hadn’t even thought about it before, but at a similar time one of the
 kinda teachers had said to me, “what school does Lachlan go to?” I was like - huh?
Then realized that Bronwyn obviously talked about him. I think it was at that point
when I realized that he really was a part of our family and has a real place in the
family. Which does create a bit of angst around whether I was doing all of this very
well at the time with the other children?
I guess it was always a question as the kids got older, and I suppose just thinking about it now with Megan and her boyfriend, and I don’t know what she’s told him, but to what degree, once I’m no longer able to articulate it, whether that be because I’ve lost my marbles or whatever (I have this fear because my grandmother had dementia- laughs), are they going to keep him alive? And if so in what form, because clearly they never met him?

How confronting is that say for the people they meet, like Megan’s partner, although for him it’s maybe not such a big issue because he’s heavily into the health field of work and she is in the health field also. So it’s not so difficult. He’s also known me as someone who works in the area of death and dying. Also Megan has always been fairly open about Lachlan and has possibly had the best connection to him in some ways. The others have always enjoyed going out for his birthday and they were given a necklace which they still wear, so it still has some meaning to them or they wouldn’t wear it, ‘cause they are now adult women who do what they want to do in other ways. So maybe he will stay there into the future?
2014 – Carol’s reflection after reading the story
The changes to my home and work life have impacted on how often I consciously focus on Lachlan. Changes of jobs to areas that have less focus on bereavement, children and families mean less overt focus on Lachlan. However, I do have portfolios in the areas of perinatal loss and vulnerable children which remind me of my life experiences. The changes to the garden have seen the death of his tree planted over the ashes and what to do with this changing space - the children gave us a new rose for his birthday, so without thinking we have a new look in the garden. The interview content remains the same, the memories remain the same but of course emotions stir. We have just passed the festive season, which is always a tricky time because his birthday is the 21st December, so it’s never a truly happy time.

Nothing has changed in the past five years in relation to when and how we talk about Lachlan but the changes to work has meant changes to how I might talk an experience more than thirty years ago. My passion for bereavement remains and I continue to take opportunities to educate colleagues, students and staff, however the degree to which I use Lachlan overtly as an example in name is far less. My role on the board of S&K has now ceased, affected significantly by the changes to the organisation and what I have to offer; that is, my personal experience and professional experiences versus a business approach to bereavement support and care in a changing welfare system.

At this time in our lives, our focus on an expected grandchild (first) and the challenges it is bringing - delight to be grandparents in conflict with fear, anxiety and a desire to protect my daughter and son-in-law from such emotional pain, vigilance in health care and baby care. This does not appear to be thought about, considered or an issue for most friends and family members. The question recently - a boy or a girl, what is your guess? Part of me says I know it is a boy (we don’t know) but I’m going for a girl because I am not sure how I will cope. We will await the joyous occasion - everyone is well at the moment!
My creativity continues, adding to his album from time to time, updating the garden, wearing a new locket (following the death of Lachlan’s paternal grandfather) with the 2 photos and the dog tags from 2009 are always worn, celebrating his birthday with a special dinner, this year including the partners of 2 of the girls. He is still our son, we wait to see if his sister incorporates him into the new addition in February 2015. Subsequently my girlfriend made a lovely small quilted mosaic of Lachlan’s photos which has been added to the lounge room canvases.
January 2015 Greg's creative synthesis of Carol’s story

What is important simply shifts and changes

Absolutely shattered by his sudden death

Shattered, but also matter of fact

A pragmatic part that cares

Family is the most important thing and there is a need to tell the story

Interesting early days of gathering photos

Anything that was his is kept together and safe

Back-ups made of precious items that link him to his mother

A little brooch becomes significant

Mother and son connected all the time

A locket and other jewellery

One with his name on it

Together, there is a continual link

Photo’s in an album, but stories in memory.

Sitting with a grandmother and sister.

Recounting everything.

From pregnancy, to the day he died.

The therapy of sitting and writing it all down.

Having the story there
Creative stuff around him and about him
Cutting photos brings a sense of ….Ohhhhhh, there’s no going back now!

Creative memories, where the photo’s tell a story
An album of his life
His life after death
A living album
It doesn’t stop
It’s ongoing

Feeling a need to do for him, what was done for the girls
On his 10th Birthday there is a felt need, to create something

So a stitched sampler becomes a family thing
Sewing together symbols representing a boy in the house

A son in the house and what he might be
There is a question of where to place it in the house?

It hangs in the lounge room in a blue frame
Because he’s a boy

Things done to keep him as a part of everyday life
A space made to be with him from time to time
He’s part of decision making and a reason to do things

It’s not planned but it’s practical
There is reflective thinking about him

Where might he be?

A sense he is looking after the family

Lachlan guides his mother from time to time

A lot of meaning

Sitting and thinking

What is the meaning of all this?

Challenged beliefs and broken foundations

It seems everything was pulled apart

But what is important simply shifts and changes

He is part of the family

Will others keep him alive?

In what form would that be?

I wonder?
Chapter Seven - A life in pictures and fabric – Kate’s story

Introduction - 2009
On the 9th October 2008, my second daughter named Georgia arrived early at 35 weeks after a normal pregnancy. She was diagnosed with non-functioning polycystic kidneys and was in renal failure. Georgia was cared for in the Royal Children’s Hospital since her birth, being treated with peritoneal dialysis to replace her renal function. Unfortunately, she was never able to come home and passed away in PICU when she was six months and one day old after complications from her kidney disease.

The things that I have done or made

Memorial Album

The first project I began working on after Georgia’s funeral was to make an album of what I describe as the highlights of her life, month by month. I wanted it to be a snapshot of Georgia’s six months that I could show friends and visitors who hadn’t met Georgia, when they came to see us. I wanted to still be able to ‘show off’ my baby. I had taken hundreds of photos of Georgia while she was in hospital and I also wanted to do something meaningful with ‘the good photos’. The album I used was given to us as a gift from my brother and his wife upon Georgia’s arrival. It is square shaped album (about 20cm) with ten black plastic coated pages, a modern bright pink cover with lighter pink agapanthus flowers printed on it.

The album was worked on over about a week in the first month of her passing away. It begins with the month of October when she was born, then goes through month by month to April. Every new month has a heading and a brief description of her age, weight, dates of significance and comments about what she was achieving. It includes photos of her and our family, which I edited to have soft edges, coloured paper as background mounts, colourful sticker letters and silver sticker butterflies to decorate. Also included are some of my favourite poems and readings from her
funeral, typed with various fonts and with colourful backgrounds. There are cards with her hand and foot prints on them, a lock of her hair in an envelope and photos of her favourite toys and gifts which are kept now in her cot at home. More recently I added a photo my mum took of her and a poem my dad wrote for Georgia.

We keep the album on a table in our living area which displays photos of Georgia and our family, along with candles and flowers.
Quilt

The second item I have chosen to describe is a quilt. I made a doona cover using basic square patchwork when I was pregnant with my first daughter. I wanted to attempt something more advanced and express Georgia’s life in the design. My mum is a very good quilter and made Georgia a small cot quilt for while she was in hospital. It has her name appliquéd on it with pink letters with white spots and a stars and moon designed material as the background. I wanted to use these same materials in the quilt I made. I firstly designed some images I wanted to use and attempt to appliqué or embroidery stitch. The designs reflect something personal about her. I used a sketch book and sketched or traced images such as the little bear that appears on the music box we played for her, the Big Nutbrown Hare from the story Guess How Much I Love You which we read to her, the first teddy bear we bought for her, a rainbow, butterflies and dragonflies, a colourful windmill, some favourite verses and her birth details featured in a large pink heart. It is still a work in progress and I actually don’t know what size it will be and how many blocks or stories will feature on it. Each story block design will vary in size, around 15cm square to 30 cm square. I have used a selection of different fabrics in white, soft pink, green and yellow tones which are incorporated into the story blocks. I have used basic embroidery stitches such as backstitch, blanketstitch, some satinstitch and French knots. I think I would like it to end up being a wall hanging to feature in her bedroom next to her cot. It might end up being around 1 – 1.5m square. While I am still working on the pieces, I keep them neatly stacked in her cot along with her teddies and toys.
Life in a different world

The scene of the conversation - Later in 2009 – Greg's perspective
I have arranged to have the whole day free from work, so that I can travel to meet with Kate – one of my research participants. It’s been busy work wise and after the interview, I plan to take my time driving home, some self-care time. I catch a car ferry across the water to the seaside area where Kate lives. I drive off the ferry and then find my way to the main street of the town where Kate lives. We have agreed to meet in a local café early in the morning, before it gets too busy. I arrive first and choose a table to sit at, that’s back away from the counter, to minimise noise levels from the street. Kate arrives soon after and after greeting each other we order a hot drink each. Once our drinks arrive, I ask if it’s OK to turn on the voice recorder and Kate nods her head.

The Conversation - Kate’s story.
When Georgia was at the hospital, we’d be there most of the time. We’d come home for a few days, and when I came home I had all these jobs to do. I was getting chiropractic care before I had Georgia anyway, so I’d come back, I’d see my chiropractor, maybe have a massage, it was kind of just my life, continuing a little bit. Just get home do all these little things, pack the car, do what I had to do here and then go back, so I kind of, maintained, that for a little bit, but thinking it’s still really weird. Yeah, I mean, I’d be up ‘til midnight or one o’clock, doing things, just so I wouldn’t have to lie still in bed and think about it. I’d exhaust myself and get everything done, so I could possibly sleep for a little bit. It’s very hard to…. let others know…. Unless you’ve been there for any length of time, other people don’t really understand and you really wouldn’t wish it on anyone.

All the nurses made me go out and see the real world. You know, I’d leave her and go and jump on a tram and then go into the city and go have a massage or something and it’s like two parallel kinds of lives…
I’d be sitting on the tram going, ‘now you know, I’ve got a baby in the hospital and this isn’t really me, what I’m doing, because actually my life is there’, and I felt like this weird sort of parent to her. I also remember times where other mothers were there are lot and staff organized for them to go and have a hair-cut and massage. It felt wrong to do that, to be consumed by yourself for that period of time.

You know I went through a period recently, where I was thinking about all the nurses and the different days we had and although she was never well, she was going OK this time last year and we thought OK she won’t be home for Christmas, but we might get her home in the new year if things go to plan and that kind of thing. In January we started getting things ready in and around the house but she took sick again. Umm, I don’t…. regret’s a very strong word, I think…. of course I wish….. Yeah there’s a lot of wishing.

Regret is like, you could have done something about it? But we know all along that we couldn’t.

Well if we’d lived closer, maybe we could have taken her home for the day and then taken her back in the evening, that sort of thing…perhaps? But Christmas day last year, we did take her over to my sister’s house for an hour or two and that was her one and only outing. Really, the hospital was our home and it was a strange existence. It kind of got….. ummm….. I think we went through that process of going Ok this is a really, really weird place and then, OK, we’re sort of used to it now (Laughs). It was kind of like these corridors are like corridors in our home, I guess and it just became natural to just be there. Although you’d walk out at the end of the day and go, ooh this is a bit weird… you know?

I’m going up to the hospital tonight (after this interview) for a parent’s session with the bereavement group and I’ve been to two earlier on in the year and thought I’d go to this one because the Very Special Kids lady is coming to the group. It’s about the creating of memories and that type of thing, I think? I just go and take Maddy up and she stays at my sister’s who lives just up the road from the hospital. I haven’t been back since October for Georgia’s birthday and I’ve got some books that people
bought as gifts, to give to the neonatal unit, so there are a couple of little jobs I want to do. So, yeah, going back to the hospital, it’s like hmm, I haven’t been for a while.

There was a time there where I went three times relatively close together and that was kinda’ OK. The group is just in the front entry building and it’s,… well… yeah, I feel I need to go now because I haven’t touched on that for a while… like counselling or a group thing like that. I’m sort of worrying a bit, yeah, because I’ll be going back there and all those memories about the hospital will come back. But honestly, they’re with me all the time anyway.

**Documenting a life and the journey**

Since she died there have been things I’ve done and of course there are changes over time. Like that first album, it’s done, it’s completed, it has had its journey. It’s still there to show and share, but there is nothing else I want to do to that. It has a lot of meaning because that was in the first few weeks where everything was just so raw and so fragile and it’s what I did in that time to help myself. I wanted to focus on the highlights of what she went through, because it was such a journey…. I was getting in my mind the dates of things, what happened, what she went through here, to here, to here, and then down here, and then back up here, so I could get in my mind that duration, that journey that we had and just sort of re-live it.

As I went through every month, I wanted to focus on what was the good thing that happened this month, you know, to help me either heal or umm… be grateful for what we did have and considering what we did face with her early on. It was putting this blurry picture back together again, because we came home and went “what just happened?” (Laughs) …you know? I would wake up in the morning and think, do we have to be at the hospital? Then think, well no. So all I could do was re-live it, I guess, because I couldn’t physically go up there. So I guess it was like re-living it and putting that puzzle together.

Then the quilt kind of happened and that will have its final stage, but the third one, the memories book, that kind of has a special significance, because my intention is for it to be handed down to Madeleine and for her to have it as a memento, a
keepsake. I guess it has almost an endless date? It continues to be a journey of now and I’ve left a few pages blank in the front, I want to also be able to reflect back on certain days. That was probably an intention, early on, to go, now they weren’t all bad days, let’s try and think of a really good day that we had in the hospital and write about that and put all the photos in about what happened. So I want to do quite a few days like that, but, that’s probably what I do in the group, … to reminisce and to reflect on a particular day and write about it and draw or whatever. It’s sort of giving the space and time for Georgia really.

You know it’s a book that’s got so many pages, but I can always get another one and add to it. The idea of what can go into it is just so open and I’ve asked my family if they want to write anything or do anything to go in it. It certainly has no specific thing of what can go in it. I could open up to a blank page and go ‘what do I want to do today’? Although I haven’t done a lot in it recently, I did a few pages in it for her birthday and what we did, wrote about it and put photos in and that kind of thing. I’ll probably do one for Christmas because I’ve written a couple of Christmas poems it’s a matter of whether I put those in as well, I don’t know.

I suppose it’s a book of reflection as well as an ongoing journal and I’m just wondering, whether I include things where Maddy connects to Georgia…Whether I put Maddy’s drawings in. She’s starting to cognitively understand and question things, like the first time she ever said something like ‘I want her back’, it was the first sign from her and I want to record that somehow. But I don’t know if this is the right book or whether I just do that in something else, for Maddy?

Things just come to me. Like I was thinking about the memory book for a while and it was just bothering me that I wasn’t going and doing something about it. I suppose you just get an urge or a thought to do it and I think I would be denying myself if I didn’t pursue it and fulfill it.....Ohh, I think it’s obviously helpful. Just last week I had thoughts about a Christmas poem and it would just go in my mind, around and around. Then one day I just decided to sit down and start writing it because it was bothering me so much, so I think if I didn’t address it, it would probably make things worse.
It was such a short period of time to have her. For six months there was a certain role I had, although it wasn’t a complete role, because she was in the hospital, but my time was divided between Maddy. Now I still feel like I need to do that and sometimes I get very consumed by Maddy and just taking care of her. So that when I do start to have a bit of Georgia time, it kind of settles it a bit I think? The fact that there is another child and you can’t just ignore that or pretend that it didn’t happen, or that she didn’t exist. I feel I need to give her the quality of time that I suppose your heart and your mind feels it needs to.

I think it’s also interesting to think of…. whether it’s something in your nature or personality or what it is, of the constant need to do something, whereas, my husband hasn’t got that. Whether that’s just at the moment, or whether there might come a time where he might have an outlet for it? He did put together a BMX bike from different parts that he’d bought on Ebay. That was probably something he did in the first few months and maybe that was something for him? It was the same bike he had when he was, like a twelve year old. So for me it was like he was regressing or thinking back to a more a time of innocence, where everything was simpler, and there wasn’t all these serious worries of the world. So maybe, yeah, that’s what he was doing then.

I think the things I’ve done have certainly given me an outlet and Dan is really supportive as well. Last night he was having a look at the quilt I’ve been working on and he came and gave me a hug and said: “It’s so good, you’re such a good mum and you know, you’re so clever” and that sort of thing and so that’s encouraging as well I suppose. I feel I can do it, I want to do it.

**Carefully stitching with care and love**

With the quilt…. like, I normally have a pretty good plan of how things will be. ….. Honestly, it did sort of turn out the way I pictured it would be. But I was open to the fact that it might change (laughs). I just sort of knew that if I took it one step at a time that it would evolve itself and I would get in my mind how I want it to look and what sort of material would work and where. For example, I realised that the other day that I’d like some cute little buttons to go in it and so went and bought some
more buttons. I guess I did have a picture in my mind, but I was open to let it change and evolve.

What I found exciting or motivating about doing it was I didn’t know exactly what it was going to lead to and how it was going to be finished. Normally for me, I’m quite.. ummm, not regimented, but I like a plan. But I just had a plan that I would take it one block at a time and see how that goes. I was very cautious, because I haven’t done anything so… sort of detailed and I just wanted to do a nice job of it. I was very careful to take my time with it and to think about it and play around with it, while I was making it. I got a few tips from my mum because she’s a quilter. I suppose it was just that feeling of taking care and time with it, which made it so much more special, to when I tend to do other things. Like, if I’m maybe making a dress or other things I’ve had on the go …… It’s not that I don’t take care with it, but I kind of go, you know, I know how to do this and I get on with it. In the end, the quilt turned out to be a different size to what I had in mind. It’s a bit smaller than I imagined, but that’s OK.

When it was coming together, I’ve made a drawn plan of the measurements. So I’ve got what this side measured and that side measured, all the sides measured, so when I measured the size of each piece I could go, OK so this bit is this size and then that bit will have to be this size and so then a lot of structure did come into it, because I’ve got this plan of…. Well you have to do that for a quilt really anyway. It was so I didn’t make mistakes. I had it in mind of what I would do, had it measured out and all that kind of thing. So that’s kind of it, it’s almost done, I just have to sew this one, a little teddy that Maddy had selected for her and I just love that one, it’s the last one I made.

He (teddy) was a sketch I’d done and had just stayed in the book and I thought I’ve got a patch left, what am I going to do? I have to do him (teddy). This pink teddy over this side is the one we bought her. I’d originally done quite a lot of these butterflies and dragonflies and in the end I went “I don’t want that many butterflies and dragonflies I just want one of each”. And this windmill is what we have in her garden and….oh this one here is a new one that evolved, it’s got four love hearts, two
bigger ones and two littler ones and a pink one and a green one and so Maddy refers to herself as pink, but Georgia likes green (laughs), so there is a bit of colour association going on there. And then it’s got her birth details in the centre. So I just brought it up with a border around it and I just sort of looked at it as I was going along and went “Oh what does it need?”

Well I think for me it’s got to be just so. When my mum was looking at what I’d done, the different patches, she was saying: ‘Oh you’ve done such beautiful stitches and sewing’. And I’m going: ‘Oh that’s so good’. It was that that sense of achievement and I do look at it, like this morning, and see how sort of perfect it is. That’s just so …. it builds your self-esteem I suppose. Well I think that’s an aspect of grief. You lose… I don’t know if it’s everyone… but you lose self-confidence. The trick is to build up a bit of confidence by getting out and meeting people and talking and not always having grief as the focus of my life.

The last week I’ve been staying up until 11pm working on the quilt. My husband says “I’m going to bed” and I’m like: “Oh all right, but I’m going to stay up and do this”. I’m just focused and driven and I get in my little zone and I just like it I suppose? It’s just a good feeling to me that, I know I think about her a lot when I’m doing it and it’s my Georgia time. I’ve been a bit aware of that, to make that time, to either do things or work on myself, for her or about her.

You know, when I started making corderoy (the teddy?) yesterday, I showed it to Maddy and said “whose this?” And she thought it was really good. Whenever I’ve been sewing it, like when Maddy’s been playing outside, I’ll just get myself on a chair and out there and just do a bit of sewing, she’ll come up and go “what are you doing” and I’ll say I’m sewing Georgia’s quilt. The interesting part is she wanted to be involved. Because I use a lot of pins and that kind of thing and she wants to have a go, I’ve actually got her a needle and thread and little pins and a bit of material and she’ll just sit down there and just put pins in this material and start to sew. It’s also been linked to her as well and gotten her involved. She loves this idea of sticking pins in to material (Laughs). And she’ll make little pictures and I guess she’s just seeing what I do, creatively with sewing and that’s how it rubs off on her. I suppose
that’s how it rubbed off on me, from watching my mum and that kind of thing. When we go to the material shop, she’ll want to pick out ribbons and that kind of thing, so I guess you’d say it’s a bit of a bonding thing. It brings me, Maddy and Georgia together.

**Gifts to share**

It’s coming up to Christmas and I think I want to turn up and show off something to the family. I’m worried about what the day’s going to be like and I play the day over in my mind and forecast it. I know there is a certain preparation about how the day might go and I think I’m quite concerned about how I will be emotionally and how others will be towards me. I’m like “for god’s sake don’t wish me a merry Christmas, whatever you do” (Laughs). We’ll have our time together in the morning and see Georgia and all that and to go there when I’m ready. I think, to me it might feel nice to just go “oh look, here’s what I’ve been working on (the quilt). So they know that I haven’t been brushing my feelings away, because I tend to think that some people maybe think that I have, you know, wondering how I’m going, that kind of thing, without asking me, you know?

I think they understand that it’s been difficult and I think maybe I want to show them something to say, “Well don’t just not talk about her today, please don’t. Maybe I want to see something from them? To see that they’re affected as well? I don’t know? It’s a significant event I suppose and we still certainly want to have joy on the day with Maddy and the other kids that will be there. But I’m sure no one will forget, that’s for sure, but I want just some way of recognizing it. I know my mum’s making things as well. I saw something she’s doing today. It’s got Georgia written on it with some beads and stuff. So she’s doing stuff and that’s her creative outlet as well. I suppose for me, it’s also because I know in the New Year that we’ll be packing and it’s, you know, not a time to have a sewing machine out and making things (Laughs). So I’ve got to get it done before then. I thought, you know, before Christmas might be a good thing. It feels like a present for her at Christmas as well.

So they’re probably the significant things. Certainly, I still have other little things we do and whatever else, like I’ve got a bracelet that I buy little bits for, G for Georgia
and then her birth stone, you know, and all the little things like that? And then I have a Georgia garden, but we have to pack that up now and relocate (laughs). I think I’m OK with it. I think I realize she is not in the garden and that it is just a stone with her name and just a few little trinkets and things, that we have in it. I might put them in my mum’s garden while we’re gone and then when we move into another place we’ll re-do that and that will be something we do together with Maddy and so that’s alright.

You know, when your child dies you don’t get to show your child off to anyone or talk about them! Not like any other parent would with a living child. With the first album that I did, it was something that I could show others. I explained what it was about when people came over and I could say “here she is, here’s Georgia”. (Laughs) Everything I read now about that time was truly me. I can almost hear myself saying it all and it was all very true of how I felt at the time. It was such wonderful therapy and I am proud that I found creative outlets to help me through such a difficult time. It was special how I could share my work with my daughter Maddy and we used those activities to bond our lives and I think it helped her understand as well. Many years on, she still wishes she had her sister back and we share those feelings together. It's a loss we share and try and come to terms with together.

The things I made are stored with many other precious items I have. As I have moved house a few times, I keep special boxes of her gifts and mementos and albums I have made. I kept the journal going for many years but have not added to it probably in the last 6 months. I take photos for her birthday and anniversaries still and these are all digitally filed now. I should keep getting them printed and added to the scrapbook journal as I go. I'm so glad I did so much in the early days, that I have wonderful things to enjoy now. Georgia's 6th birthday was acknowledged by our families planting 'forget me not' seeds in their gardens and taking photos of their stages of growth. At Christmas, Santa still delivers gifts for Georgia's stocking and Maddy takes care of these gifts. Although as parents we are divorcing, we remain friends and

2014 - Keeping Georgia in our lives –Kate’s reflection after reading the story
Everything I read now about that time was truly me. I can almost hear myself saying it all and it was all very true of how I felt at the time. It was such wonderful therapy and I am proud that I found creative outlets to help me through such a difficult time. It was special how I could share my work with my daughter Maddy and we used those activities to bond our lives and I think it helped her understand as well. Many years on, she still wishes she had her sister back and we share those feelings together. It's a loss we share and try and come to terms with together.

The things I made are stored with many other precious items I have. As I have moved house a few times, I keep special boxes of her gifts and mementos and albums I have made. I kept the journal going for many years but have not added to it probably in the last 6 months. I take photos for her birthday and anniversaries still and these are all digitally filed now. I should keep getting them printed and added to the scrapbook journal as I go. I'm so glad I did so much in the early days, that I have wonderful things to enjoy now. Georgia's 6th birthday was acknowledged by our families planting 'forget me not' seeds in their gardens and taking photos of their stages of growth. At Christmas, Santa still delivers gifts for Georgia's stocking and Maddy takes care of these gifts. Although as parents we are divorcing, we remain friends and
we celebrate or memorialise Georgia's special days in our own personal ways, but separately now. I can't imagine never not keeping her in our lives. There will always be small but significant ways I will bond with her memory and as Maddy gets older, I'm sure it will change to consider her needs or understandings.
January 2015 – Greg’s creative synthesis of Kate’s story

Pictures and Images

Georgia was in hospital
Her parents were there most of the time
Short visits home
Life continuing a little bit
Exhaustion brings sleep
Wishing
There’s lots of wishing

Such a short time to have her
For six months there was a certain role
Not a complete role
Time divided between her and her sister

After Georgia died, things have been done and there have been changes over time
There is the first photo album
It’s done, complete, having its own journey
While it’s still there to show and share, there’s nothing else to do to it
It has a lot of meaning
In the first few weeks, everything so raw and so fragile

   The album helped

   The album brought focus to what she went through

   Such a journey

   Setting straight the dates of things

   What happened?

   Here and here, then over there, down there, back here

   Re-living that journey

Also a focus on some good things, to heal and be grateful

   Putting the blurry picture together

   Thinking, what just happened?

   Re-living it to put the puzzle together, in an album

Then there is the memories book

   It has a special significance

   An intention to hand it down

   As a memento, a keepsake

   It has an endless date

   It continues to be a journey
Trying to include the good days in hospital

They weren’t all bad

It’s giving space and time for Georgia

It’s a book that has so many pages

There can always be more and pages can be added

It’s just so open

These things just come

There had been thoughts of a memory book for a while

A place for an urge or a thought

You’d be denying yourself to not pursue it and fulfil it

It’s obviously helpful

It’s a book of reflection

An ongoing journal

The quilt just happened, one step at a time

It would evolve itself

A thought in mind of how it would look

But happy to let it change and evolve

Taking time with it and thinking about it

Playing with it
A feeling of taking time and care with it
So much more special

Focused and driven
Getting in a little zone
It’s a good feeling

Thinking of her a lot when working on it
It’s Georgia time
There is another child
You can’t ignore that
You can’t pretend it didn’t happen
Like she didn’t exist

There is a need to give her quality time
A mother’s heart and mind needs to do that

The things that have been done have given an outlet
It’s so clever
A feeling to do it
A wanting to do it

When time is given to Georgia
It settles things a bit
In December 1997 our son Andrew was born without any fuss or drama at all. He was a healthy baby up until the early morning of the 25th of November 1998 when he let out a terrible scream from in his cot. I picked him up to cuddle him, but he had a massive seizure while he was in my arms and temporarily stopped breathing. He was taken to the hospital and they were not able to diagnose what was wrong. So he was then transported to the a specialist children’s hospital where more tests were done. There we were told he had a ruptured brain aneurysm and that he would die. Andrew died a few hours later over at another hospital where they were going to try to operate to possibly save him: he died before they could operate.

I had wanted to celebrate and remember Andrew in some way, and the thing that came to mind was to design a tattoo that would stay with me forever. I did not have any other tattoos nor had I ever even thought about getting one. But this seemed right. I drew many pictures with the dolphin as the theme as it meant so much to me and Andrew liked them too. There was a picture of a dolphin on Andrew’s bedroom wall that I had taken when on holidays in New Zealand. When Andrew woke from his sleep, this was the first thing that he wanted to touch when he got out of the cot. The other part of the picture was of the stars in the night sky which we told our other daughter that Andrew was the brightest star in the sky.
The scene of the conversation - Later in 2009 – Greg’s perspective

I drive out to a suburban area of a large regional town in Victoria, Australia, to meet with Craig. I know Craig from a bereaved father’s support group that I have been involved with for some years and am looking forward to talking with him in some more depth about the tattoo he has spoken about often; though I haven’t heard much until now in relation to how it came about and what real significance it has for him. I knock on his front door and Craig greets me with a handshake and a smile. Craig shows me into a small lounge area that is away from the busier part of the house. We sit either side of the coffee table and Craig tells his story in an open friendly way.

The conversation - Craig’s story

I’ve had the tattoo for quite a few years now. I think it probably wouldn’t have been twelve months after Andrew died when I got it done. It was pretty early. I did add to it a little bit throughout, you know, the course of the next year or two. Just a few words added and all that sort of stuff, plus the dates. But if anything as time goes on, you know, like it’s over ten years now, it still helps me think about him. The meaning behind it initially hasn’t changed - I don’t think that will change.

I’ve always had a little fascination with the tattoo, not ever having had one before or anything like that. I didn’t know of anyone else that had a tattoo for that reason. I just felt that it was something really permanent that was with me always. It certainly seemed the right fit for me. It wasn’t painful to get done and it means more to me than anyone else so, what it means to me is all that matters. As soon as I had it done, I felt that I haven’t done the wrong thing. I felt this instant sort of connection to Andrew there that I could focus on. It gave me something to focus on and think about him and of course being a dolphin…well I mean a dolphin’s a beautiful creature anyway - I’ve always loved dolphins anyway, so for me it’s quite peaceful and it’s certainly helped me in that way I suppose too.
It’s still the first arm I wash when I’m in the shower. I always wash that arm. I always shave the hair over the tattoo so it’s always clear. I don’t know whether it’s just a habit that I’ve got into washing that side because I just want to see that glistening all the time. So I don’t think it’s diminished at all really, in as much as the big effect that it’s had on me.

I always still like looking at it, especially in the shower, because the blues show up more and the colour shows up really well under water which, being a dolphin, I reckon that’s really good. It took a fair while to come up with that design, you know, thinking about how I can incorporate all of the things in it as far as, you know, we told my older daughter at the time that he was a star in the sky, plus the fact that he liked that picture of a dolphin in his room and all that sort of stuff. So I was just trying to incorporate the whole lot.

I did mention my ideas to the tattooist but he was the one that coloured it that way. What I gave him was a little note pad the size of...about that...the size of your microphone, and I drew roughly what I wanted, as I can’t draw for nuts, but it was a general idea. He just said leave it with me for a week and come back and then we’ll do it. He designed something up and worked out where to put Andrew’s name and all that sort of stuff and came up with the final design.

I came up with the concept, but he came up with the finished product and I was really happy with it, even before I got it done. The tattooist said “I’m not going to do it unless you’re happy with it”. I was extremely happy with it. It was funny because when I showed my wife, my little sketch or one of my little sketches on that little note pad she thought that’s how big the tattoo was going to be. [laughter] Yeah, it was a surprise when she saw it all the way across my arm and it was four or five inches [laughter] across it sort of threw her a little bit! It was a bit disconcerting for my wife a few times, especially when we were.... uummmm, making love, and she was looking at it. She was not really wanting me to get it in the first place because it was a bit disconcerting for her and it was a bit strange and uncomfortable for her, but
I don’t think that lasted long. No, I didn’t even think of the position of the tattoo, to be quite honest. It wasn’t about anyone else, it was just about me. [laughter] But she doesn’t mind it at all now, you know; so it’s OK.

**Staying connected**
I think my daughter, who was born after Andrew died, likes looking at it. She reckons it’s really nice. I mean, she was the only one in the family that never met him, but she likes looking at it. She just says: “It’s so pretty”. I went to a bereaved dad’s golf day at one stage and I mentioned that I’ve got it and three of the other dads said that they’ve all got tattoos as well! We all showed each other and it just blew me out of the water, because I mean no-one else had ever spoken about it and then all of a sudden they said “Yeah, well I did this” [laughter]. You know, varying sizes and, you know, different ways they’d done it.

I think it did make a difference to how I travelled with my grief. I think as soon as I had it done and anytime I look at it I’m thinking about Andrew, so to me that is a positive. Anytime I look at it or touch it or see it in the mirror, I’ve always got the thought of Andrew. I suppose there would be a spiritual aspect really, you know, to some degree. I suppose there is some sort of link like, I’m, you know….. [pause]. My wife sort of talks about there being, you know, forces, you know, not necessarily religious or whatever but...ummmm...like I’ve had tarot readings and all that sort of stuff too. So I’m not a disbeliever that people can sense these sort of things. I think the tattoo certainly gives me some sort of a link in some way between me and him. It’s a positive energy. It’s about as close as you could ever really get, isn’t it? It’s not going to get any better than that unfortunately.

**2014 – Craig’s reflection after reading the story**
There are things that I still do today, sixteen years later. Firstly, I always wash the arm with the tattoo first in the shower, and do keep that part of my arm shaven all the time. The one thing that I now seem to do, whenever I get a little bit stressed or anxious about things, I find myself rubbing or holding my arm where the tattoo is, as if I need reassurance or comfort. I believe it helps me think straight.
What I have noticed in recent times, that I have been the one sort of consoling people, and it has happened a few times is, people that I have known for a while, in particular a nurse at the Red Cross blood bank where I donate plasma, has known me for about five years now. But I went to donate one hot day and wore a singlet top there instead of my usual work clothes. She saw the tattoo and read what was written on it and she asked me about it and started to cry after I told her a little of what happened. I found myself in the position of consoling her. It made me feel a bit lost, as I had not told anyone about Andrew for some time. I felt guilty that she was crying and not me. I do love the tattoo still and I am sure I always will. I keep telling my wife that I am going to get a tattoo with her name and the girls on the other arm, but I never will, the only tattoo I will have is for my darling boy Andrew.
January 2015 – Greg’s creative synthesis of Craig’s Story

**Between Father and Son**

A father wanted to celebrate and remember his son Andrew in some way,

*Something that would stay with him forever*

*Pictures of dolphins meant so much*

*A picture of a dolphin on Andrew’s bedroom wall*

When Andrew woke from his sleep, this was the first thing that he wanted to touch

The father was fascinated by the idea of doing something

*Something really permanent to connect to Andrew*

*Always there and the right fit*

*Not painful*

*What it means is all that matters*

The tattoo was done twelve months after Andrew died

*Ideas were offered*

*The Tattooist coloured it*

*It’s been added to over two or three years*

*Just a few words and dates*

*It brings thoughts about Andrew*

*The meaning hasn’t changed*

*I doesn’t seem like it will*
It is an instant connection to Andrew
    Something to focus on
    Being a dolphin
    Beautiful creature
    Quite peaceful
    It helped

It’s the first arm washed in the morning
    Always washed
    Shaved, to keep it clear
    Just to see it glistening
    It hasn’t diminished
    The big effect

    Looking at it
    Especially in the shower
    The blues show up more
    The colour shows up well under water
    Being a dolphin, that’s really good
    It took a while to design
    Trying to incorporate everything

Andrew liked the picture of the dolphin
The younger daughter likes looking at it
    “It’s so pretty”, she says
    “Really nice”
It has been shared with other bereaved Dads
Surprising how many of them have a tattoo as well

It has helped with the grief
Anytime he looks at it
He is thinking of Andrew
It’s a positive

When he looks at it, touches it, sees it in the mirror
He always gets the thought of Andrew
It’s spiritual really
A link from father to son
Chapter Nine - Carried along by pictures and words – Tracey’s story

Introduction - 2008
Ariel, our younger daughter, died in a drowning accident at home. The first thing that came to life in the early week after Ariel died was the scrapbook. I was having torturous, sleepless nights with thoughts of Ariel flooding my whole system. I wanted to write stuff down because I knew I would be likely to forget the little things one day. I got onto the computer and just started writing all the things steaming through my mind. It was important to me to retain this information for Mercedes too who was 3 1/2 at the time. I felt like I was being 'carried along' as the project evolved into creating a scrapbook/storybook that incorporated the written memories along with photos for the things Ariel did and the things Ariel and Mercedes did together.

I called the book 'Mercedes' Little Sister'. Her favourite book at the time was Angelina's Little Sister, so it was something she could relate to. It was mainly created during the early hours when I couldn't sleep so it was a great help to channel my energies. For the first anniversary of Ariel's death, I reduced it made it into a little booklet so others could have a copy.

I started writing poetry around four months after Ariel died. I had a constant stream of thoughts coursing through my mind, thoughts I needed to say. My mind was so busy I don't even know what activities my days consisted of, sometimes not even remembering how I got from place A to B when driving! Not quite sure what prompted me to write my thoughts and feelings down in the form of poetry. I have journaled before in the past and had some understanding of the therapeutic nature writing could provide. Journaling just seemed too overwhelming though and when I sat down in front of the computer and started to just write a few words about how I was feeling, a floodgate was opened! I was knocking out poetry regularly and began to realise it caused me to feel less confused. I would also read and re-read what I had written, trying to make sense of my feelings and seeing my feeling in black and white really helped. I wasn't that good at articulating them otherwise. I even used my poetry
as a basis for some grief counselling sessions, putting it front of the counsellor and saying: 'Well this is where I've been at lately' – It saved so much time trying to explain! The poetry writing lasted with the same intensity for around two and a half years after Ariel died and the need to write has lessened. I compiled the poems into booklets and again, handed them out to friends and family at the first two anniversaries. Other bereaved parents also find great value in the poetry booklets, probably way more than I realise.
The scene of the conversation - Later in 2009 – Greg’s perspective

I’m walking into a familiar building opposite a large regional hospital, located about an hour from the state’s capital city. I’ve worked in this building for about four years in a bereavement counselling and support service. I’ve recently changed jobs and moved to another office in the same building, but the office I’m going to today is the office where I used to work. I’m going to meet with and interview Tracey, who now works in the same role that I used to. We agreed to meet in this office as it was the most convenient meeting place. I climb the stairs, walk along the corridor to the office and am greeted by Tracey. We chat briefly and move into the counselling room and settle into the comfy chairs, underneath the memorial quilt, created by several bereaved parents, that’s hanging on the wall. Tracey moves into telling her story after I have set up the voice recorder.

The Conversation - Tracey’s story

I was struggling with sleeping after Ariel died and I was particularly energised when I came out of the support group I attended. Just from, I don’t know, sometimes it was hearing others’ stories. But possibly it was just having your senses heightened. The writing definitely emerged as a coping strategy, particularly after I had gone to the support group and was then not be able to sleep when I got home. I find it very difficult to articulate what happened the night Ariel died and so for me the book
serves a great purpose because I’ve gone into quite a lot of detail in the book as I have my poetry...ways that I can’t really utter otherwise.

I know I’ve seen women come to the support group and be able to articulate themselves quite succinctly not long after the death of their child and I’ve been in awe of them. But obviously it’s just not my style. It’s like I can’t even get the words out. So definitely I’m better at writing, but I’ve found that it’s tapered off now. I think it’s more when my feelings are most intense I found that it was more of a life raft. I think it definitely helped me express myself.

I don’t why it has been easier for me to find the words and the feelings from sitting in front of the keyboard. The words were certainly all spinning around in my head for months and I thought I really must get back to doing a journal because years ago I used to keep journals. But in this situation I just felt too overwhelmed at trying to write about it, even in paragraphs. Then I thought ‘Well maybe I could just do a couple of poems’ and I don’t know why because I’ve never written poems. The first four just all came out in a pretty short space of time from each other and it’s like ‘Yes, that’s what I’ve been thinking’. I know when I used to get to the roundabout on the road near home I’d have different plates I’m spinning in my head about different threads of thought in my mind.

I was trying to process the reality of what had happened and to get each thread down on paper in some way was a relief, because then I could continue on with whatever was going to flow after that. It seemed that I was a bit stuck in my thinking because all I kept thinking was about the guilt and I would scream out: ‘How could I have done it?’ ‘How could I have done it?’ That was too hard to do all the time, because it was like being re-traumatised. But for some reason, once I’d written the poems down I would read them back frequently and then when it became a booklet of poems I would read them every day. I don’t know what that was about - whether it was saying something to me. It’s like I never got tired of reading them and it was like it was new information every time. Because it was out there on the page, it was like I put it out there to re-integrate it somehow. For some reason, I find that it’s expressed better and more fully through those methods that I used.
The guilt poem, which I called ‘The Signature One’, because it was the first one and is a bit of a summary for everything I feel. It’s also an introduction because it was when I was starting to explore that issue and I was very big on accepting whatever responsibility I had in a way that I could then sort of hopefully stick with it enough and release it, rather than just not to be that way. So it was a bit of a statement, a bit rhetorical in a way. By expressing, how guilty I am, kind of knowing that you know, in the sense, all the mothers that exist on earth probably feel some degree of guilt for certain situations anyway, because that’s how we’re created somehow. For this particular tragedy, the depth of responsibility and guilt was intensely greater and this poem has been read at the National Swimming Conference held in New South Wales last year when Laurie Lawrence first started filming my little segment for their DVD about water safety.

When I actually read my poem out, tears were streaming down his eyes so he’s a very sensitive soul. According to reports from my contact who has written the booklet that includes Ariel’s story, she said the whole place was in tears and she did get a bit of angry feedback from it. It was to swimming teachers and coaches that’s what the conference was for, and yeah I got some feedback saying: ‘Oh, you know, you didn’t tell us that you were going to play that’ and it was said as a criticism. What they were trying to do was just bring home something practical on how important the work is that they do and the education they do impart. Not that I think in our situation with the bathtub at twelve months old would have saved Ariel’s life in the particular circumstances that unfolded that night, but it’s water familiarization they are trying to promote.

So I felt good about that and I’m glad a few more people have shed some tears over it. I know other mothers at the support group have expressed the same idea. Sometimes we just want to tell people because we want others to hurt a little bit too. There’s a bit of guilt associated with having those motives also.

With the poems, some of them kind of rhyme and have rhythm and others don’t. Sometimes having it purposefully rhythmic helps you actually try and express yourself. I don’t find that it’s limiting. It actually helps me explore and stretch
myself a bit to try and find something to say within the rhythm I’ve created, because just the first half might come out very easily and it’s like ‘Oh I’ve got to finish that off somehow because it just sounds weird just finishing it there’. It’s almost like some of them I’ve written as I’ve breathed. I remember one of them about ‘Flashback’ was written when I was breathing very lightly and fast and that’s because I was imagining having flashes of remembering what it was like to lift Ariel out of the bath. I was having flashes of it but not really wanting to entertain it at all, but I thought if I write this down then that might stop me from, I don’t know, wrestling with it so much. I suppose also a desire to communicate to people, that it does go on and it does continue to affect you and it’s more than just missing my child. I’m finding more and more that let alone the death being disenfranchised to whatever degree, the trauma’s just not acknowledged whatsoever. The trauma, because it is an energy in itself, stirs me up quite separately from feeling dragged down by missing Ariel. So I find that is impossible to articulate verbally at present.

**Holding the memories and taking them forward**

Not long after she died, I’d be laying awake at night thinking: ‘Oh, I must remember that, must remember that’ and I thought I’d better write this stuff down. Then I thought: ‘Oh, I could make a book’. I’m not really into scrapbooking in a pure sense. It was sort of like, I did most of it on the computer, so it’s computer photos that I had and I’ve just, printed them off and I’ve written a little text that kind of tells the story of her favourite things, like the fact that she used to sleep a lot. The fact that she used to hold her feet all the time and little particular things that, you know, I probably would have forgotten. But even if she had lived and grown up I might have forgotten as well? These things all of a sudden become so important because they are all you have to remember her by.
I took 412 photos of her that are in existence and I just couldn’t stop looking at the photos. Every now and then a friend would give me one that they had on their camera and it was almost like another complete different facet that I hadn’t seen. I now have to study it because it was an angle of her I hadn’t seen on a day, that I wasn’t watching her and someone else was and they captured that. So I think the scrapbooking, apart from the story telling that the photos offer, is really important also. By continually going through the photos, deciding what ones I’d choose to include, deciding what expresses her best for this little piece of information and what do I want to share, and even enlargement photos that I got at the time I’m starting to sort of change now. I’m starting to select other photos that I’m putting around. I think that really probably show or display to me a greater connection but I couldn’t show them earlier because it hurt too much.

I handed the poetry books around to my family and I produced a little booklet that was like a mini version of the scrapbook that sort of just told the story of Ariel. Not including as much detail about the death, because I was realising that people find that difficult, but I was explaining what was special about her and all of her little intricacies and personality traits and stuff in that book. For me, it was just, I don’t know, I couldn’t spread that far or wide enough. I did get some backlash from my family, I was a bit tentative in the second year when I told them that I’d written the book. I suggested that they needed to ask for a copy because I found that it was too
hurtful to have them criticize. The fact that I felt I had to put that out there, probably
served the purpose of me wanting people to know about Ariel, but I also needed to
express how much it hurt to be separated from her.

I think many of my sensitivities around Ariel’s death has always been geared towards
Ariel’s older sister and whether that’s ended up being a bit of a life raft in itself,
because it takes the focus off me, I’m not sure? Certainly initially, when she died, I
tried to make sure she was included in everything and tried to continually have put
myself in her head or her space to try and work out, you know, how would I like to
be told, how would I like to be included if I was that age? I don’t think it really
changes much from being a child to an adult other than you can articulate it better
when you’re bigger.

**Mercedes’ Little Sister**
The book I put together is called ‘Mercedes’ Little Sister’ and pretty much based on
the idea that there was a book she was reading at the time about Angelina Ballerina.
Mercedes read those series of books and there was this one called ‘Angelina’s Little
Sister’ so I kind of stretched it on from that and said this is about Mercedes’ Little
Sister. We would go through and read it and it was effort to try and simplify,
describing death, how she died, what dead meant to her. I think now that Mercedes is
older she actually finds the way I’ve written to be quite confronting and she’s not as
comfortable to look through it anymore because she’s more abstract I guess?
Mercedes even told me at one of Ariel’s birthday celebrations, to not bring it out and not to show certain photos that were from around the time. I’d made an effort to create another little flipbook for the other kids in the mum’s group and Mercedes told me that it was too sad and that I wasn’t allowed to give it out to the other kids. I explained that the other kids probably wouldn’t find it as sad as she does and that it would help them remember her, so then she allowed me to.

Interestingly, I’m seeing now that Mercedes is starting to share her knowledge with Indigo (sister born since Ariel’s death). It’s very cute. She shares what she knows in a matter of fact, sort of loving way, so I’m satisfied that she’s integrated it in ways that you can’t necessarily plan exactly, but, I’m starting to see it manifest in a positive way, because it just becomes a part of you.

**Grief and trauma entwined**

I’m finding that I think it’s probably more that traumatic aspect, that I’ve only just realising two and a half years into it, is probably the part that I’m struggling with more. I know that’s tied in with the grief but it complicates it. I think there are some separate elements to it that sort of need to be looked at separately. It’s not like I’ve got to get all sad and into Ariel every time I try and deal with the trauma.
Definitely what I’ve done is a ‘head’ way to deal with my emotions. But I tend to deal with things in a head way and I’ve realised that more and more. Even when I was studying and starting to learn about different ways of describing grief at the Grief Centre, they talked about instrumental grief and intuitive grief. I still would have felt that the instrumental stuff is a way to get to the emotions.

But now I have accepted that this was my grief in itself, rather than ‘Oh, it was a pathway I was on to try and get to my emotions’. I’ve certainly felt everything emotionally as far as that goes, but I’m a big time thinker and was born that way. I accept that now and need to embrace that.

It’s strange though, because I don’t see myself as good with words, in the way the poems come across. I’ve had a couple of people ask me for advice on how to write a little poem for this and that, and I’m like: ‘Well...??’ ‘But you’re good with words though’ they say. I say: ‘Well, they’re not my words they’re borne out of a certain experience and they’re partly what Ariel had to say’. I find it difficult or I feel that talking about it doesn’t do it justice.

**Being called to spend time with Ariel**

With the writing and poetry, I think it was very much driven by Ariel really. In some ways, I feel that she might be more known dead than alive, which is a bit of a weird thing. Something I’d prefer not to have, but her death has brought changes in our lives. But it’s more than just the fact that: ‘Oh, we’ve got a history now with a dead child’. It’s just brought a sort of, I don’t know, eternal changes It’s been a process of allowing me to make differences in society and the community in a fuller and more expressive way than I’ve ever been able to do previously. I feel that Ariel kind of wrote the poems in a Moses on the mountain kind of way.

When I was writing them, that was my time with her; that’s for sure. I used to kind of look forward to those times that I set aside. If I woke up at night it was a good way to make use of my insomnia, but it was also a time to spend with her. Maybe, that’s why I kept re-reading them so much in those early days.
It is also, in a way, perhaps a mystical thing – Ariel, I felt, was the drive. It was also my drive to connect and her drive to not quite disappear. But I’m not very good at articulating that sort of thing. [laughter]. Because it’s not a straight ‘Oh yes, I’m going to see her again one day and that’s wonderful’ [laughter].

People have come to me who are right into those sort of things, talking about the afterlife. Even my hairdresser goes to meetings where they have angels visit them and all this sort of thing and she saw Ariel’s photo when I opened up my wallet to pay and she said ‘Who’s that? Who’s that little baby?’ and when I explained, she said ‘You’re going to think I’m mad’ and I said ‘Oh no, any information’s good information. Do tell.’ She was convinced that Ariel had visited them at their last, I don’t know, spiritual meeting that they’d had and so I gave her the photo and I said ‘Oh well, show it around to the others that go and see if it resonates with them’. It’s just... hmmm, personally I think it’s probably a bit bonkers, but I like talking about her in any way shape or form. If someone else wants to grasp hold of her.

I mean I always try and embrace whatever is meaningful for others and allow them to continue working with that as they go along. Sometimes people have been bringing me bags with Ariel written on it and there’s a bookshop in Sydney called Ariel [chuckles]. I mean even the two days...one or two days after she died, we were preparing for the funeral and I felt that I was in a bit of a trance. I was just looking around at all the buildings and all I could see was the shape of the roof that made an A. So there’s always this precipice of how much of that is me...how much of that is something I don’t know about?

I think, not just associated with Ariel’s death but in terms of the way I would live my life and make my choices, I feel that, at times, there’s a sense of beckoning to contribute to the choices that might be there to be made. At other times, you need to pull back and just kind of have that discernment as to know how much to get involved in a choice that there is to be made. I’d certainly never accepted that Ariel necessarily goes on to live another life in another realm. That could be possible, but I don’t throw my spiritual thinking around those ideas. I find it very unhelpful. I find that I’m even a little bit alone amongst bereaved parents in that way, because I’ve
mixed with a lot of bereaved parents who can’t wait to see their child again and that helps them go on. I don’t feel that I exist that way at all but it by no means lessens any kind of hope I have for some kind of connection. I don’t quite understand that myself because I’ve had a religious upbringing and it’s something I’ve got to pick it apart all the time. [laughter]

Regarding my work now with a bereavement service - Well, I just think it’s one of those cyclical things that couldn’t happen anywhere else at the moment, apart from Geelong. I think Ariel is part of both the Peninsula and Geelong because she died here and it’s part of her story that she’s a local here. I think coming to work for Hope is part of Ariel’s legacy that isn’t necessarily just a black and white decision I’ve made because I already had a counselling background and combining that with having experienced the death of a child, I feel that there’s more to my direction here than other things that could have played out. In terms of the way I feel connected to Ariel, or her memory or whatever it may be, means that I feel a great deal of connection by working here.

I think that when you’re the parent of a dead child you’re going to be changed anyway, so I better get used to it, even if it wasn’t that way before. If people thought I was weird before, then I’m certainly very weird now but I’m feeling completely sane and that I’ve got a lot to offer and can educate people in a gentle way that hopefully won’t scare them off. I think Ariel brings that gentleness and we’re just realising this now, that’s one of the most prominent comments of her personality that was ever mentioned by anyone else - her gentleness. So perhaps that is part of her nature, that I’ve taken on in some sort of mystical way?

2014 – Tracey’s reflection after reading the story
My response now to what I said in 2009 about the things I was doing to process Ariel’s death…

Photo Book

The story/scrap book I created about Ariel’s life was certainly something to immerse myself in during the months following her death. The way I understand it now as I
approach eight years since she died and five years since the interview, is that I
wanted to be immersed in her. I didn’t want to forget the little things about her.
Although my grief was agony at the time, somehow I hoped that one day I would be
at an emotional place where I would be able to flick through the pages and feel joy
and celebrate her existence. I called the book *Mercedes’ Little Sister* and I wrote the
words in simple language so I could read it aloud to Ariel’s older sister Mercedes,
who was three years old at the time.

Apart from my own use for the book I’d created, I also took it along to the Empty
Arms support group as my thing to share Ariel’s story. Ariel died in such tragic
circumstances which I felt such so ashamed about and speaking of it brought
unbearable humiliation as I hadn’t at that point began to differentiate between Ariel
and who she was / the tragic way she died / the part I played in her death. People
couldn’t tell any of this by just looking at me. It was easier to just pass the book
around and receive some little bit of healing from the tears of others paging through
it.

With Ariel having died in 2006 and shortly after joining the Empty Arms group, I
then transitioned to being one of the leaders of the group when I started working on
staff in 2009. In 2014 I continue in a leadership role to support not only the newly
bereaved who continue to join but also those further along the journey who’ve
become parent supporters and co-facilitate the group. Interesting, I still take my
photo book, although it has become two books now. Around 2011, Ariel’s younger
sibling wanted to know more about her and was becoming aware that she was the
only one in the family who hadn’t met her. The world of digi-scrapping and online
photo book creation had really come a long way so I created a photo/story book about
Ariel for Indigo and called it *My Baby Big Sister*. I used words in a way Indigo
herself would had used to speak wanting to not only help her get to know Ariel better
but to incorporate how Indigo’s own birth came about. I didn’t want her to feel like
she was a replacement for Ariel and by writing it in simple terms in a book it can be
repeated as its read and re-read – genius! Mercedes was around 8 at this time and her
sensitivities were changing and she no longer wanted to say, look the images of
Ariel’s body after she’d died so I also created for her an online photo book version of her original book, making the adjustments she wanted. I was also able to add additional pages to her which included photos from Children’s Memory Mornings and birthdays/balloon releases we have had over the years.

So something that really began as a private way of trawling through the early months of grief has evolved in our family as central to the few things about her that are out on show around the house and I still take both of them with me to Empty Arms each month for new parents to look through and for those having subsequent children to build into their own ideas how they might incorporate the life/memory of an older child into their own family story. The girls also take them along to the Children’s Memory Mornings and put them on display and sometimes enjoy showing them to the other kids there.

**Poetry Writing**

My experience of the poetry I wrote hasn’t really altered much since I reflected in it in 2009. I suppose I would like to collate them into a single little book as newly bereaved parents have been very interested in them over the years, particularly if their child has died in an accident.

I was reminded how I read and re-read them just after the time of writing them and was trying to make sense of why I might have done that, but hadn’t really found an answer. I don’t know if this is an answer now but given that many of the poems were trauma-related, I’m thinking I was in such a state of disbelief, that it was hard to believe that it was actually my life that I was reading about. Now that I’ve spent the last couple of years actually processing the trauma, I actually find them very edgy to read if I try to do so now. It makes complete sense to me now, how some family and friends criticised me for sending it around to them as it would be pretty horrible to read through! Maybe a bit of me regrets having done it but not all of me regrets it. The bit I am a little less comfortable at having done is to be filmed while reading out one of my poems and having it played at the Swim Australia International Conference. There’s no way I would agree to that kind of thing now. I would feel too
exposed. I accept that it was ok for me at the time, I was still very much in a haze about the events of Ariel’s death and Indigo was about 15months old at the time so bereaved-mum-of-another-young-bub-haze was there too. I’m now comfortable with the need to be private about the way Ariel died and don’t mind talking about it where appropriate. I think I used to equate my need to be private with ‘I must be guilty/have something to hide’ so put myself out there to try to prove to myself and others that all was transparent, not 100% sure but that’s the best way to make sense of it at present.

**Overall**

Although reading through some of what I said seemed a little all over the place, I’m also pleasantly reminded how all my thoughts were formulating at that time. I was very much on the right path when I was exploring the complexities of grief in relation to the traumatic way she died and have been having EMDR treatment (on and off when I can afford it) since 2012. This has been truly transformative for me. My feeling is nowadays that I can fully celebrate her existence my life, family life and work life. I can do this without the shame ripping me in half. I’m privileged among bereaved parents to be able to do this as many reflect they have to shelve memories and feelings about their children as ordinary life and work becomes busy.
January 2015 – Greg’s creative synthesis of Tracey’s story

A Mystical Way

There struggles with sleep after Ariel died

Energised after support group meetings

Senses heightened

Writing emerged as a coping strategy

It was difficult to articulate what happened the night Ariel died

The book and poetry serves a purpose

Writing lots of detail that otherwise can’t be uttered

When the feelings are intense and writing is like a life raft

Helping express the self

Why is it easier to find words and feelings, sitting in front of a keyboard?

Flashback

Light and fast

Flashes of remembering

Flashes that a mother doesn’t want to entertain

Write it down and stop wrestling with it

It goes on and on and it’s more than just missing her child
Stuck thinking

“How could I have done it?”

Over and over

Re-traumatised

Write a poem

Read it back

Every day

Write more poems

Read them

Every day

There is new information each time, saying something

Never tire of reading them

Slowly integrating, from the page into the self

Words spinning

Journaling might be good?

No. Too overwhelming to write even paragraphs

Maybe poems?

Never written poems before

Four come in quick succession

Yes! That’s what she has been thinking
Different plates spinning in the head
Different threads of thoughts
Trying to process the reality of what had happened
Getting each thread on paper
Relief!
Flowing on to what comes next

The poems
Some rhyme, some don’t
Having a rhythm, helps expression
It’s not limiting
Some are written to the rhythm of each breath

The guilt poem
A summary of everything felt
Exploring the issue
Accepting any responsibility
Sticking with it and releasing it

The guilt
The guilt of mothers
A public reading of the guilt poem
Tears streaming down their faces
Everyone
Felt good that others shed tears for Ariel
There’s some guilt in feeling that too!

Writing the poems
That was her time with Ariel
She would look forward to those times
A time to spend with her
It’s a mystical thing

Ariel was the drive
A drive to connect
Her drive to not disappear
Her mother likes talking about her in any shape or form
Not long after she died
Awake at night
The thought comes – I must remember this
Must remember that
Her favourite things
She slept a lot, she held her feet

Need to write it down

Oh, let’s make a book

A mini scrapbook made for others

It told the story of Ariel

What was special, her intricacies and personality traits

Spread it far and wide

Wanting people to know about Ariel

And to know it hurt so much to be separated from her

Dealing with things in a ‘head’ way

A big time thinker

Always have been

But strange that she doesn’t think she’s good with words

Yet others see her as good with words

But these are not her words

They were born from a particular experience

And partly what Ariel had to say

It felt driven by Ariel

Perhaps she’s more known dead than if she were alive?
Her mother would prefer that not to be the case

But her death brought changes to lives

Perhaps Ariel kind of wrote the poems in a moses to the mountain kind of way

At times there is a sense of beckoning

Working in bereavement counselling

A cyclical thing that couldn’t happen anywhere else at any other time

It’s part of Ariel’s legacy

She brings a gentleness to the work

She was gentle

Perhaps that has been taken on

In a mystical way?
Chapter Ten - Steffie’s Gift – Philip’s story

Introduction - 2009
On August 26, 2007 our daughter Stephanie died. She had turned 20 only nine days earlier. Steffie was our youngest child. We also have a son, Terence, and daughter, Jessica.

Steffie had undertaken a course in Youthwork at RMIT in 2006 but due to depression had been unable do little more than casual work in 2007. But during 2006, as part of her course, she had worked on a voluntary basis at Reach Out for Kids (ROK) in Nunawading. She loved it and never stopped talking about it.

Steffie had been suffering from depression for almost a year, at least since we had become aware of it; but it had been going on for longer than that. In the end, it seems it became too much for her. We were all devastated by Stephanie’s death and the situation was complicated by her leaving a sizeable estate for someone her age. She had received an inheritance from her maternal grandfather. The proceeds from her estate would come to my wife, Marika, and I, as her parents but it was the last thing we wanted. It just made us feel worse.

That year Marika and I had become involved with mental illness support group. We had done this so we could better understand what was happening with Stephanie and hopefully provide her with better support.

The scene of the conversation - Later in 2009 – Greg’s perspective
Travelling to the capital city in my state by train, I’m wondering how I will recognise Philip, the person I’ve had email exchanges and brief phone conversations with. I get off the train and walk the short distance to the business club, where we are meeting in the café/lounge area. Philip has been there this morning doing some study, so it’s a
convenient place to meet. As I approach the building, a quick phone call ensures that we find each other in the foyer and Philip leads me to the café area. It’s well after lunch time; so it’s reasonably quiet. We choose a place to sit, settle into the comfortable chairs either side of a table. After some introductory chatting Philip begins to talk about Stephanie, whom he refers to at times as Steffie.

The conversation - Philip’s story.
After her funeral, a family friend (who had been a recent confidant of Steffie’s) had suggested that we might be able to do something to support young people with mental illness. In discussion with Terence and Jessica, this suggestion started to develop and take form. If we could use the proceeds from Stephanie’s estate to help youth and those suffering from mental illness on an on-going basis, then we could carry-on the work she was going to do with youth and something good may come out of her own mental illness.

Steffie’s funeral was on the Friday. Sunday was Fathers’ Day: it was not a good day. That night Steffie visited me. She said she was sorry for what had happened and she had a conversation with Marika but I couldn’t hear what was being said. (Marika denies all knowledge of this.)

Steffie gave me two presents for Fathers’ Day – a bottle of whisky and a box of chocolates. This had become pretty much standard in recent years. When I awoke in the morning, there were no presents but Steffie had signalled her approval of our plans – for the establishment of Stephanie’s Gift. I also remembered that she had said we should look in her filing cabinet. The implication was that we would find something there that would help. I thought it had something to do with her old school. We didn’t find anything to do with her old school, that was relevant, but we did find that at different times and through various jobs, Steffie had been a member of four superannuation funds. Her membership of two of the funds was no longer active and there was little or no money held there but two were active and also provided death benefits. The payout from these would double the funds we had available to establish Stephanie’s Gift.
In early 2008, Stephanie’s Gift was founded and just prior to June 30 received formal approval to operate as a private ancillary fund. Stephanie’s Gift is a private charitable fund that makes donations to other charities that work in the areas of youth and mental illness. We don’t have the skills to undertake such work directly but we can help fund the activities of those that do have the skills. This year we made our first donation – to ROK. The funds donated are sufficient to fund school holiday activities for a year. This year the program is known as STEFF: Supporting Teens, Empowering Family & Friends.

When the family friend made the comment about doing something, it wasn’t something that we sort of explored in any great depth at the time but I know when she made that comment it was something that I thought ‘Oh, yeah, ok, alright, that’s something that we could look at’ so I suppose it did strike a chord with me. I don’t know that it particularly did with my wife at the time and I’m not even sure that the kids necessarily heard of it at the time so it was something that was just there, it was discussed briefly amongst you know the few people that were in that group having that conversation at that time and yeah it was probably left on the basis that I’d thought to myself ‘Yeah, alright, that makes sense...that’s something that we could look at’. But I suppose at that point I was thinking ‘Well, ok, there’s a little bit of money but there’s not a lot of money there, not a lot that we could really do terribly much with so what do we do?’ and that was probably about as far as my thought processes had got with it. I think for me I did talk about it with my wife afterwards. I don’t think it was discussed with the kids and when I say ‘afterwards’ this would have been in the days afterwards. I think she was in general agreement and said ‘Yep, ok. That’s a good idea. Let’s think about what we could do’.

It was only afterwards when I had the visit from Stef (visual presence – dream-like) when we discovered that we were going to have a lot more money than what we’d thought, that it then all started to take shape. I suppose actually it was in the morning when I woke up and I was looking for the bottle of scotch and looking for the box of
chocolates and of course they weren’t there but that’s when the name Stephanie’s Gift hit me because that was her gift, telling me about the life insurance policies. That’s where the name came from, I thought ok what we’re going to do is going to be called that. [laughter]

**A dream into reality**

When Stephanie’s visit to me led to discovering the extra money available, it was a question of ‘What are we going to do?’ ‘This needs to be dealt with.’ and you know we’ve got to do something that would be fitting, something that would be appropriate so that there were those sorts of thoughts but I won’t say that they were in any way particularly formed.

And it was really from that point that it all started to slowly crystallise so we then started talking to others. Of course we had to speak to our solicitor and then we had to speak to someone in the finance/accounting field, who we’d been dealing with for a number of years. We said “look this is the situation, we know that you do work on the philanthropic side of things and so this is what we’re looking at now, you know, are we in a position where we can do something”. Working through it with them, to be blunt, we were told it was a borderline case. We said fine, we’re happy with borderline so long as we can make this work [laughter]

In going through that process we looked at a lot of options that we could have undertaken, but some options meant was that it was less involvement for us and left us with less control over the whole process and so, you know, while that was just something that we could have done it was not the way that we wanted to go. We said ‘No, look this is going to be our family undertaking’ and you know this was always going to mean much more to us as a family than perhaps working through other third parties’ which were the types of other options that were available.

Then there is the day to day operational perspective where we actually helped to make this happen. Does it take up a big part of our time doing that? Look, initially it did when we were trying to set it up, because it’s, you know, a little bit of a complex
process trying to do this. So that took up a lot of time initially. Once we got it up and running and for the first twelve months, although it probably didn’t take up that much time, you know, we’d have the occasional board meeting throughout the year just talking about where we were up to, what we thought we were going to do in terms of our giving strategy and also an investment strategy, that sort of thing. It was really only at the end of the first year where we were in a position to make our first donation and we made that to Reach Out for Kids which was where Steffi did her student placement and, you know, she had a really strong connection there, so we’d said right from the start basically that the first donation we’re going to do is to ROK. It seemed to be the obvious one to go with. But when the time came and we were ready to do that then that again involved a little bit more of our time, because, well, we had to make contact with ROK and, you know, explain to them. They were aware of what happened with Stephanie, they knew right from the start but then we hadn’t sort of really told them anything else. So we explained to them what we’ve done since and what we were proposing to do and, you know, of course they were very thrilled with that. Then there was meetings with them to talk about, you know, what the funds we were going to donate might be used for.

So it took up a bit of time and then as we’ve moved into now...well we’ve come, now, effectively coming to our second...the end of the second year of operation. This year again has become a bit more involved. You know, there’s been changes to government legislation in the way these funds operate so that’s taken up a bit of our time but also we’re now finding that we’re building a good relationship with ROK and that relationship is now going from strength to strength...so much so that when we caught up with them a few weeks ago to talk about what we’re going to do for the next twelve months they actually gave us a written submission saying ‘Well, look, this is what we would like to do’ and what we’ve created with them is what we’ve called the ‘STEFF program’ and STEFF stands for Supporting Teens and Empowering Family and Friends.
Well, we’ve spent a bit of time working out what name we would come up with. The reason why we came up with the name...because we hadn’t even thought about it...was that when we first contacted ROK and they came back to us saying ‘Well, what we’d like to do with the funds is to establish the Stephanie Bayley program’ and we thought ‘Oh no. No that’s not where we want to go’ because, you know, for anyone who’s going to be involved, the Stephanie Bayley program is going to be meaningless...the name is not going to mean anything to them.

So, we thought about it and we said to them: ‘Look, appreciate the suggestion but we would like to come up with a different name. Something that can mean something to everybody’ and so that’s how we came up with the name. You know, once the family gets talking amongst ourselves working out ‘Oh what can we do’ and the thing is that Steff did call herself Steff...we called her Steff. So, she wasn’t really Stephanie. [laughter] So, anyway this year they’ve given us a written submission in terms of what they want to do for the full twelve months and this is something that the leadership team at ROK including the senior group of young kids there - they’re sort of years 10 through to 12, have come up with themselves and the proposal this time is to actually look at mental illness in young people and the ramifications that come from that. The signs to look for, explaining to other young people, you know, this is what it’s all about because it’s something that really isn’t discussed all that much among young people. It’s pretty rare that it ever gets talked about.

So they were going to build a full twelve month program about involving young people in their local community in this and they presented that to us and we talked it over with them and one of the things that we suggested after it was presented to us, was we said ‘Well, look, you know the one thing that’s not here is involvement of the parents’ and I said ‘Really, you know, this...the work that you do here needs to be presented to the parents as well. To say to the parents: ‘Look, this is what’s going on. These are the signs to look out for. These are the resources that are available if you need help’’. As I said: ‘Look coming from our own experience, this is what we missed out on...This is what we didn’t pick up on’. So, anyway, they’ve taken that on
board. There’s now going to be two presentations over the next twelve months to different groups of parents - one in the Whitehorse region, one in the Maroondah region because that’s where ROK’s based in Nunawading. They’re going to have guest speakers coming along. I’m hoping they have people from BeyondBlue and others involved and in fact speaking to them today they asked whether we would talk about a parents perspective and I said ‘Well, you know I kind of expected this...it was obvious and it’s something that we really should do but I’m not sure if we’re ready to do it yet. But, you know, I’ll sort of take it on notice. So, as an activity it’s growing...It’s starting to build its own momentum.

**More than memories**

Look, in terms of what it means to us emotionally and I’m now going to talk about myself and my wife because, you know, for us this is a very key part of our lives. It is our ongoing connection with Stephanie. It’s the way that we can still keep her as being very real to us in an ongoing basis, rather than just sort of looking back and having memories. This is something that still keeps her in the present and will always keep her in the present.

Our other daughter made a comment to my wife perhaps three weeks ago and it was along the lines of, you know, and I may be taking this out of context, my wife may have taken it out of context too because she relayed it to me, but it was along the lines of: ‘I don’t know why you’re doing this’ - in other words persisting with Stephanie’s death. ‘It’s not going to bring her back’. That’s basically what she said. I don’t really understand what the context was for making that comment but it just struck me as being a surprising comment to come from her because she knows very well the reasons why we’re doing it. I mean she’s as involved as what we are from the point of view that, you know, she’s part of the foundation that we’ve established and she has as much say in it as any activities that we engage in as anyone else so it just seemed a bit of a surprising comment. But I guess it was raising the question well ‘Why are you doing it?’ The answer is we’re doing it to keep Stephanie in the present and, you know, there’s also the other reasons of saying: ‘Well, ok. We’ve been given an opportunity here to make something out of Stephanie’s life and do it in
a positive way, where we will be doing the work that she thought she was going to do if she’d embarked upon the career that she wanted to have’. There’s a very strong connection from the point of view that we’re working with young people and working with those that have a mental illness. So there’s that part of it. The Stephanie that died (or how she was at the time she died) was not the Stephanie that we knew. To set up this fund, links us to who she was to us. It’s part of keeping her in the present. If we didn’t do that then she would be in the past and it would be just photographs and memories.

Just continuing on with that, you know, the foundation does have a life of its own from the point of view that it does have a legal existence that goes on and that means that when my wife and I can no longer do this, the kids can keep doing it and their kids can be involved. It’s inter-generational because, you know, our son, who I haven’t mentioned up until now, but he is our oldest and our daughter are very much involved in it and it keeps them involved. And, you know, regardless of whatever my daughter said three weeks ago, you know, I really hope that this is keeping Stef alive for her. Whether it works out that way in the end or not I don’t know but my wife and I are hoping that that’s the way it’s going to go. So then Stephanie stays real for all of them and you know she’s always going to be a part of our family.

**A place of connection**

As for other things relating to Stephanie, we have a holiday house down on the Gippsland Lakes which we bought when Steffi was only 18 months old. It was something that she was very, very excited about, [laughter] in the context of an 18 month old, but she knew that we’d got this house. There was a boat that came with the house and after buying the house as we were driving home she kept on saying ‘Boat’ ‘Boat and so, anyway, we ended up calling the house ‘Boat’ and that was the name that we put on the house so that was significant to us. It wasn’t significant to anybody else but we very much associated with Stefani and, you know, we had three kids in all and Stephanie was the youngest and basically the three kids grew up down at the holiday house on school holidays...they would always be there at school
holidays...It was on the water. We had a little sort of beach out the front of the house and they would be down at the beach from early in the morning until it got dark at night, you know, and they had a lot of friends down there as well so for us as a family it has always been very, very significant.

So, I guess about 15 months after Stephanie’s death, we decided that we would finally renovate that house, because it was an old house and we’d been talking about it since the day we’d bought it basically [laughter]. You know, one day we would renovate this house. So, anyway, we finally took that decision. Having taken that decision, I’ve got to tell you the project is still going [laughter] and it’s still got a long way to go. I can see it’s going to go for another twelve months yet. And, yeah, we might have it finished by then but that was another thing that happened and then there are the trees. Well, you know, over the period we’ve bought two trees that were both connected with Stephanie and have been saying: ‘Ok, we are going to plant these trees’. Now we have planted one - one has been planted in the centre of our front yard at home and the other one is ready to be planted in the centre of the yard at the holiday house when it’s finished. So we’ve probably had it for twelve months now...It’s still sitting in a pot...We’ve had to put into a bigger pot [laughter]... but they’re both flowering trees. Both red flowering. One...the one that we’ve planted at home is a flowering Wattle, a Weeping Wattle and the other is a Flowering Gum. So, that’s another one of the things that we’ve done, but it was really the establishment of Stephanie’s gift that I would say is the most significant thing for us.

**Changing direction**

One of the other things that happened was that it meant a complete change in career direction for me. In fact, career is even the wrong word because I think, to be honest, I lost interest... in my career, so, you know, since Stefani’s death I have started a PhD at Monash. So there’s been that and that’s progressing - I’m now 18 months into that. It was a bit through circumstance to some extent. It happened almost, well let’s say nine months after Stephanie’s death. The catalyst...the particular catalyst if you like, was the fact that I was retrenched from the position that I was in and that forced me to sort of sit back and re-evaluate things. You know, the initial response that you get is the outplacement counselling and all that sort of thing. This is my
second time or was my second time through this process and so I knew what it was all about...I knew it was all going and I thought quite frankly I’m just not interested in it anymore. I don’t want to go back to work. I have had enough of full time employment and all that sort of stuff. I’d rather do something that I want to do.

So after a little bit of time pondering different things…it was probably another six months of pondering, I bit the bullet and started the PhD. Now, why a PhD? Because I suppose earlier on I had been sort of academically orientated. I’d completed an MBA twenty years earlier. At that stage, once I’d got through that I sort of said: ‘That’s it, I’m never studying again’ [laughter] ‘I’ve had enough’. But over the years after that, you know, I had from time to time sort of said: ‘Oh, you know, I wouldn’t mind going back and doing a PhD’ from the point of view that it’s a research exercise. It’s completely different from any other tertiary course because, you know, being a research exercise, as you know, you basically run it at your own pace. You’re researching in an area that’s of particular interest to you and you can just focus on that the exclusion of everything else. So, anyway, that’s sort of really the circumstances that got me into doing that.

I’m not going to say that I was 100% dedicated to my career - I wasn’t a company man or anything like that but I was, you know, fairly focused on my work. Having said that, you know, the family was always very important too. You know, they talk about work life balance which is a load of crap. But I did try to achieve more balance than perhaps a lot of other people. But having said that, it was still more orientated towards work. That’s not the case anymore. So it’s a very different attitude to the way we go about things now.

If I just sort of come back to the PhD process, which you’re obviously familiar with. You do your first twelve months and then you’ve got to go through the confirmation where you’re told: ‘Well, yes’ you know ‘You’re doing a good job, keep going’ or ‘No, you’re wasting our time and yours and go and do something else’. Well, that came up earlier this year and of course all the young PhD students get incredibly
stressed about that whole process. Now that’s not to say that I didn’t feel a little bit of stress but, you know, I was pretty relaxed about the whole thing and I was quite prepared for being told: ‘No, you’re wasting your time, go and do something else’ but nope, that’s not what happened and in fact they were, you know, very complimentary and very enthusiastic about what I’m doing which was completely unexpected. For the moment, it looks like it’s meant to happen so I’m still going with it.

You don’t know how to deal with things early on after something like Stephanie’s death. You don’t know where to go. But, you know, we sort of muddled through and I suppose and then over time as we’ve muddled through I guess we’ve come to the realisation that we can best look after ourselves by doing what we think is right for us. I suppose we’ve been lucky from the point of view that we have been in a position where we can say ‘Alright, you know, there are things that we used to do that we just don’t want to do anymore’ and we’re not going to do them and we’re going to do things differently. Obviously not everyone can be in that situation.

In terms of other changes, I was just thinking of it when you were talking about changing the way you do things and in my case being perhaps more laid back....or more accepting of whatever happens. One of things that my wife and I have been doing since all this change has come through, is that we now spend a lot more time at the holiday house. So we’re getting down there every three or four weeks and we’ll be there for a week at a time and, you know, I can do the work that I need to do down there and, in fact it doesn’t really matter where I am now, I can work anywhere. So...even sort of taking that a little bit further - the way I work now is really quite nomadic. I probably spend a couple of days a week at home, I might spend a day or two in here (RACV Club). I could be at Monash at Caulfield or [laughter] anywhere.

We had no direct grief and loss counselling support. We did attempt that once as a family. The four of us, went and saw a psychologist that Stephanie had seen at one stage although she wasn’t seeing at the end, so she knew a little bit about Stephanie.
But the kids took an instant dislike to her. The rapport just wasn’t there and so we didn’t go back. The kids themselves unfortunately didn’t get any other support after that. My wife and I got a little bit of support from one of the people at the Mental Illness Fellowship who we had been involved with previously and she used to come to see us once a week at home and just help us talk through things. But I mean her background is working with mental illness; it’s not grief and loss support. But, you know, just having someone to talk to was useful... and at least they knew what we were going through and knew the background to our situation so, in some respects it may have even been better because grief and loss counsellor coming in cold... wouldn’t know where we were coming from and wouldn’t make that connection so that probably was better...We kept that up for I guess four months or thereabouts and thought well we’ve probably gone as far as we can go with that.

The other organisation that we made contact with and I guess we communicate with in terms of their newsletters and so on is Compassionate Friends which is where I saw what you were doing and responded to that. My wife and I both really enjoy reading that only because I think...on the one hand it can really make us quite upset but on the other hand it reminds us that there’s a lot of other people out there going through the same things as us. You know, I think we can relate to their experiences and at the same time learn from their experiences.

And I think, you know, from that point of view as a family we’ve always been fairly self-contained and fairly close and so we’ve always dealt with things amongst ourselves by and large and so in terms of how we’ve dealt with this, while there has been some outside involvement that we’ve sought, most of the time I think we’ve taken the approach that we probably know ourselves. So long as we allow ourselves to do that then that probably is the best way to go and I mean that’s more a realization, that I guess that has come over time.

The things we have done, like Stephanie’s Gift and other things, I think it helps a lot. I suppose it’s for all those reasons that we just talked about. You know if I think
about what we do now, both my wife and myself and the kids, you know, in their own lives, we’re all still grieving - there’s no doubt about that. You know, we’re coming up to the third anniversary in August and, you know, it’s still very real, it’s still quite raw for us and so on a day to day basis alright we are sort of getting to watch three years down the track and perhaps it’s not quite as raw as it was you know even last year, each year it does diminish a little bit I suppose but it’s...I think we all still struggle with it.

2014 – Philip’s reflection after reading the story
When I read the first part of constructed narrative now, the part that I sent to you, the first thing that comes to mind is the pain of that time, although fortunately, not its intensity. That has moderated with time. The pain is still there but now it is more of a longing for what was, and what might have been.

The other thing that stands-out from the narrative is how lost we sound. Not sure of what to do or where to go – just feeling our way. It seems we were feeling our way with the establishment of Stephanie’s Gift, with the change in direction that our lives had taken, abandonment/loss of a career, taking on a PhD, what we were doing with our holiday house.

The transcript of me talking reveals someone who had definitely lost his way, who struggled to get his thoughts together, and didn’t seem to really care. All of these things have settled now, for the most part anyway. But it will be the seventh anniversary of Steffie’s death in August and a lot has moved on since then. Moved on seems a better way of saying it, as things have not necessarily changed. And of the changes that have occurred not all were for the better. Some decisions were made in haste at the time, through a desire to move on and quickly get things back to normal. But that can’t happen, there is no getting back to normal, there will eventually be a new normal but that is it. There is still a hole in our family where Steffie used to be and that will never go away.
We have two grandchildren now, our daughter Jessica’s boys. Jess talks to them about their Auntie Stephie. The eldest says he sees her and talks to her in his room. She is not forgotten. We still celebrate her birthday every year.

The most important thing we did to keep Steffie’s place in the family was to establish Stephanie’s Gift. It has done what it was intended to do. It has carried out, through experts, the youth work that Stephanie was going to do. The emphasis on mental illness has not been so strong, other than a lot of the work being potentially preventative – which really is better still.

It has been a focus for the whole family, with all involved in deciding the charities we are going to support and the investments to be made, so that we can continue to provide that support. We work with Anglicare Victoria now, funding an intervention program for Years 7 & 8 students in schools in the eastern suburbs of Melbourne. The program is into its third year and its best yet in terms of the responses from participants and the number of schools the program is being run in. ROK, the organisation that Steffie had worked for and which we initially supported, was absorbed into Anglicare. A former chair of ROK joined us in funding the youth intervention program, last year.

We have also worked with Mornington Peninsula Youth Enterprises, a local organisation that takes troubled older youths out of school and gives them practical training and skills in a commercial plant nursery. I have joined the finance committee of MPYE. The funding that we have provided to these organisations to date, amounts to more than one-third of the capital that we had to establish Stephanie’s Gift. Yet, through the investment undertaken we have increased the capital base of Stephanie’s Gift by more than 50% over the same period. As a Private Ancillary Fund, Stephanie’s Gift cannot seek donations from the public. It is just our family’s charitable foundation, and it will go on.

I finished my PhD last year and am seeking consulting work now in my area of expertise.
We finished the holiday house, even though we demolished the old one and built a new one. The first thing we did, all of us, when the house was finished, was to plant the tree that we had kept in a pot for almost four years to be a memorial to Stephanie. We planted it in the front yard and built the garden around it. It is a beautiful flowering gum that seems to flower constantly throughout the year.

The holiday house is also important to Jessica and our son Terence, not just because of their childhood memories of the time spent there but also because that is where we scattered Stephanie’s ashes. Our two grandsons were taken down to the water, soon after birth, to be introduced to their Auntie Steffie.

There is a ritual we have. Every night between 4.00 to 5.00pm we light a candle for Stephie. We do this wherever we are. We blow it out when we go to bed and say goodnight to Steffie.
January 2015 – Greg’s creative synthesis of Philip’s story

Always in the present

Didn’t know how to deal with things

Early after her death

Don’t know where to go or what to do

We muddled through

Then a realisation

Just do what feels right for us

At Steffie’s funeral, a suggestion was made:

“Do something to support young people with mental illness”

Perhaps something good can come out of her own mental illness?

Father’s Day, after her funeral, Steffie visits and approves these plans

She says “look in the filing cabinet”

A link to enough funds to start a trust fund

Stephanies Gift was founded

STEFF - Supporting Teens, Empowering Family & Friends

An ongoing connection to Stephanie

Keeping her as being very real

In an ongoing sense

Not just memories and looking back

It keeps her in the present

Always in the present
The question is asked
Why are they doing this?
It won’t bring her back
The answer –
To keep her in the present
A chance to make something of Stephanie’s life
Work that she wanted to be doing had she lived

There’s a strong connection
The Stephanie that died – or how she died
Is not the Stephanie that the family knew
The fund links family to who she was
It keeps her in the present
Otherwise she’s only in the past
Photographs and memories
Now she can stay real for all the family
She’s always a part of the family

There is a longing for what was
What might have been
Lost
Now things have settled a little
But there is still a hole in the family
Where Steffie use to be
That will never go away
A holiday house bought when Steffie was 18 months old

She was very excited

A boat came with the house

Steffie kept saying “Boat” “Boat”

The house was named ‘Boat’

Very significant

Always associated with Steffie

Times with family and friends

At the house

Finished the PhD

Finished the holiday house

Planted the flowering gum

Built a garden around it

Scattered Stephanie’s ashes in the water there

Grandchildren taken to the water

Introduced to their Aunt Steffie

These things that were done help a lot

For many reasons

All still grieving, no doubt

Each year passes

Not quite as raw

But still a struggle
A ritual
Every night
Four or five PM
Light a candle for Steffie
Blow it out at bed time
“Goodnight Steffie”
Chapter Eleven - Trees by the river – Jasper’s story

Introduction - 2009
I find that what I did and had to do was only for myself and my kids. It did have nothing to do with having others understand it. I'll give you an outline of what happened:

Michael died suddenly by suicide by shooting himself in the head with a 1st World War 303 gun. He made up a cartridge for it as they were not available anymore. The result was that he blew most of his head off and his whole bedroom, walls, ceiling, cupboards etc was covered in blood and brains etc.

Thus what I had to do first was to restore this room so it could be used again. I cleaned up and repainted and turned it into play and games room. It still stank for about six months because of all the blood that had run behind the skirting boards. My daughters didn't quite realise what the smell was and often were in his room reading books or playing monopoly. They felt close to Michael doing that.

We buried his ashes across the road from us under an existing oak tree near the water's edge of the Yarra river. Again this was done not for others, only for us. We can sit under his tree which overlooks the river and it’s only just by walking across the road.

What I did for myself had started already over six months before he died. I had started painting and drawing around that time. At the six months mark before his death, I had a very strong dream which I had to put on canvas. After his death, I realised that the dream was about losing him. One month before his death, I had a dream which told me exactly how he died. I have never been able to remember that
dream since his death, but a close friend of mine visited me after his death and asked me if I had remembered that dream which she then went on to repeat for me.

After his death, I did a lot of abstract painting which was purely for myself to try and get to grips with what happened. It is not beautiful and only useful for me. I also made a few leadlight windows, but I could not say that that had anything to do with his death. Most non-bereaved parents would not understand what I have done.

My daughter Nadine died aged 26 after a four year long bout of very serious depression. Approximately a year before she died, her psychiatrist told me that her depression was incurable and indeed she was finally successful in taken her own life after many previous attempts, eleven years ago this month. She had sought plenty of help over those years but it never worked in the end. The four year struggle to keep her alive while I already lost one child by depression took a lot out of me.

We did plant a tree with her ashes next to the tree where Michael’s ashes were buried. I feel they have each other there. Grief resolution was and is still very difficult as I knew what it was all about but couldn't go through the same process as after Michael's death. I tried The Compassionate Friends again, but as I had been a group leader etc., I was the expert and not the bereaved parent who needed help.

After Michael's death it took seven years before I realised that he had taken up a warm comfortable spot in my heart. I have not achieved that with Nadine. I feel that the grief over her death has never been resolved and never will be.

The scene of the conversation - Later in 2009 – Greg’s perspective
I’ve driven to the capital city from my rural home for other work, but today I only have a few hours work in the afternoon. So I’ve taken the opportunity to meet with Jasper, one of my research participants. The suburb is familiar, one of the older suburbs not far from the city, located near a river. I pull up in a street lined with
homes that I think would have been built from the 1920s to the 1950s. I enter the little gate and walk along the path to the side door and knock. Jasper comes to the door and shows me in to the kitchen and dining area. I set up my voice recorder after initial greetings and we then sit down as Jasper tells me his story. After we finish the interview, Jasper will walk me to the trees near the river.

The conversation - Jasper’s story.
I started painting by chance because I met one of my early friends. - He is a painter and he was one of the original founders of the group in Fitzroy. He hasn’t got famous yet but one of his co-founders is a big painter and makes a fortune. But anyway, he encouraged me to go into painting and he....well it turned out to be interesting. Well I did a painting six months before Michael died, where I’m looking in the mirror and I’m sitting in a room and all that’s showing is my hands and shoulder and the head of a child, but in the mirror I can’t see the child. There’s no child but the hands are there. There are different interpretations of it. You could say that I foresaw what was happening in the future, or I might also have been not so much foreseeing it but I might have been catching my son’s thoughts relating to his trauma. I didn’t realise at the time that he was already suffering from depression, but over the years working my way back and hearing remarks from other people, it was obvious that he was suffering from depression around the time of his death.

He was hiding it. Yes, the mask of depression. And once before he died I dreamt exactly how he died except I can’t remember the dream. Michael had a very close friend here. I was single at the time looking after the kids and I told her the dream. Then after he died, she came up to me in tears and she says do you remember the dream and I said: ‘No’ and I still don’t remember it now. She actually helped clean up. She described exactly how it happened too. It’s quite amazing.

You know the only thing I knew about Michael and the depression was about a month before. I knew something wasn’t right because, he was still at high school, and he asked me for some help with this mathematics. Now he was a very bright boy, very intelligent you know. He said: ‘Ok Dad do this question’ and I looked at it and I said: ‘Michael it’s from three years ago, you could have done it three years ago’
He said ‘I just can’t do it’. I didn’t realise that was a sign of typical severe depression, you know, your mind doesn’t work on you. When I had actually asked him: ‘Is there something wrong with you? Are you ok?’ ‘No, no, no, I’m ok, I’m ok.’ I actually was seeing a psychologist at the time because I had trouble with my ex-wife and I was just trying to sort everything out and I mentioned it to them. I said: ‘I think there’s a problem there but I don’t know what’. And she said: ‘Well you can’t do anything if he doesn’t talk’ and a few weeks later he was dead, you know.

He died by putting a shot gun in his mouth, that’s how...there wasn’t much left of him. He died in March and he had been in Holland in September to visit my family. He was staying with my brother and he had talked to my brother and said: ‘Oh, if you put a gun in your mouth you shoot a hole in the back of your head’. Why he ever said it I don’t know and he apparently already had a gun in the house, which I didn’t know about. My daughter knew about it and my daughter actually helped him smuggle it in the house, but she didn’t know why he wanted it, but he said the family needed protecting and this is the daughter who subsequently died also.

**Changing horror into a place to be together**

It was terrible...We did get a professional cleaner in but he actually gave up after four hours...He couldn’t cope. Well when I first went into find him I went into the room and I thought: ‘Geez, who in bloody hell has been smearing jam all over the walls?’ Then I looked around and then I saw him sitting there with the gun, it was a terrible mess...You cannot believe it. That friend of his helped to clean up and my ex-wife came over and she stayed for a while and then we did a lot of cleaning and painting because the room actually stank for about six months...It was a bit hard to actually be in there because of the smell of it. The girls didn’t seem to realise what it was, so they had no problem with it. We had it painted quite a lot because of evidence left behind. But for me it’s a comfortable room, you know, I’ve slept in there and my daughter comes over and she’s often slept in there quite comfortably. It’s a spare room.

Well it achieves the whole future, because when he died, you know, I could have shut the room up and never gone in there, but I said: ‘No, no. I think it will do. This will
turn it into a beautiful clean room and we’ll put toys in there and games there’ and the girls actually, you know, when they were playing Scrabble they always went in there on the floor and so it was comfortable. He was 15, so they were 14. Yeah, we used it a fair bit and I was trying to teach myself piano, which never worked. So we had a piano in there and subsequently computers in there and so on.

Because we use it every day, you’re not so aware of it anymore really. It’s still often called Michael’s room. So I think the real connection will never go away but it’s more on the subconscious level rather than a conscious level. Well, look, ummmm, having the room there is still like I have Michael there and I don’t think I could move out. I don’t think I could buy a house anywhere else because I feel I would leave him behind and I would go to an empty house which will always be empty forever and that’s... well...I don’t like that idea.

**Breaking the silence**

I think I mentioned at some point that going public was a big thing for me. At the time it was a big thing and I think it was good for me because I felt I was bringing it in the open. People really don’t like talking about it...suicide, because when I came in there was another group leader of the suicide group and they did not go near the media at all, you know, not at all. And the media were always asking for people to comment. So, I mean that was an important issue for me, going public, which I could do easily because I wasn’t married at the time anymore. I just started with Compassionate Friends and there was actually very little known about it. I mean I was one of the first ones probably to go public about suicide and I mean in no time at all I was in the *Sunday Times*, *The Age*, the *Sun Herald*, ABC on the TV on the three commercial channels and there was nobody else much, speaking about it, you know.

Around this time, I was having issues with my daughter and the mental health system. I really wanted to go public but she didn’t want it because she worked in a public library and she couldn’t face the public. My daughter, got sick at the time that Kennett came into government and she rang me up twice: ‘Take me to hospital, I can’t cope and am having thoughts of suicide’. So I took her in the car and she said: ‘If I had to go home I wouldn’t be sitting here next to you’. I took her into hospital
and they took delivery of her and then sent her home straight away - no beds available and this is after what she had said to me, you know. I then went on to the Health Commissioner and there was a big stink about it. It should have been public really...you know. But after that, my daughter went like that quite a few times because she just wasn’t coping. Anyway, after that I had to actually talk to the doctors because every time I visited my daughter they all kept running and sort of saying to me, you know ‘What can you do with her? Blah, blah, blah, blah, blah’ So just as I’m not wanting to criticise any of the doctors, I was criticising the system.

Well, with my daughter was actually very lucky because the one thing that was that even if you were family, you had no control over what happened with her because she was an adult. But things changed and if my daughter agreed that I was her guardian then the doctors could talk to me. She was finally connected to the East Melbourne Clinic and the psychologist sort of got to know me and the moment she felt there something not right she would be in touch with me and if I felt it isn’t right, we actually had to go out together to try and save her. She would lock herself in her house and was not having a bar, we knew she had a knife, you know, so, we had to break in. That arrangement actually delayed her death by a year...two or three years.

Familiar but very different
With the death of my daughter ten years ago – after Michael’s death, it was very different from Michael. The main thing is you expect to go through the same grieving fears but it doesn’t work that way because you know all the answers about grief already through Compassionate Friends and you know what’s going to happen to you but it doesn’t happen the same, it doesn’t happen at the same time and the intensity is different and maybe a bit too much to deal with somehow too, you know? I had four years of time trying to keep her alive, you know, there were quite a few serious occasions there, so it was different to Michael. I sort of knew for a year she was going to die and that was very hard too. It’s now over ten years since she died and that’s never settled with me.

I did go back to Compassionate Friends but I just...I couldn’t deal with people going through the initial grief again in the groups...It was just too much for me...It wasn’t
doing anything for me. Starting up initially after Michael was ok because that’s the whole idea for it, but it didn’t work anymore after my daughter died. So I never sort of had anything better. I was on my own really.

I think I tried painting once but it straight away became, you know, the red, particularly red bullet type things came back. I put them all alone up on the ceiling I could get them out if you want to see them but... Yeah, well, to my mind it wasn’t me intentionally explaining it or re-visiting it, I was just doing it because it came out in me. There was a painting I did and I didn’t see anything awful really and when I turned it around upside down it is all guns interlocking. It was just incredible and I had no...... It was just amazing what comes out of your mind. It’s so strange. That is certainly not on the conscious level. You know we’re talking a lot more about abstract paintings here, because a lot of people don’t understand what the abstract painting really is about. But really stuff just comes from the subconscious and it tells a lot about artists if you can understand what you see.

A lot of it was actually to do with Michael’s death and I did a lot of painting. Then, I realised I wasn’t getting anywhere. I had to stop. My friends are still asking me: ‘Well come back and do painting again’ because of the guest classes and I can just join in for free. He’s got a whole group going there. But I can’t anymore because I’ve tried a few times and every time the same image is coming through and the images are very bloody and jagged, you know, so I think initially it helped me to sort it out, but ahhhh, it’s just not comfortable any more. It stopped being useful. I think there’s just a niche in my brain where the trauma is sort of bottled up and I think I’ll never get it out of me somehow. It’s best if I leave it alone I think. I’ve done so much over the years trying to deal with it in different ways it...yeah. In the end you’ve got to be able do what you feel comfortable with and seven years after Michael’s death I was quite comfortable and I could say Michael’s got a warm place in my heart. They do say typically it takes seven years for you to sort of, you know, learn to live with it comfortably. So that was the case for me, but then my daughter got sick and then it’s really been difficult. She never could get over her guilt feelings
about the gun, you know. Even though from the start she’d been told, you know, that it’s nothing to do with you.

**A connection in nature**

As far as the things I’ve done since their deaths, well I think the trees are probably the most important things I’ve done, in a way, because the two of them are together and it’s in a comfortable surrounding. It’s not in a cemetery. I don’t particularly like a cemetery. I didn’t want the ashes and I didn’t want to go there. So it’s the trees that sprouted as an idea, even though it’s very public. But people going past just don’t know and they will never know because it is a public park. It is still considered significant to me and particularly in summer, nearly everyday, I walk past there, where the trees are. I do walk a minimum of half an hour every day and it’s a lovely walk along the park. And now I can just walk past or just sit down or whatever, you know. I usually just walk past and sometimes I’m down there and think about them, but other times you just brush your hands against the leaves of the tree and say hello to them, you know?

Well in doing these things, I think basically it’s an emotional decision to start with which I suppose you don’t rationalise. Basically, you feel that this is what it should be. Yeah. And, like you know, with trees - I think I was the one that came up with it and then the girls got in there and they decided to pick a spot but they picked a spot which I would have preferred to be somewhere else but I had to do it because they were happy with it. It is almost a learning experience really because, you know, what do you do when your child or children die? You sort of need to go with your feeling which I think a lot of people do, but there are a lot of other people trying to tell you to do different things. I didn’t particularly take notice of people who said ‘No, you can’t do that’. I think I didn’t quite know what I wanted and I think I was quite well aware that I had to do what was right for me and I was able to ignore other people, you know.

I think if it felt for me instantly right for me to do the trees and to some extent his room. I didn’t, you know, feel the need to question it, probably because I didn’t see anything wrong with it, I didn’t feel that it would be disadvantageous to my surviving
things, which I think proved right, you know, because I felt comfortable with it. I think as far as I lost them in the physical sense I just didn’t want to lose them into the emotional sense...your child will always be your child dead or alive, you know, so the best is to turn it into a positive experience as well. Of course the trees are always there and I can do it in my own time. If my wife doesn’t feel like it she doesn’t...she just comes home. I think they’ll always be important to me...always will be.

2015 – Jasper’s reflection after reading the story
My feelings towards the trees haven't changed. When I go there, I always touch the leaves or the tree trunk and say hello to my kids. I don't go there too often anymore as I have got an arthritic knee and don't include that track along the river in my daily walks anymore. I also don't feel the need to go there too often. Also, my feelings towards my children haven't changed at all and I have a great relationship with my surviving daughter even though she has left Victoria and now lives in Queensland.
January 2015 – Greg’s creative synthesis of Jasper’s story

It was terrible
When he was found
Such a mess
Like strawberry jam all over the walls
Him and the gun
A terrible mess
You cannot believe it

A shot gun
Smuggled into the house
His sister knew, but didn’t understand
A shot gun
Placed in his mouth
In his room
Not much left

Hints of depression that weren’t known
An intelligent boy
But his brain not working well
Questions with obvious answers
Things he could once do

The mask of depression
Michael hiding it
A dream told of what would happen
A forgotten dream until…
Michael’s friend remembered it
She held the dream and re-told it
Quite amazing!

Started painting by chance
Six months before Michael died
An early painting
Hands, Shoulder and head of a child, plus a mirror
But no child can be seen in the mirror
Was this foretelling what was to come?
Many interpretations?
Was he catching his son’s sense of depression?
Depressed, but didn’t know at the time

Cleaning and painting of his room
Lots of painting and cleaning
Now it’s a comfortable room
His father has slept there
His sister has slept there
It’s a spare room
Making use of the room

Achieves a whole future

It could be closed and never go in there

But “No. No, this will do”

It can become beautiful

A comfortable room

With games, toys and eventually a piano

Scrabble played on the floor happily

Michael’s room

The real connection will never go away

Having the room

Is like having Michael there

Couldn’t move out

It would feel like leaving him behind

An empty house

That would be empty forever

Then the daughter

Struggling with mental health

The system failed her

To hospital, but no beds

Doctors say “what can we do with her?”

Then with her death

It was very different to Michael’s
With a second death
You expect it to be the same
But it doesn’t work that way
You know what’s happening
But it’s not the same
Different timing
Different intensity
Maybe too much to deal with?
Four years trying to keep her alive
One year knowing she was going to die
So very hard
It’s been ten years now
It’s never settled

Attempt at painting again
Red, red, lots of red
Bullet type things

Then one abstract painting
Didn’t seem so awful
Turn it upside down
Guns interlocking!

Incredible
Amazing
What can come out of your mind
   So strange

There’s a niche in the brain
Where the trauma is bottled up
   It is best left alone
So much done to try and deal with it
But in the end you need to do what feels comfortable

Seven years after Michael’s death
   Quite comfortable
Michael has a warm place in the heart
But with the daughter it’s been difficult
She never coped with the guilt about the gun
Even though she was told her it was nothing to do with her

The things done since their deaths
The trees are the most important
   The two of them are together
It’s a comfortable surrounding
   It’s not a cemetery
Don’t like the idea of a cemetery
   Didn’t want their ashes
So the trees sprouted as an idea
The trees are still significant
Nearly every day walking past there
   It’s a lovely walk
   Sitting or whatever
   Usually walking past
   Sometimes thinking of them
Sometimes brushing hands in the leaves
   Saying hello to them

The trees feel instantly right
As did his room to some extent
   No need to question it
   Nothing wrong with it
   Not disadvantageous
   It felt comfortable

Lost in the physical sense
Didn’t want to lose them in the emotional sense
   Your child is always your child
   Dead or alive
   Turn it into a positive experience

   In doing these things
   It’s an emotional decision
   You don’t rationalise
You just feel that this is what it should be

The trees were father’s idea

Then the girls joined in

Together the spot was chosen

It’s a learning experience

You need to go with your feelings

The trees are always there

He can do it in his own time

They will always be important to him

Always will be
Chapter Twelve - Making some good come of it -
Judy’s story

Introduction - 2009
Our son Patrick died of bowel cancer in October 2002. He was 34, the eldest son of
four. He left behind two infant daughters to whom we have no access. Patrick was a
fine young man and an achiever in several fields. He had obtained an MBA. Patrick
had a great sense of humour and was inspirational to us all during his illness. I recall
some of his last words to me – “make some good come of this Mum”.

The following are some of the things I have done since he died.

Heart necklaces
My individually hand-carved (by my husband) hearts are approximately 5X4 cms. I
undercoat each before painting them with detailed and meaningful designs, after
which they are glazed. A brass loop is applied followed by a finishing ring and hung
on leather thonging, ready to be tied at a suitable length around the neck. We often
apply a broach back for pinning to garments.

Writing
For two years, I wrote of the life and times of Patrick and our family. Perhaps
enlightened, I have since continued writing stories for his two little girls to receive at
a later stage, because at present we are denied access. Being on The Compassionate Friends (TCF) magazine committee, I regularly find my work published here as well as in overseas magazines. I outsource others’ work and try to inspire people to write. My stories have been re-printed and used during support group meetings, in public speaking and on The Compassionate Friends website.

**Handbags**

I enjoy making rather eclectic handbags. Though I have made dozens I never repeat the same fabrics or finishes. I use an old industrial sewing machine as, with padding, stiffening, lining and pockets, they become quite difficult to handle. I do not use mass produced clips, clasps and closures and try to resource vintage materials and unique trappings. My husband patiently creates wooden toggles, buttons and finishes.

![Handbags](image)

**Vases**

I find plain unglazed vases at opportunity shops. I started with one and have now painted and glazed many and they are really attractive. I like to make something of
nothing. These and my hearts were exhibited at The Queen Victoria Women’s Centre.

Volunteering
After two years attending a TCF support group, I was able to volunteer. I attended several training courses and educational seminars. I think I am useful in several areas. I have a special concern for the newly bereaved as individuals, especially those geographically and emotionally isolated. I deal with grief calls on a roster – day and night, I write anniversary cards, keep track of the TCF guestbook and as a voluntary community educator, have delivered several public speaking appointments and facilitated art therapy events.

Rituals
I keep a treasure chest full of both heart-breaking and humorous items from Patrick’s life. My husband made a lovely cedar box for the paper mementos.

The scene of the conversation - Later in 2009 – Greg’s perspective
I’ve been at meetings in the outer suburbs of the city for my current work role and knowing this was happening, I have arranged to meet with Judy, who is one of my research participants. Judy lives only twenty minutes from where I have the meetings. So after eating some lunch, I head out to her home, located closer to the bayside area of town. I drive through tree-lined streets and find myself shifting focus
easily from work to my research. I’ve not met Judy before, but from her correspondence, she seems a very creative woman and I’m looking forward to meeting her. I park outside her house, walk up the path to her front door and ring the bell. Judy comes to the door and shows me in. As we walk through the house, Judy points out things that she has created or collected. Moving into a lounge area, we sit in lounge chairs with a low table nearby. The story of Judy, Patrick and her family unfolds.

The conversation - Judy’s story
Well I had Patrick for 34 years, you know, and as he said ‘Mum, I’ve had a complete life’ and I know what he meant. I think he felt complete in that he had the little girls and he’d been places. He’d done things, you know. You’d say he’d had a good life. I can be very satisfied that he did a lot of stuff in his life. When Patrick was at the end of his life he was saying things like ‘make something good out of this’. I think I’m carrying that out? I think I would have done that even if he hadn’t said it, but certainly he knew that I was capable of making some good of this, though it was a big thing that I had to do.

Patrick was more an academic and he would have loved to have been creative. His brother’s an artist and the other brother’s an architect and he would have envied them their talent and said he never got any of that, you know and he really didn’t. The problem was he was being coached to do medicine and therefore he didn’t have space to do any of the arty things, but I think he could have if he had time. He even liked classical music, although he was a young man about town. He did like wood and he’d sculpt this thing with his father but he didn’t have the same talent with wood that my husband had. My husband made that corner cabinet over there (pointing) and Patrick would just think that was amazing. He’d say ‘I’d love to be able to do that’ and they’d go out the back and he’d watch dad work, but no, he had his own thing going.

Oh yes, I think he would love the things I’ve done since he died. When he was alive, I can remember him coming in after being away for a while and asking: ‘What on earth have you been up to now mum?’ ‘What’s going on?’ He would look around to
see if there was anything new. Or he would bring a girl home and say ‘Oh, come and see my mum’s stuff’. Whereas the other two boys, who are far better artists than me, they wouldn’t do that, because I think they could see through my little bit of talent or whatever you might call it. But Patrick thought that I was pretty good [laughter]. So yeah, I suppose I was trying to do a little bit of good after he died and that’s why I like to give things away. I love giving things away. When I get really old, I’ll give things away to people and I’d rather do that than send all this to auction or something, you know?

With the writing I’ve done since he died, I think I started about five weeks after we lost our Patrick. I’ve written a lot of short stories before that and I’ve won a couple of awards and I thought well there’s something there, you know? I haven’t got the oomph to go out and say: ‘Look, aren’t I fabulous’ or anything like that. I just sort of kept on with it. When I got it awards, I thought well I can write and yes, after Patrick died I was just clearing things in my own mind, you know, and crying over what had happened, you know...It wasn’t awkward and nobody else looked at it. I’d leave it out...I’d leave the page on the computer and my children never did look at it. Yes, I think it was about working it all out and also for my family to hopefully look at one day. For them to be able to think about what we went through and also for his little girls. I had two books going - one for each little girl and I would write them letters to let them know about their father because I think that’s important.

After Patrick died, one of the first things I did was find the Compassionate Friends. I sort of hung around a bit and was sort of accepted there and they noticed that I was useful for certain creative things. They asked me to do things and that made me feel really good because I wanted something to come of Patrick’s death I guess. Coming up eight years ago, when I was sort of caring for him, though not in my home - he was a grown man, I wanted him to do something. Now as I said he’s not a creative fellow. He’s more academic, but I wanted him to do something creative to fill in time. So we talked about that and he went out and bought a model with a remote control, a huge thing. The trouble is he’d done that within days and I thought: ‘What
am I going to do with him next?’ So I thought about doing mosaics myself...simple things...I didn’t know what I was doing, but I wanted to sit there with him and do things, just to take his mind off things.

The pieces coming together
We had scrounged from the street lots of bits of furniture and stuff like that in the hope that he would, like his father, you know, do things up and so on. We also went to antique shops together so he could have a sense of a future with his house. I wanted him to get interested in his house and his shed and doing things and he did. He did a bit of it, he didn’t have much energy. But I was happy doing mosaics myself and he just sort of watched because it wasn’t the thing for him at all. But that developed into a bigger thing and I had something going at his place and something going at my place and this mass of tiles and sticky stuff and mess everywhere and that sort of developed and really couldn’t stop, even after he died. I gave a table to the Compassionate Friends and from that lots of other girls asked me if I’d do some with a butterfly, which is the symbol of The Compassionate Friends.

I was just happy to do that for quite a while and under each one I put in loving memory of my son and that’s sort of gone all over Victoria. I’m sort of pleased about those tables and I’m so glad that I did that writing under them, although they were really in memory for their own children’s sake. But I wanted to sort of carry on Patrick’s name. So the mosaics went on and on and on until I found these similar tables in Target and I thought right mosaics have had it for me, like they’d become the ‘in’ thing and that’s fine - they’re still lovely and I loved them. It was very satisfying and it was colourful and cheery to do them and lovely to see something grow from nothing. My husband was marvelous. He cut the shapes for me and we sort of worked together. I went out and scrounged for bases, I’m a great scrounger, and he would fix those up and make sure that they were finished very nice. So there were lots of mosaics and then I think I got into handbags next.
Something to hold and carry

Interestingly, the handbags were again making something out of nothing and I wanted to give these beautiful things away. Patrick had a partner and I really had her in mind, thinking I wanted to make her a lovely handbag, but it went on further from that. The handbags weren’t really her thing because they’re a little bit like shabby chic or something and she’s not like that - she’s a business girl. From that idea, the fabric started coming in from all sorts of places and I accepted them graciously. All this stuff is here in my home. I started making handbags and I had a handbag occasion for The Compassionate Friends, where they actually bought them. I’d usually give them away, but they actually bought them because this was a special event and covered all my expenses for my whole handbag career.

Eventually, the handbags sort of dwindled out because I said I, you know, it wasn’t a business...It was either getting into business or just sort of floating along and it wasn’t for business at all. It wasn’t to make money. It was just originally about keeping in contact with my son’s partner and giving her something to connect her to us. It had just grown out of that. I liked the idea of her having something, something to connect with us because he had two little babies and I could sense this sort of drawing away from us, as you do. But I was really anxious to, you know, keep her and I didn’t actually know what to do. So the handbags were one project.

Hand to heart

From the handbags, the next thing that emerged was when my husband carved me a little wooden heart. I love hearts. I brought one to The Compassionate Friends and the CEO asked me if I’d make a hundred and eighty. So that filled in a lot of time. My poor husband was carving these hearts most beautifully, cutting each one and he would come in and say: ‘Is this one perfect? and I’d say: ‘It doesn’t have to be perfect; if each one is different it doesn’t matter’. Each one had a different design. I really loved that and it was very...well, very proud to be there and they’d be given out to VIPs or anyone who comes in and they were given to all the volunteers at Christmas time.
I think at one time, there were hearts all over the house - hearts and butterflies. When my husband first gave it to me, I wouldn’t have appreciated a diamond ring any more than that. It was just lovely. So I was decorating these hearts and I just gave them away to anyone and it became really like an excuse for talking about my son. It was so nice to have one of my little hearts and they were all for Patrick and there was something in having the hope that giving one might draw someone to say: ‘How are you?’ Because I miss that very much, I understand that, you know, people aren’t always comfortable with bereavement. But I find that any chance I can get to mention Patrick is a wonderful thing. Not in a morbid way, but to talk about something silly or, you know, to say: ‘Patrick used to do this or that’. I think that invites people to come in and talk about him. Well, Yeah, it suddenly came to an end because I gave them all away. But I had a lovely time wrapping them all in little bags and tying things on them.

By this time I was helping at The Compassionate Friends quite a bit and this is when I started to write anniversary cards for the organisation and they would be sent to other bereaved parents. That was very good for me. I liked to look up the person on the database, to see how old their child is in order to work out if they need teddy bears on their card or what. I sort of did it in my own way and found my own words and way of expressing something, you see. If it was a young girl, it might be a pink and purple butterfly or if it’s a boy, you know, it might be a masculine looking butterfly.

I’ve always liked to make something out of little things and I’ve lived to make something out of nothing. I just like colours and simple designs and I’m not a great artist at all. I didn’t go to any classes recently or since Patrick’s death to learn anything more as I wasn’t into that. So I think it was a matter of just simply desperately trying to find something to do.
I’m always saying to others: ‘Find something to do. You know, write about it’ which is easy for me I can just sit and write. I do realise how hard it is for some people to actually write about things though. I knew it would be very good for me and I suppose I’m trying to make Patrick pleased with me that I’m trying to do something worthwhile. I did go back to College and I thought: ‘Oh he would be pleased with me going off to my lecture. I thought I was pretty brave. It was a scream really. I did enjoy it and I thoroughly enjoyed the essays and, you know, I was proud of myself and I think he would be proud of me too because I wasn’t that sort of person in his view. So there you go. Now I’m going to go to philosophy classes.

I guess what I’m doing is…I’m scratching around with different things to make it work. Scratching around; this is my way of putting it...You could say, it is my way of grieving rather than getting so down, and that can happen because I actually have had anxiety through the years. Yes I suppose doing things is for me, holding things together, you know, like thinking: ‘Oh I’m getting down. I must go and do some mosaics’ or something busy. It was that sort of motivation. I mean I always like to be in control. Since Patrick died, I just call it utter sadness and that’s my sort of depression, I think?

Now I’m doing carpets, which is another example of putting little things together to make a whole thing. They’re made out of what most would call scrap material I suppose. Although, I do buy the right colours and stuff like that; so that’s another thing. I’m making them and each stitch is like a mosaic. It’s building up to something that’s a complete thing. Yeah. I keep thinking I’m making these for Patrick’s little girls one day.

I’m pleased with my work and I really do think that. Yes, Patrick would find a lot of pleasure in my things.
It’s sort of repetitive work where you don’t have to really think about it, you know. You don’t always have to think about what you’re doing. Your mind is open to other things. It was very joyful stuff doing those things and it just lifted my spirits.

I still find ways to connect to him, sometimes while I’m working on things. Every aeroplane that goes over, I talk to Patrick, you know. I’d say: ‘Hi’ and if I don’t and I hear it just about gone I’d say ‘I’m sorry I didn’t say hello to you’. So, I suppose I would talk to him in a way, you know, and sort of say: ‘Oh, you see, oh that house has been pulled down’ in such and such a street as I’m driving the car. You know, I don’t see that as odd in any way.

I say sorry when I forget to wave when the plane goes by in case he’s looking down thinking: ‘Oh mum, you’ve forgotten me’. No, you don’t forget but I do realise that you’ve got to not pretend that you’ve forgotten but it’s more pretending that you’ve risen above that. It depends on the day but I was brought up to believe that there’s a heaven and we all go up there and meet each other and all that. It’s very simplistic isn’t it? But it’s a comfort to think that we are all going meet up there. I think that’s what the hope is that there is something else. But I’m not one of these people who have visions and ghosts and things like that. I put my feet on the ground but I can still, you know, hope that there is something.

It doesn’t end
Do we just accept life and that it ends? I can’t. Maybe they’re brave people that say: ‘There’s nothing out there...There’s just blackness’. I think they’re brave to stand up...What right has anyone got to say I think I’m more right than the others?

There’s a value in doing things, even just going out shopping and buying yourself something nice to say that you value yourself. I don’t think people realise that they are helping themselves by doing something. It’s like saying I’m miserable today, so I’m going out to be miserable and after a while you think: ‘Oh, I’m not so miserable’. It’s happened, it’s lifted. You know. My mother used to say: ‘To have a friend is to be a friend’ and to take it upon yourself to connect yourself with other bereaved
people. Many would say: ‘Oh why would you want to do that for? It doubles your own misery’. But it doesn’t actually.

Yeah well they think that’s the full story. He lived and he died and that’s very sad or it’s very sad that he died. But have a look at the fact that he was alive and in a photo, there he is fishing and talking about things he did….‘Oh, you can’t imagine how funny it was and this and that’ and that’s just lifting to do that. Obviously, I want things left for the next generation to remember Patrick by, especially these little girls who have been blighted of their father and that’s a bit of a strain I tell you.

Well I think you’ve got to realise that your life is going to go on. You know, although you say I can’t bear it, I’m not going to live it. Your life is going to go on. So you might as well accept that and make what time you’ve got useful. At least don’t give up on your own life. You know, you can’t just stop breathing. That’s how I felt when people said: ‘How are you?’ right at the start. I would say: ‘The air goes in and the air goes out and I’m still alive’. So yes, I suppose you could say, well the air will go in and it will go out, you’ll still be here and at some stage you’ve got to decide whether you’re going to take up the chance to move ahead depending on how long the bereavement has been. To not move ahead at that stage would mean you can’t make some value come of your child’s example. But it is very difficult. Yes I can almost hear him say: ‘Oh mum, you know, get off that’ and ‘get on to…’. Yes, I do hear that from Patrick: ‘Oh god mum, you know, get on with it’. You know, him speaking as a grown man.

2014 – Judy’s reflection after reading story
I’m still involved with The Compassionate Friends and I fit in where in where I can. That’s how I cling to my son. I can’t ever imagine not being part of the organization as it is the only time I feel I am “doing something about it” After twelve years, I often have to remind myself how it feels to be recently bereft of a beautiful child. When I speak to parents seeking comfort in the early days of grief or in times of their despair, I must go back to my own new sorrow and to what I needed to hear. I am a non-
professional and I have time to talk to parents about their child as a unique individual and get to know them. In the past two or three years, I have moved from being a needy mother to a sort of mother figure to others. I feel I have followed out the wishes of my Patrick. Nevertheless, I still feel I drag a heavy tarpaulin with me. I think about painting but, although therapeutic, I think I am only capable of dark colors and miserable subjects. I have managed to do some bright art work for TCF and that’s what it is – cheery. It is hardly from the depth of my feelings.
January 2015 - Greg’s creative synthesis of Judy’s Story

**Something for Patrick**

Patrick was part of his mother’s life for 34 years

He said …“I’ve had a complete life”

He had his little girls

He’d been places and done things

A good life and a lot of stuff

Before he died he said to his mother….“Make something good out of this”

Patrick the academic

Would have loved to be creative

But he had his own thing

He would have loved the things his mother did since he died

He was always asking “What are you up to Mum?”

“What’s going on?”

His mother started writing 5 weeks after he died

Clearing thoughts in her mind

Crying over what had happened

It wasn’t awkward

No-one else looked at it

It was about working it all out

And for the family to look at one day

And for his little girls

One book for each on the go
Writing them letters
To let them know about their father
That’s important

Wanting something creative to do with him
Mosaics came to mind
Scrounging furniture to work on
She’d work and he’d watch
Tiles, sticky, stuff, mess everywhere
It continued after he died
Some with Butterflies
For Compassionate Friends
With ‘In loving memory of Patrick’ underneath each one

Handbags
His partner in mind
Making something out of nothing
Fabric from all over the place
Shabby chic
Given away mostly

Little hearts
Carved by his father
Painted by hand
Intricate designs
Brass loops
Leather thonging
Worn around the neck
Gave them away
An excuse to talk about her son
Any chance to mention Patrick
A wonderful thing

Scratching around
Scratching around to try and make things work
Her way of grieving
Doing things
Holding things together
Since Patrick died

Doing carpets
Putting little things together
To make a whole thing
Making them out of scrap material
Each stitch is like a mosaic
Pleased with the work
Patrick would find pleasure in these things

Repetitive work
Don’t have to think
Mind is open
Joyful stuff
Lifted my spirits
Connect to him
Sometimes
Talk to him
“Hi”
Patrick lived and died
It’s sad that he died
But look at the fact that he was alive
Look at the photos of him
There he is fishing
Talk of what he did
It’s lifting to do that
Wanting things for the next generation
To remember Patrick
Especially his little girls

You’ve got to realise that your life is going to go on
Although you say I can’t go on and can’t bear it
Just accept that and make your time useful
Don’t give up on life
You can’t stop breathing
When people ask how I am I say..
“The air goes in and the air goes out, so I’m still alive”
Part 3 – The mystic and meaning

Introduction to part three

This section focuses on my engagement with the research and my writing of the thesis to include theoretical considerations relating to ideas, concepts and referents that were utilised. It begins with an outline of the epistemological considerations and moves into methodology and methods. Then in the latter part of this section, I consider the research in relation to broader grief, loss and bereavement theories, while moving through to what has emerged for me in relation to the phenomena, including thoughts on theory building and future considerations in relation to the topic. This section includes a more detailed explication of the creative and arts-based process of ‘doing research’ and I will continue with the arts-inspired writing style where I feel it can add something ‘other’ to the more academic writings included in this section.
Chapter Thirteen – Epistemology

Approaching the research design
Earlier in part one, I noted that the process of deciding to undertake the research emerged from my personal experience as a bereaved parent and because of the work I have done in supporting families who have had a child die. Having seen many examples of spontaneous creative activity and experienced it myself, I found little in the literature to assist me in understanding this particular facet of grief specifically from the personal experience perspective of bereaved parents.

I chose an approach to the research that is congruent with my view of the topic, my life experiences, work and study, taking the position that I cannot separate myself from the research and the writing of the thesis. It would be misleading of me to ignore or not reveal my influences, as I do have biases and preferences and these should be made explicit, wherever I am aware of them. I accept that there may also be biases and preferences that are out of my awareness and there may be times where the reader will see my bias or preference, while I have not.

A core bias relates to the personal impetus (me as a bereaved parent, social worker, artist, counsellor/therapist) behind the research, which has me seeing this topic as important and significant. There is a key assumption on my part that many bereaved parents engage in what I call spontaneous creative activities related to a child who has died and a further assumption that these activities are significant in some way. While this assumption is based on what has I have directly experienced, seen and been told, both as an individual and professionally, I do need to caution myself and others that there may be bereaved parents who do not engage in spontaneous activities in relationship to a child who has died and even if they do, they may not experience this as significant. I wanted to state this early in this section, because it indicates my intentionality towards the subject matter. Based on this assumption, I am writing my thesis from a perspective that many bereaved parents can and do engage in spontaneous creative activity following the death of a child, but I do not
suggest that all bereaved parents will and do engage in these activities and find them meaningful.

The thesis and the topic are both immersed in personal and inter-subjective experiences that relate to existential questions, such as: what does it mean to exist as a human who faces the experiences connected to the beginning of life, uncertainty of future and the reality of death? Robert Neimeyer (2006) suggests that the human search for meaning becomes particularly intense after a death or loss, because these events raise profound issues regarding the significance of life itself – and existential crisis (Denzin 1989, Klass 1999, Moustakas 1990). Due to my own experiences and worldview, I was drawn towards an epistemology and methodology that is quite existential, phenomenological, post-modern, arts-based and qualitative in nature.

Having experienced my own existential crisis following the death of my daughter, I engaged in attempts to re-construct meaning and struggled to re-learn how to live in the world (Attig 2011). In my role as a grief and bereavement counsellor and therapist, I am constantly connected to other people’s engagement with meaning seeking and their attempts to re-learn how to live in the world following a loss or a death. This thesis is part of my own ongoing meaning seeking, which crosses backwards and forwards between personal and professional aspects of my life. Indeed in some ways this thesis could be seen as a continuation of my own creative process relating to my daughter’s death.

Phenomenological research, such as this, is seen as a highly self-reflexive practice:

“As I come to know this thing before me, I also come to know myself as the being who intuits, reflects, judges and understands.” (Moustakas 1994 p. 32).

Emmy Van Deurzen (1997 p. 5) would frame this as an existential journey, where the researcher is prepared to be touched and shaken by what happens along the way, not fearing limitations, weaknesses, uncertainty and doubts. In doing this the researcher makes contact with ‘everyday mysteries’ that move beyond their own preoccupations, knowing and sorrows to more openly confront death and perhaps
rediscover life. From my own meaning seeking, through researching the topic and writing the thesis, I hope that others can gain from the understandings that emerge in this overall process of exploration.

**Finding a background for the quilt**

I view existentialism in very broad terms to encompass multiple points of view, but a primary consideration is the existential suggestion that life can only be understood through living it and immersing oneself in it (van Manen 1990). There is then a relationship to phenomenology, which is broadly considered as the descriptive study of whatever presents itself to consciousness and thus requires attention to the life experiences of an individual person (Moran & Mooney 2002). I see a connection between post-modernism, existentialism and phenomenology, with post-modernism being described as bringing into question any assumptions about groupings of people, such as all women, all rural dwellers, all men, all children and all bereaved parents, therefore favouring an understanding of individual experience, differences and diversity (Briskman & Noble 1999; Rosenau 1992). To further clarify these epistemological considerations, I want to share my understanding of referents in this thesis such as existentialism, phenomenology and post-modernism, including how they might be related for the purposes of the research.

**Existentialism**

Existentialism is not a particular ‘school of thought’ but is rather a collective term for people who view the world in a way that suggests that life is not something which can be adequately understood through generalizing or applying universal ideas or theories in order to explain human existence. In our human world, we do not have one general or universal theory to explain all aspects of human life, nor death, grief and bereavement for each individual. Soren Kierkegaard (1951) is often seen as an early existentialist thinker with his work dating back to the nineteenth century. Kierkegaard felt that the imposition of any form of abstract objective order on human life is rather akin to squeezing human beings into a kind of cage (Miller 2008). Instead, Kierkegaard proposed a form of radical subjectivity: the freedom of an
individual to innovate her or his own unique view of life and reality or the subjective choice of one’s own personal truth in the face of objective uncertainty.

Walter Kaufmann (1975) suggests that perhaps the one essential feature shared by those who adopt approaches that might be labeled existentialist, is perfervid individualism:

“The refusal to belong to any school of thought, the repudiation of the adequacy of any body of beliefs whatever, especially systems, and a marked dissatisfaction with traditional philosophy as superficial, academic and remote from life – that is the heart of existentialism.” (1975 p. 12).

Martin Buber suggests that there are not any absolute formulas for living and that no preconceived code can see ahead to everything that can happen in life. Rather, as we live, we grow and our beliefs change and so we live with this constant discovery. By having openness to the adventure of a heightened awareness of living, we should stake our whole existence on a willingness to explore and experience. (Hodes 1972). Existentialism focuses on the immediate reality that is experienced by those people present and avoids intellectualisation and categorization of human experiences. In simple terms, things simply are as they are, to whoever experiences them (Reber 1985 p. 256).

Jean Paul Sartre (2007) suggests that existence precedes essence, meaning that we first experience someone or something and can only then consider the essence of that someone or something. Therefore, it is only after we encounter the existence of something that we can explore the essence of what makes that something exist. This is a primary reason for my choice in placing the stories of participants and their experiences of the phenomena as early as possible in the thesis – the existence of the phenomena comes first, followed by my attempt to understand the essence of this phenomena. The structure of the thesis aesthetically represents my experience in coming to this research. I realised the existence of the phenomena and then sought to understand the essence of it.
Existentialist ideas propose that humans always start from an upsurge into consciousness of our here and now experience of existence. An existentialist approach to life is more concerned with the immanent experiences of life, the messy actualities of here and now existence, personal choice and action in the present moment (Miller 2008). Emmy Van Deurzen (1997) describes existentialism as an attempt to consider everyday human reality in order to make sense of it, making it perhaps as old as the human ability to reflect. Robert Miller (2008) engages with the later existential ideas of philosopher Martin Heidegger (1889-1976) and elaborates on Heidegger’s concept of ‘being’. Miller highlights Heidegger’s view that we must not only consider the human view of life and experiences, but importantly we must consider the ‘being’ of the individual who is living and experiencing life. Heidegger’s idea of ‘being’ is concerned with not only the individual being (as a human being), but also ‘being’ in the sense of everything around us that ‘is’ and from which we as individuals have emerged and continually live within. In short, we are beings living in the ‘being’ of life as it presents itself to us.

In his book *Being and Time* (1927), Heidegger describes how human beings are absorbed in the world, inextricably responsive to it, concerned with it, since fundamentally our being is an opening onto existence. We are not complete sealed-off subjects separated from an outside by the skin of our bodies. Each human existence essentially is interaction with the world and with other people and hence human existence is intersubjective (Madison 2005). These ideas of ‘being’ have strong resonance with Taoist and Buddhist concepts and I will talk in upcoming paragraphs of my personal connection to Taoist ideas. Heidegger’s ideas have informed my approach to the research significantly and the thesis is my attempt to elucidate my experience of ‘being’ in relation to the phenomena, participants, readers and the writing of the thesis.

**Personal perspective on existential concepts**

I initially came across existentialist thought and actions, as a sixteen year old, when I began training as a potter and craftsperson. The studio in which I began working
functioned along the traditional lines of an apprentice – master relationship, with skills and knowledge being handed down from master to apprentice over time. The lineage of this studio had strong links to Japanese pottery and ‘eastern’ modes of thought, such as Zen Buddhism and Taoism. It was here that I began to accept an understanding that many things in life can only be experienced directly by an individual and that these experiences cannot be reduced to an objective thought or explanation. Many things are about the living of the experience and how we are, as individuals, in the living of that experience. While I spent a great deal of time talking with the master potter and reading and studying the classic texts on the craft of pottery and the philosophies of Eastern scholars, I was also given many practical tasks.

Though many of the tasks seemed irrelevant to me as a teenager simply wanting to become a potter, I can see with hindsight that these tasks allowed me to experience the world of the potter and what it means to be a potter. I was reminded by the master potter regularly that “these things are what they are, and if you intend to make pottery you will need to learn from the experience and your own relationship to the experience, rather than simply reading about it or being told about it”. For example, I could read about or be told about the process of digging clay from the ground and then preparing the clay to be used to make a pot, but it was only through doing and experiencing this process that I was able to have a more lived and embodied knowledge of the process. In this way, I was invited to engage with ‘being’ as a potter rather than simply conceptualising ideas on what I thought a potter was and should be. Writing this thesis has been like that for me, experiencing and learning about the process as I am doing it without always knowing ‘why’. In this way, I engaged with the ‘being’ of my research – to connect to Heidegger’s idea.

Phenomenology
Existential thought within the history of mankind has arisen in reaction to dogmatic and pedantic attempts to control human destiny though rationalization or ideas that suggest a pathway to objective truths. People such as Kierkegaard and Nietzsche challenged the push towards rationalism in their era and Husserl devised his
phenomenological approach in direct protest against the dominance of scientific investigation in research (Van Deurzen 1997). Heidegger (1996) challenges the concept that all things must have a reason by quoting a verse from the poem *The Cherubinic Wanderer* by Angelus Silesius (1624-1677) -

The rose is without why
It blooms because it blooms
It cares not for itself, asks not if it is seen.

In considering this verse with relation to a human interaction with the rose, there is of course going to be many aspects of the rose that are experienced; its smell, its colour, what it reminds me of and its texture. None of these things necessarily explain the reason that the rose exists, but they allow me to experience the rose in its fullness. This exploration of the rose is phenomenological. What is this that I am encountering and how am I encountering it?

Edmund Husserl, considered by many as the person who brought phenomenology into awareness, suggested that truth is grounded in human experience and that we ‘experience before we objectify’ (Strasser and Adelstein 2009). Husserl saw phenomenology as being focused on the human experience of things – as they present themselves to the person (Moran & Mooney 2002). In simple terms, there is an emphasis on how something is experienced in relation to what is being experienced and therefore phenomenology is inter-subjectively focused. Martin Heidegger (1994) focused on the ‘being’ of human beings and sees phenomenology as attuned to that which shows itself to the ‘being’ of a particular person or something that comes into the light of day in relationship to an individual. The focus on phenomenological research is not so much towards the thing itself, in this case spontaneous creativity in relationship to a child who has died, but more towards the individual human experience of the thing itself, in this case the bereaved parent’s experiences of spontaneous creative activity in relationship to their child.
Ernesto Spinelli (2007 p. 107) suggests that the phenomenological exploration of an experience requires attention to the noematic elements of a person’s narrative – that is to say, the topic of the overall story or ‘what’ the story is about, alongside attention to the noetic elements of the person’s narrative – that is to say, the referential aspects of the story or ‘how’ the person experienced what they are talking about. Spinelli (2007 p. 107) goes on to suggest a type of ‘phenomenological openness’ which he refers to as ‘un-knowing’. This brings an attitude of receptivity to the mystery of another person’s experiences in the world as expressed in the stories they tell. This can also be considered as an aesthetic attitude (Miller 2008), bringing a sympathetic attention to and open contemplation of what is being experienced at any given time.

Phenomenology is more a particular way of approaching human experiences, rather than a prescriptive set of guidelines for researching a topic. There are strong links connecting existentialist thought and phenomenology to more recent postmodernist thinking. Heidegger (Hicks 2002) offered the following conclusions that form a bridge between phenomenology and postmodernism, with these ideas accepted by the mainstream of postmodernism, perhaps with slight modifications:

1. Conflict and contradiction are the deepest truths of reality;
2. Reason is subjective and impotent to reach truths about reality;
3. Reason’s elements—words and concepts—are obstacles that must be un-crusted, subjected to deconstruction, or otherwise unmasked;
4. Logical contradiction is neither a sign of failure nor of anything particularly significant at all;
5. Feelings are a deeper guide than reason;
6. The entire Western tradition of philosophy—whether Platonic, Aristotelian, Lockean, or Cartesian—based as it is on the law of non-contradiction and the subject/object distinction, is the enemy to be overcome.

**Postmodernism**

Postmodernism appears to present itself as anti-philosophical, rejecting many traditional philosophical concepts. Yet, the writing of a postmodern account of
anything, presupposes at least an implicit conception of reality and values. And so despite its official distaste for some versions of the abstract, the universal, the fixed, and the precise, postmodernism does suggest a framework of premises within which to situate thoughts and actions. Postmodernism generally holds to the idea that it is impossible to speak meaningfully about an independently existing reality. Postmodernism substitutes instead a social-linguistic, constructionist account of reality (Hicks 2002).

Although the term postmodern was originally intended as a temporary expression that would be used until another word that more accurately describes our current circumstances could be found, the term postmodern, in a very postmodern-like way, has stuck with us. Cooper & White (2012) refer to Professor Zygmunt Bauman, suggesting the term ‘liquid’ instead of ‘post’ as it seems that our current times are much more synonymous with the fluidity of water than with the concreteness of the previous, so-called ‘modern’ era. While ‘liquid modernity’ may describe with greater accuracy the context within which societies currently live, the use of the term “postmodern” is more readily identifiable and understood. However, this thesis has a certain liquidity about it.

I view postmodernism as being highly relevant to my research, given that the available literature quite clearly reveals the different and diverse experiences of people who have had a child die. The literature also suggests that professional distancing when engaging with bereaved parents is generally unhelpful and limits the potential to understand their experiences. Postmodernism puts forward a theoretical framework, which embraces uncertainty and dispenses with the modernist concepts of objectivity, professional distance and notions of stable ‘truths’ (Irving 1999; Rosenau 1992). This brings openness to what is before us and calls us to simply embrace whatever presents itself. A thread runs back and forth between phenomenology, existentialism and postmodernism and from my perspective that thread relates to the idea that views research of any human experience as being connected to identifying and engaging with the individually changing human
experience in an attempt to understand that experience as fully as possible (Cooper & White 2012). However, any understanding derived is accepted as always being incomplete, subjective and fluid.

**Personal perspective: Taoism**
From around the age of nineteen my personal understanding of postmodernism and existentialism was extended through the study and practice of Tai Chi Chuan (a Chinese martial art), which has been a daily activity for me over the past thirty-one years. I was introduced to and studied the ideas of Chinese scholars, particularly those relating to the philosophy of Taoism which has strong links to the practice of Tai Chi. Taoism, as an ancient way of knowing, suggests that in order to live life fully and in harmony with our surroundings, we need to embrace the unknown and allow ourselves to simply respond to what life brings to us and let things be as they are. Sometimes this is described in the idea of ‘going with the flow’, which is often taken to mean the flow of nature. Taoism suggests that each of us experiences the world in our own unique way and that it is not useful to judge or categorise people or things outside of ourselves, because life is very much about perspective and what we each bring to any situation (Blofield 1979; Coutinho 2004,). There are direct parallels here with the work of Martin Heidegger and his concept of ‘being’.

Vagueness, subjective reality and seeming paradoxes are embraced in Taoist thought (Clarke 2000), much like postmodern thought. In this way, individuals can transform themselves through considering, understanding and accepting their place in the world in relation to the uncertainties of life, such as death and loss. Heidegger suggests that we should live toward death as this will cause us to focus more acutely on matters of ultimate concern in life, appreciate and embrace our here and now existence and spur us on to live more resolutely, passionately and creatively (Miller 2008). In the grief and bereavement literature, it is acknowledged that the experience of grief is highly individual, bringing uncertainty and a struggle to transform previously held meanings in life through living with and facing the reality of death (Neimeyer 2006).
At its core, Taoism asks that we seek to understand the world around us on its own terms rather than imposing rigid predetermined ideas upon what we experience. It is very much a phenomenological stance to understanding life experiences. This allows one to open up new understandings, rather than simply limiting or controlling life according to fixed understandings. Within Taoist thought, so-called objective rules and laws are considered to be the invention of humans who are simply trying to exert control over others and nature itself. In reality, there are no rules or laws which can be universally applied to all people or all situations in the eyes of Taoist thinkers (Blofield 1979, Coutinho 2004). To me, there is a direct relationship between Taoist thought and the existential concepts mentioned earlier.

In his book on Taoism, John Blofield (1979 pp. 44-45) offers some insight to Taoist thought by saying: “The corollary of letting things be as they are leaves people free to do their own thing. This teaching contributed to the fondness of Taoist adepts for seeking places of solitude, where one can be free to act in accordance with the prompting of the heart, unfettered by laws or the usages of society.” Here I see a relationship with the concept of spontaneous creativity after the death of a child, where bereaved parents can perhaps be given freedom to act in accordance with the promptings of their hearts in response to the death of their child or children.

The concepts of Taoism have been familiar to me much longer than I have been engaged in studying and working as a social worker or grief, trauma and bereavement counsellor. I remember reading Taoist concepts and finding many things that rang true within the context of my life and how I had come to view the world. In many senses, it feels as if I am not following or adhering to Taoist ideas, but more that Taoist ideas help me to understand and explain how I experience and live life. Through the writing of this thesis, I have come to see how influences and knowledge from earlier in my life connect with or have a relationship to my choices of epistemology, methodology and writing style for the research project. Generally, I would see myself as more interested in lived experience and the qualities of human experiences (the ‘being’-ness of life) and less interested in measuring cause and
effect. In this thesis, I focus on understanding and meaning rather than measurement or comparison which aligns with the use of qualitative research.

**Situating the research in a qualitative paradigm**

Within the field of research, there are two significant paradigms that are commonly discussed; qualitative and quantitative. Each of these paradigms have a particular focus that reflects the type of research and the nature of the questions being asked or the knowledge being sought. Qualitative research is more concerned with the qualities of entities and/or experiences and these qualities are not measured in terms of amount and frequency. Quantitative research on the other hand is focused on measurement and analysis of causal relationships between variables (Denzin & Lincoln 2008). This thesis is situated firmly within the qualitative paradigm, due to my focus on the experiences of individuals and the quality of these experiences. Within this paradigm, there are multiple ways of considering how qualitative research might be carried out in practice. Qualitative research cuts across various fields of practice, disciplines and subjects and widely varying methods and approaches are used. The common theme, however, is the focus on the quality of something more than the quantity or frequency of it (Denzin & Lincoln 2008).

Using Denzin and Lincoln’s (2008) concept of eight historical moments in qualitative research, from 1900 to current (see appendix d), I see this piece of research as moving between the last three of these moments –

- 6 - Postexperimental enquiry (1995-2000), where researchers find novel ways to portray and politicise lived experience through the use of ethnographic creative writing and poetry, multi-media texts, visual forms and co-constructed/multi-voiced representations.

- 7 - Methodologically contested present (2000-2004), a time of debate amongst massive deregulation within qualitative research and contestation with conservative regimes over what counts as valid research.

- 8 - Fractured future (2005 – current), academic work seen as praxis, with generation of new ethics and emphasis on social justice principles and development of aesthetics and teleologies for a globalized world.
While grappling with the multiplicity of ideas around carrying out qualitative research, I become familiar with what are considered ‘emergent’ approaches to social research (Taylor & Wallace 2007, Hesse-Biber & Leavy 2008, Liamputtong & Rumbold 2008, Ellingson 2009) that are congruent with these three historical moments. Within this emergent context, the qualitative research design I have created would be considered a hybrid, in that it I have borrowed and adapted concepts and methods from across a range of disciplines and their boundaries in order to explore and understand what I see as a complex issue that also crosses disciplinary boundaries (Taylor and Wallace 2007). This can also be termed as crystallization within qualitative research, where there are many facets to the methodology and methods used (Ellingson 2009). In writing this thesis, I see myself as both an ‘insider’ and an ‘outsider’ exploring multiple subjectivities:

“Working right at the limits of several categories and approaches means that one is neither entirely inside or outside” (Minh-ha 1991 p. 218).

Overall, the referents for this qualitative research project and the writing of the thesis are eclectic, blending existential, phenomenological, post-modern, narrative and interpretive influences (Denzin 1989, Moustakas 1990, Ellis & Flaherty 1992, Hesse-Biber & Leavy 2008). These referents then inform a heuristic phenomenological, participatory and arts-based, methodology and related methods (Reason & Hawkins 1988, Moustakas 1990, Liamputtong & Rumbold 2008, Hiles 2008, Leavy 2009,). These approaches support the idea that my knowledge comes from learning and experiences both inside and outside of formal academic research, blending personal, academic, and professional aspects of my life as a researcher. Due to all of these influences the methodology is hybrid in nature, blending many perspectives and influences.
Chapter Fourteen – Methodology leading to methods

Interpretive Interactionism: A starting point
Interpretive interactionism is one of the initial referents that suggested a direction for the methodology. Interpretive interactionism is an approach that focuses on capturing the “voices, emotions and actions of those being studied” (Denzin 1989 p. 10). Denzin (1989) argues that the biography and the self of the researcher are critical aspects to be explored in the research itself, because this underpins the research process and influences the all-important interpretive process. Denzin makes links to the thoughts of C. Wright Mills (1959 p5) who suggests that “the scholar connects the personal problems and personal troubles to broader social issues and contexts”. In the context of the research, I am interested in the spontaneously creative processes that bereaved parents engage with and my understanding of the place, and or purpose, of these processes within the broader social and cultural context.

Heuristic phenomenology
From exploring interpretive interactionism, I began to see connections to existential and phenomenological ideas and eventually came upon the concept of heuristic phenomenology, which became the referent that was applied more-so in this research than interpretive interactionism (van Manen 1990; Moustakas 1990; 1994; Hiles 2008, 2002, 2001) Heuristic phenomenology sits as a key part of the methodology and methods with other approaches, such as interpretive interactionist (Denzin 1989), autoethnographic (Ellis & Bochner 2000), arts-based (Liamputtong & Rumbold 2008; Leavy 2009) and participatory research (Reason & Hawkins 1988) acting upon, moving through and within it.

These approaches place an emphasis on life experiences that radically alter and shape the meaning and understanding that people give to themselves and their experiences (Denzin 1989; Moustakas 1990; Hiles 2002, 2001). Denzin (1989) describes these experiences as epiphanies or as having the potential to create or trigger a
transformational process in the individual. Denzin (1989) goes on to suggest that epiphanies are events in which individuals are so powerfully absorbed that they are left without an interpretive framework to make sense of their experience. The death of a child is undoubtedly a life changing event that can and does trigger a transformational process in the individual and also leaves people feeling they have no points of reference (Klass 1999, Miller 1999; Raphael 2006; Stebbins & Batrouney 2007; Jeffreys 2011).

**Autoethnography**

Perhaps a key aspect of this theoretical base is that both Moustakas (1990) and Denzin (1989) suggest that the self of the researcher are critical aspects to be explored in the research itself. Emerging from my biography and my sense of self, the events and troubles that are written about are ones that I have already experienced or witnessed first-hand (Denzin 1989; Moustakas 1990; Hiles 2001, 2002). In this sense the research process incorporates an autoethnographic process, where the lived experience of both the researcher and co-researcher’s become highly relevant and are explored through evocative personal stories that relate to the topic (Ellis & Bochner 1992; Ellis & Bochner 2000). These methodological referents give a focus to capturing and honouring the “voices, emotions and actions of all those involved in a study” (Denzin 1989; Moustakas 1990). Autoethnography brings a personalisation of scholarship (Schwartzman 2002).

Carolyn Ellis (2004 p. xix) describes autoethnography as a form of research “that usually features concrete action, emotion, embodiment, self-consciousness and introspection….claiming the conventions of literary writing”. Stacy Holman Jones (2008 p. 208) suggests that autoethnography is about “setting the scene, telling a story, weaving intricate connections among life and art, experience and theory, evocation and explanation….and then letting go, hoping for readers who will bring the same careful attention to your words in the context of their own lives.” Sarah Wall (2006) makes direct connections between autoethnography and heuristic phenomenology noting that autoethnography is sometimes known by other names, such as heuristic, but regardless of the label or name the style and methodology of
heuristic research is significantly autoethnographic. Muncey (2005) offers ideas on how to do autoethnography, suggesting the use of snapshots of experience, artifacts/photos/documents, metaphor and psychological and literary journeys. Muncey (2005 p. 10) continues by saying that these approaches then reflect on and convey “a patchwork or feelings, experiences, emotions and behaviours that portray a more complete view of a situation or indeed life”. The notion of a ‘patchwork’ speaks well to the metaphor of a quilt and to the hybrid nature of the methodology and methods that I have used.

**Hybrid-creative methodology**

A hybrid-creative methodology allows for varied forms of immersion in the topic, encouraging the use of intuition and deep self-reflection which can lead to breakthroughs of new knowledge that can be viewed from many angles (Denzin 1989; Moustakas 1990; Hiles 2001, 2002; Heaton 2002; Ellingson 2009). Given the exploratory nature of my research, I have tried throughout to maintain a sense of openness and ‘unknowing’ (Spinelli 2006) or the process of identifying and setting aside pre-conceived ideas, in order to create the potential for seeing new ways of doing, seeing, learning, expressing and presenting things in relation to the research topic.

Some of what you will have read and will read is included because of informed guesses, hunches and imaginings that are motivated by passions that connect to my curiosity in undertaking this research (Smith 2003). It is also true that there are scholarly theories and bodies of knowledge that support and elaborate on my individual understanding of how this project should be conducted. It was challenging in many ways to undertake the research and write it into a thesis in a way that illustrates my personally developed methodology and my subjective experience of the research in the light of more broadly held scholarly/academic theories and concepts.
A pleated text
Autoethnography has a strong focus on writing styles and again I needed to choose a style that felt congruent for me. Wanting some balance between the personal stories and the academic writing, I certainly didn’t want to privilege the academic writing more than the personal stories. A solution for me came in the work of Laurel Richardson (2006) who describes the idea of a ‘pleated text’, which brings together both academic and personal writings. This allows for the inclusion of personal stories that give personal and individualised context to the writing of research. The result is an academic text that has significant pleats or sections that reveal the lived experiences of both the writer and participants in relation to the topic and the research process. There is a movement in and out of the pleats, rather than a smooth uninterrupted surface. It becomes a process of not only writing research, but also using writing, based on personal stories, as a form of analysis and enquiry into the experiences of participants and myself, giving an inside perspective, alongside more academic writings that also enquire into the participant experiences from an outside perspective. Laurel Richardson and Elizabeth Adams St Pierre (2008) clarify that the act of writing, in and of itself, in relation to personal experiences or any topic is an act of research and analysis, suggesting that understanding and meaning emerges in the formation of words and choice of language used on the page. We do not need to move from the particular to generalisability in order to analyse stories. It’s possible to use an approach that adopts a position of seeing the personal stories as requiring respect and engagement rather than the stories being seen as data to be categorised (Bochner 2001).

Arts-based and participatory methods
Grief, loss and bereavement attract multi-disciplinary perspectives both in counselling practice and theory (Stroebe, Hannsen, Stroebe & Schut 2001). A multi-disciplinary or hybrid-creative methodology gives some room to cross disciplines and perspectives relevant to this particular topic. I found a helpful way to move across disciplines and perspectives is to adopt arts-based and participatory research methods. An arts-based approach brings participatory aspects to the research, allowing for a personally situated, creative and emergent process that encourages
participants to become co-researchers who engage in their own exploration and expression of the phenomena being studied (Liamputtong & Rumbold 2008; Reason & Bradbury 2008; Chilton & Leavy 2014).

The arts-based approach emerged for me through what I see as an affinity between research practice and artistic practice, (Leavy 2009). Obviously, my own background as a craftsperson is relevant and no doubt informed my choices here, alongside a social work background that values collaborative and participatory approaches and a topic that relates to creativity. Arts-based research is seen as particularly useful for projects that seek to explore, discover and describe and is seen as an effective way to communicate the emotional aspects of social life and raise awareness of aspects of life that may have been previously subjugated (Leavy 2009; Chilton & Leavy 2014). Arts-based research is seen as a very rich way to access experiential knowledge as part of a participatory process with co-researchers and it can effectively be used to bridge the practitioner/researcher (which is my position) divide that is often present in traditional research (Liamputtong & Rumbold 2008). Arts-based research can be used to bring more engaging richness and depth of personal experience to a topic that may not be possible with more traditional forms of research (Liamputtong & Rumbold 2008; Leavy 2009).

Arts-based research can also be used to engage a broader audience and contribute to a de-colonisation of knowledge, where the research seeks to reach out and bridge the traditional divide between academic knowledge and lived experience knowledge that comes from everyday experiences (Moustakas 1995; Hesse-Biber & Leavy 2006; Taylor & Wallace 2007; Denzin & Lincoln 2008; Leavy 2009; Ellingson 2009; Chilton & Leavy 2014).

The topic itself incorporates the notion of being creative and bringing something new into existence, so an arts-based approach presents itself as highly appropriate to the topic. I have used mostly literary and visual arts techniques but was open to techniques used and suggested by participants, provided they could be incorporated
within the thesis format. An arts-based and participatory approach also articulates well with heuristic phenomenology as a personally situated, creative, emergent process that seeks to provide an exploration and creative expression of the phenomena being studied (Moustakas 1990; Leavy 2009).

**Heuristic phenomenology that is creatively hybridised**

Previously, in part one of the thesis, I referred to the heuristic phenomenological referents adapted for use in my thesis based on the ideas of Clark Moustakas (1994) and David Hiles (2001, 2002, 2008). I then outlined related concepts that informed the way in which the thesis is shaped. I note those again here -

- **Intention or desire** – Determine the phenomenon to be focused on and consider the orientation of the mind to this. Limited use of a basic literature review to consider key elements for possible consideration.
- **Phenomenological reduction or reflection** – The textual description of what is perceived and experienced using both written and other texts (in my case, evocative writing poetry, photography).
- **Intersubjectivity** – incorporating empathy for the ‘other’ or the other world outside the gaze of the viewer. Bringing in the stories and perspectives of co-researchers through co-constructed narratives. Exploring identified topics of significance.
- **Synthesis** – Intuitive integration of the fundamental textural descriptions into a cohesive elucidation or statement of the essences of the experience of the phenomena as a whole.

In relation to the above, I have noted below the heuristic phenomenological referents that point towards the state of being adopted while carrying out the research writing the thesis (or making the quilt).

- **Epoche or mindfulness** – Bracketing out or setting aside assumptions, prior thought, desire and judgement. In particular epoche helps to move into the stances of intuition and imagination.
• **Intuition or surrender** – Surrendering to the immediate experience of the phenomena and research process in order to engage intuition, where there is an openness to whatever may be revealed without concern for what is learnt, what others have said or what may have been previously theorised or supposed.

• **Imagination** – Use imagination to actively observe and create cracks and disruptions in what is perceived to be ‘real’. Use of Arts-based techniques to do this – poetic writing, drawing, photography, etc.

The above concepts are important but are loosely held as points of departure for the application of methods in both the research and writing. In order to explicate my methods more clearly, I will draw on some of the concepts, processes and phases of heuristic research as developed by Clarke Moustakas (1990) which I have adopted as a frame of reference. I use these concepts to inform headings in this methods section. Under these headings, there will be connections, adaptations and departures with/from the methods originally outlined by Moustakas, but all aspects resonate solidly with heuristic phenomenological enquiry.

Adding to the above concepts I have outlined how Clarke Moustakas (1990) identifies two aspects of heuristic research by creating the following table. Column one outlines what he calls concepts and processes relevant to heuristic research and column two outlines what he identifies as the phases of heuristic research.

<table>
<thead>
<tr>
<th>Concepts and Processes</th>
<th>Phases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identifying with the focus of the enquiry</td>
<td>Initial engagement</td>
</tr>
<tr>
<td>Self-dialogue</td>
<td>Immersion</td>
</tr>
<tr>
<td>Tacit knowing</td>
<td>Incubation</td>
</tr>
<tr>
<td>Intuition</td>
<td>Illumination</td>
</tr>
<tr>
<td>Indwelling</td>
<td>Explication</td>
</tr>
<tr>
<td>Focusing</td>
<td>Creative synthesis</td>
</tr>
<tr>
<td>The internal frame of reference</td>
<td>Validation of the research</td>
</tr>
</tbody>
</table>
Together, the concepts, processes and phases overlap and relate to each other so that number one in the first list of concepts and processes informs number one in the second list of phases. In this way the identification with the focus of the enquiry is necessary for the first phase of the initial engagement with the research. This pattern continues through two to seven within the framework of Moustakas (1990). I actually see the ideas in a fluid, perhaps postmodern way with numbers three to six of the concepts and processes being important to all areas of the research and I have applied them as such. This may or may not be at odds with the intention of Moustakas’ in portraying them in the way he has, but this was my way of understanding the concepts, processes and phases that he outlines. This table provided me with a useful way of thinking about the methods I would use in my research.

Point of Return – Alternative reading of thesis

For those readers that decided on the alternative reading of the thesis and took the point of departure just before Chapter Two, then this is the point at which you might like to return to Chapter Two and continue on from there. Otherwise simply read on.
Chapter Fifteen - Methods

Finding the phenomena: Identifying with the focus of the enquiry and my initial engagement with the research.
Moustakas (1990 p. 15) suggests that ‘through exploratory enquiry, self-directed searching and immersion in active and direct experience of something, one is able to get inside the experience and become one with it’. This indeed was my experience with choosing the focus of enquiry and engaging with the research. My own experiences of spontaneous creativity after my daughter’s death, is presented early in the thesis, as it reflects a starting point or beginning. Through finding ways to write about and present my personal stories, I was able to reflect on and search my own sense of the experience that I was wanting to explore. Added to this was my experience of working as a counsellor with bereaved parents and my noticing that many engaged in acts of spontaneous creativity after the death of a child. These two aspects together allowed an immersion into the experience being explored through active and direct experience. The blending of personal and professional experience led me to the phenomena as a research topic that felt like it was calling me to explore it and understand it more fully. Heuristic research is an internal searching through which it is possible to discover the nature and meanings of experiences, while developing methods and procedures for further investigation and analysis (Moustakas 1990 p. 9).

Once I had identified the phenomena and the focus of my enquiry, I continued to search, within my own experiences, the experience of others and within the current literature relating specifically to the death of a child and to grief and bereavement in general. In the current literature I could find some stories where examples of spontaneous creativity by bereaved parents were presented, but the experience itself was not explored in any detail. I found literature on the experience of having a child die and how that impacts on the lives of bereaved parents and families. I could find material in the current literature that talked about the ongoing and changed relationship between bereaved parents and their child who had died. However, I
found a lack of exploration of the experience itself and I then identified this as the focus of my research. Of course this is all based on my own perception of the topic and my subjective experience of it. In order to explore the topic fully, I needed to engage with the participants who would provide stories of their experiences of the phenomena.

**Engagement with participants**

While I have offered an overview of my recruitment and engagement with participants in part one, as a lead-in to reading the participant stories, I will re-visit some detail here before moving into a more detailed and theoretically driven explication of this process.

Participants came to an informal one-hour information session to hear about the research. For those that couldn’t attend, I engaged with them on an individual basis to offer the same information. In these sessions I discussed the research in more detail, answered questions and invited participants to formally agree to participate in the research. Each potential participant was given a plain language statement and a consent form. Potential participants had the opportunity to contact the researcher to ask questions before agreeing to participate in the research. Participants were given approximately one week from the information session to formally agree to participate and return the signed consent form. Participants were fully informed of the fact that this was a formal piece of research that will contribute to meeting the formal requirements for the award of PhD at Deakin University in Geelong, Australia. All participants were required to have access to support services that related to their personal situation in order to ensure they have access to independent counselling and support if needed. For those that did not have access to this support, but wanted to participate, assistance was given to locate appropriate and acceptable support services that could be accessed by the participant.

Once participants were selected and had signed the consent form, I invited them to immerse themselves in considering their own experience of the phenomena I was referring to. The research participants generally understood the topic to be about
intuitive or creative things they had done after their child or children had died. In
short, there was a shared sense of the phenomena, but the description of the
phenomena itself only became clarified through the research process itself. Early on,
there were times when I would refer to the phenomena as emotions, intuition
creativity after the death of a child and then later still it was creative meaning
reconstruction after the death of a child. The clear naming of the phenomena or
experience remained a little elusive until later in the research process and eventually
became known as the experience of spontaneous creativity following the death of a
child. Basically, I invited the eight participants to offer examples of things they had
done that resonated with their experiences of the phenomena as they understood it.
This moved me into the next aspect of the research.

Self-dialogue and immersion in the phenomena and experience
While I waited for the participants to provide their examples of the things they had
done in relation to their child or children, I began a self-dialogue about my
experiences of the phenomena and wrote about my own experience of creating a
poem just days after the death of my daughter and a later experience of taking a
photograph after writing messages to her on a beach. Through this self-dialogue,
themes and questions emerged for me as I considered receiving the examples from
participants and then arranging interviews with them. I asked myself questions like:
‘what is it about the phenomena that I want to understand more about?’ and ‘I
wonder how the participants experienced the phenomena for themselves; what was
important to them?’ This then formulated itself into areas of particular curiosity
about the participants’ experience of the phenomena and I was able to consider how I
might bring that curiosity to, what was to be, an unscripted interview with each
participant. The interview would follow on from the initial information and
examples they were providing.

Over this time, I kept copious notes as thoughts and questions popped into my head.
There was a continuous inner dialogue was occurring. I made use of mindfulness and
self-awareness processes that I had learnt from my years of Tai Chi practice to notice
how I was feeling and responding to the self-dialogue that was occurring. When
something felt significant or resonated strongly (even if I didn’t understand it), I would make notes that I could return to with a view to perhaps integrating them into the research or writing of the thesis. It was all rather uncertain but exciting at the same time, propelled by this sense of something significant that was present, but hadn’t yet fully revealed itself. Moustakas (1990 p. 45) points out that “this kind of personal, private immersion provides the initial essential preparation for discovering the nature and essence of a particular experience”.

**Moving into the interviews**
Parallel to my own immersion in the phenomena, my engagement with the participants was intended to also move them into a space of self-dialogue and immersion in relationship to the phenomena. In providing examples of the things they had done, it was inevitable that they were reflecting on their own experiences while connecting to events that had led to the experiences they had. The participants also knew that I was going to interview them in person and continue to talk about the topic with them.

Out of respect for the participants, for ethical reasons (given the sensitive nature of the topic), and for the best possible process in conducting the research, I wanted to interview the participants as soon as I could after they had provided their examples of things they had done. The examples would form the basis of our discussion in the interview and because I had invited them into this state of self-dialogue and immersion around the topic, I felt it important that we meet and talk together in person as soon as possible. This would allow their self-dialogue and immersion to meet my own and together we could explore their experience of the things they had done in relationship to their child. I also needed to consider how they were being affected by the research process so far and consider the level of support available to them in living with their grief; offering connections to further support if needed. The reality was that all participants indicated they had access to good levels of support and they seemed to find the research process interesting and engaging and it seems they welcomed the opportunity to talk about their child or children openly.
The interviews
The interviews were conducted at a location mutually agreed upon by myself and the participant. Some interviews were conducted in the homes of participants and others were conducted in more public locations. Each interview began with brief introductory chatter and then with myself offering a starting point of the following nature: “What part do the things you have done (in relation to your child) and the creative process, play in your life and what do these things mean to you?” From this point, the interview unfolded in an unstructured way, with the participant talking about their experiences and myself holding a sense of my curiosity about the phenomena and the participant’s experiences. This created a more dialogical interaction where we were both contributing to the participant’s telling of the story. Each interaction was unique apart from the similarity in the way the interview started. In this manner, the narrative was co-constructed as the participant told their story, because particular details were being offered in response to my presence, curiosity and interaction (Polkinghorne 1988; Ellis 2004). Because of this, the interviews reflect an inter-subjectivity in relation to the phenomena, with my own curiosity informing my interaction with the experiences of each participant (Spinelli 2007).

Each interview was audio recorded with each participant and myself mutually agreeing on when to start and end the recording. Some informal discussion occurred prior to and after each interview. These informal and unrecorded interactions (including other sensory information during the interview) were held by me in memory as my own inter-subjective sense of the person and their experience. This sense would be brought forward as I worked with the transcripts later on and this helped me incorporate a deeper sense of how the person expressed themselves and the personal nuances of the story being told.

In an effort to continue the process of immersion in the experiences of the phenomena, I decided to manually transcribe all the interviews. I simply put on a set of headphones and transcribed the recordings verbatim into a typed electronic
document. The transcripts included all dialogue from the interview. While very labour intensive, this process allowed me to become very familiar with the nature of each interview, the voices of the participants, their stories and indeed a sense of their child who had died. Certainly my experience of listening to the interviews repeatedly in order to transcribe accurately, left me with a very strong sense that the deceased children of these parents (myself included) were very present in our interactions, through referring to them, recalling them and considering what it was like to be talking about them in this way. I realised that these stories spoken by the parents also contained parts of the stories of their children and so it felt important that I not lose a sense of the parent along with their child in writing up the stories.

**Incubation**

In all honesty, I was exhausted by the transcribing process. It was useful and left me with a feeling of how these stories held experiences that were very significant. They were significant for the parents of course, but they were also significant to me because I could to see and hear the lived experience of engaging with the phenomena at a level of detail I hadn’t found in other literature. However, finding words to express the significance or meanings contained in these stories remained elusive at this point. Upon reading the raw transcripts, something seemed to be lost in just reading the verbatim words spoken in the interview. It felt like there was less sense of the person, their child and what they had done. The conversation in the transcript was unstructured and it stopped then started, it returned then deviated, would perhaps return with changed focus and so on. It was like holding something important and not knowing how to show it to others in a way that would present the reader with a sense of what the conversation felt like to me. I also felt the need to bring a ring of truth or verisimilitude to the story in relation to the participant, their child and their experiences.

Stepping back from the transcripts for a while, I turned my attention to reading about and considering possible ways to present the stories that were now in written form. I extended my searching further into the areas of heuristic and autoethnographic research and explored books and articles about emergent qualitative methods. For a
while, the transcripts sat to the side without me looking at them, but I held a sense of what was there and waited for something to emerge that would offer me a suitable way of engaging with and presenting the participant stories. The term incubation was very appropriate to this part of the process because it was like sitting on something and waiting for it to hatch or emerge, bringing a greater sense of life to how these stories could be presented. I was waiting for the egg to start cracking open, so I could greet what was inside. Moustakas (1990 p29) quotes Michael Polanyi (1964 p. 34) in relation to this idea:

“The way you reach the peak of the mountain…...Our labours are spent as it were in an unsuccessful scramble among the rocks and in the gullies on the flanks of the hill and then finally, when we would give up for a moment and settle down to tea, we suddenly find ourselves transported to the top…..it comes in a flash after a period of rest or distraction”.

**The listening guide**
The first signs of something useful emerging from the period of incubation occurred when I came across the idea of ‘The Listening Guide’ (Gilligan, Spencer, Weinberg and Bertsch 2006). Described as a pathway to discovery when discovery hinges on coming to understand something of the inner world of another person (2006 p. 253), the listening guide draws on voice, resonance and relationship as points of entry into the world of another person’s experience. The approach offers a pathway into relationship with another rather than being focused on interpretation of another’s experience (Brown & Gilligan 1992). By using literary and musical concepts such as voice, resonance and counterpoint to engage with the variety of expressions that each person brings to an encounter, it joins the work of feminist, cultural psychological and anthropological researchers in their efforts to maintain a sense of the participants voice that is not overridden by, but is in relationship to the researcher’s voice (Gilligan, Spencer, Weinberg and Bertsch 2006).

Buoyed by reading about an approach that seemed to fit my methodology, I made some early attempts to use the listening guide in working with the participant stories. The original listening guide concept suggests a series of steps. I admit that initially
the idea of following specific steps felt out of keeping with my approach, but I was willing to give it a try. I realised that while the words ‘a series of steps’ were used in the literature I viewed on the listening guide, the sensibility of the approach was quite open ended and required subjective decision making and choices on the part of the researcher. I needed to experiment with the approach so that I could sit with how it felt and allow a little more incubation time, but slowly I was moving towards things being illuminated.

Finding the plotline
The first step was to ‘listen for the plot’ or listening for a sense of what each story was about. Even at this early point, I couldn’t stop myself bringing in other theoretical ideas about this. So in listening for the plot, I adopted a phenomenological position of ‘epoche’ or bracketing out pre-conceived ideas about what the story was about. I wanted to put aside the idea that this story was about the phenomena I was exploring, because that was my pre-conceived notion and this could stop me from hearing what each story was about for the participant. I made notes about my sense of what the plot was in each story. I heard plotlines in participant stories. The following is an example –

‘This story is about a mother whose daughter died during birth. The mother loved the daughter so much that she never wanted to lose her connection to her daughter and so she wanted to do things for her daughter and make things in relation to her that were the best they possibly could be. Using her background as an artist, she created things to help her make sense of the experience of having her daughter die.’

These plotlines were used to keep me connected with the overall story as I worked with the transcripts and then created co-constructed narratives. The plotlines were only used for my own personal process and I decided not to include them in the thesis because I felt that the reader could then be free to identify their own sense of the plotline in each story.
I poems

The second step in the process of the listening guide was to create what are called ‘I poems’ (Debold 1990). This requires going through the transcript and underlining all the ‘I’ statements made by the person in the interview along with accompanying verbs or other words that seem relevant or say something significant. Then taking these underlined ‘I’ statements they are stacked in sequence on top of each other to create a poem. The idea is to try and capture something of the voice that relates to a sense of self or the ‘I’. I worked with two transcripts and immediately found a problem in doing this. Firstly, it dawned on me that in some transcripts, the participant didn’t use ‘I’ statements very much and in other cases there were lots of ‘I’ statements. I noticed that even if ‘I’ statements weren’t used there was still a sense of the ‘self’ in what was said. For example one person could say ‘I felt sad and so I went to bed’ while another version could be ‘felt sad and bed seemed like a good option’. I couldn’t find a way to grapple with this so that it felt comfortable.

Secondly, the couple of ‘I’ poems that came together felt a little like a type of psychoanalysis of the individual. I sent some of my work back to the participants whose transcripts I’d used and my sense was that the ‘I’ poems didn’t resonate greatly with them. Of course, this method is sometimes referred to as a form of psychological analysis and this was the aspect that didn’t seem right for my needs. However, after experimenting with the ideas, I realised that I could draw on some of the concepts around voice and relationship together with perhaps a use of poetry to express aspects of the person’s experience.

Already from my engagement with the participant stories, I was starting to see and notice things that would pop up out of the narratives. Words like pride, love, care, always connected, wanting to do things for and longing kept presenting themselves to my awareness. Something was starting to come to light about the topic and I felt ready to engage with the transcripts, eventually using a hybrid approach that I created myself by drawing on several theoretical bases.
Using the listening guide as a type of reference point to engage with the stories of participants seemed congruent with my methodology. Gilligan, Spencer, Weinberg and Bertsch (2006) suggest “the listening guide offers a way of illuminating the complex and multi-layered nature of the expression of human experience”. While I found aspects of the listening guide rather prescriptive and perhaps overly analytical for my needs, there were key components of the method which I felt I could adopt.

The key components of the listening guide that I have used are:

- A series of listenings, with each designed to bring the researcher into relationship with each participant’s distinct and multi-layered voice.
- Each listening amplifies or identifies different aspects of the person’s voice or experience, with an awareness of possible contrapuntal voices (like listening to a piece of music and listening for the different instruments which may be playing in contrast to each other, while contributing to the overall sound of the piece of music).
- The voice of the researcher is present in the research process.
- Active presence of the researcher who engages with the unique subjectivity of each participant.

Using the listening guide as a referent, what I needed was a process that would guide me in hearing the varied voices within each participant’s story. Something which would orient me towards the aspects of their experiences I would be listening for. I was also looking for something that would allow a somewhat holistic immersion in each interview transcript in order to illuminate the parts of the transcripts (or participant’s story) that related to the phenomena of spontaneous creative acts following the death of a child or children. Thankfully, I had come across another concept in my searching that offered something that I could add to the listening guide and create my own method for engaging with the transcripts. This process would see me reading-listening to each participant’s subjective experience through my own subjective experience and understanding.
The elements of life: A personal perspective

In my current counselling practice, one of the sites I work from is within a natural therapy clinic in a small country town. I often have enjoyable collegiate conversations with the owner of the clinic who is a naturopath and body therapist with many years of experience. He reads constantly and widely about research and modes of practice. One day, as I was about three years into my research, I was talking with him in the staff area of the clinic and he asked me if I was aware of the work of Karla McLaren? I said no that I hadn’t come across her work. He suggested that I might find her concepts useful both personally and professionally and promptly gave me a USB drive with audio files of Karla McLaren (2005) talking about the idea of working empathically with people in the helping professions. I went home and began to listen. Apart from a lot of material that made great sense to me, I noticed immediately how Karla McLaren was using a reference point of exploring human experiences through understanding the elements of life.

I had been familiar with the Chinese system of elements through my study of Tai Chi and to some extent through my exposure to eastern modes of thought while being a potter. These elements are seen as the core aspects of life and within the Chinese system they are referred to as earth, water, metal, fire and wood. Drawing on her knowledge of several cross-cultural systems of thought where similar elemental approaches to life are used, Karla McLaren had researched similarities and difference in elemental theory and arrived at an elemental theory that is suited to working empathically with people in supportive roles such as counselling, psychology and psychotherapy. I was intrigued and realised that, potentially, here was something that I could apply to not only my counselling practice, but also to my research.

Drawing on elemental theory

In the following paragraphs, drawings and table, I have tried to condense the concepts around the use of an elemental theory, using material from Karla McLaren (2005) and James Schombert (2002), who in turn refer to ancient understandings of these concepts.
The ancient Greek scientific theory of matter and the interrelationship of matter, proposed by Empedocles stated that all matter in the universe is composed of some combination of four elements: Earth, Water, Fire, and Air. Plato later revised the idea of four elements to five elements, being strongly influenced by a mathematical concept developed by Euclid, referred to as the five platonic solids. Euclid found that there are only five solid shapes that can be made from simple polygons (the triangle, square and hexagon) and Plato related this to the previous four element system. This is illustrated in the following diagram –

Plato’s five elements within the universe were earth, water, air, fire and aether (quintessence). (Schombert 2002). These were very early attempts to understand the basic elements of life and how combinations of these elements form different substances, objects and how these elements sustain life. In some cultures these elements were related to aspects of being human with the suggestion that human life required an interplay of all the basic elements, indeed the suggestion was that all things could ultimately be understood to consist of combinations of these elements (McLaren 2005).

The are two significant variations in names that Karla McLaren uses, one being because the metal element in the Chinese system is often seen as similar in nature to the air element in the Greek system. The term air is used in the McLaren system. Secondly the wood element in the Chinese system can be viewed as similar in nature
to the idea of aether (ether) or quintessence in the Greek system. In this case McLaren adopts the term wood. Karla McLaren (2005) synthesised the concept of five elements and applied them to the elements of human existence. The synthesis of this elemental system can be most simply illustrated in the table below –

<table>
<thead>
<tr>
<th>Element</th>
<th>Corresponds to</th>
<th>Human Existence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Earth</td>
<td>&gt;&gt;</td>
<td>Physical</td>
</tr>
<tr>
<td>&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Air (Metal in Chinese System)</td>
<td>&gt;&gt;</td>
<td>Cognitive</td>
</tr>
<tr>
<td>&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Water</td>
<td>&gt;&gt;</td>
<td>Emotional</td>
</tr>
<tr>
<td>&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fire</td>
<td>&gt;&gt;</td>
<td>Spiritual</td>
</tr>
<tr>
<td>&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wood or Nature (ether – quintessence)&gt;</td>
<td></td>
<td>That in which the other 4 elements exist</td>
</tr>
</tbody>
</table>

**An elemental grief scale**

I began to search in the fields of grief and bereavement practice, social work, psychology and psychotherapy for any reference to these elemental ideas. I had noticed for many years that in the field of grief and bereavement it was common for texts to refer to the fact that grief affects people emotionally, cognitively, socially, physically and behaviourally. Usually only some of these were referred to and at times physicality, or the body, was included while others were left out. I always felt that there seemed to be a focus on only some aspects of life, while other aspects of life were ignored. Yet when I looked at holistic approaches to counselling, I found some reference to body, mind, emotions and spirit, which comes very close to Karla McLaren’s concepts and those of elemental theory.

At this point, I discovered the work of David Fireman (2010), a social worker, who had developed what he termed a ‘holistic grief scale’, using five aspects of life to represent the various aspects of being human. He lists these aspects as –
• Emotional
• Cognitive
• Physical
• Social
• Spiritual

These five aspects made a great deal of sense to me as they matched up well with the elemental theory I had been exploring and the focus of Fireman’s material brought it directly into my field of practice. The idea provides an excellent way to assess the needs of individuals in a holistic way, by paying attention to different aspects of their lives. I had loosely been using a similar existential idea in my counselling practice, based around the concept of their being four dimensions or worlds in which human beings exist (Van Deurzen 1997). Emmy Van Deurzen (1997 pp. 100-101) describes the four worlds as being physical, social, psychological and spiritual. Within this concept, the emotional aspect of life is seen as part of the social world, because emotions are key to our interaction with others and the world around us. I had always felt that the emotional dimension or world needed to be a separate dimension in its own right and David Fireman’s concept highlighted this again for me.

Based on all of this information, I developed my own version of an elemental theory. The focus was on considering the different aspects of human existence and on drawing attention to the different elements of life when someone is grieving. I used most of the labelling of elements from David Fireman’s work, but made some adjustments based on my knowledge of the Chinese elemental system and by interpreting the work of Karla McLaren (2005, 2010) and Emmy Van Deurzen (1997). The key changes are that I identify one element as environmental/social and another as spiritual/philosophical, alongside the physical, emotional, cognitive elements. The environmental/social element is for me the element which engages us with the world around us – all parts of our environment (natural and manufactured) and other people/beings, it is the element in which everything is situated and is about our relationship to the ‘other’. The spiritual/philosophical element is for me about our engagement with the less-tangible world around us – beliefs, ideas, and a sense of
something beyond the physical and perhaps beyond life as we know it (things that are not tangible but present in some form).

To illustrate my elemental theory I use the following diagram –

The physical element is placed at the centre, based on the idea that we can only experience the world because we exist as a physical being and it is through this physical reality that we engage with or have awareness of all the elements of existence (Damasio 2000). I accept that there are multiple ways of viewing this and another option is that four elements are situated within the larger element of environmental/social.

**Elements become voices to be heard: Merging of methods**

With attention to elemental theory, I began to see how I could use these ideas within the listening guide method. Based on the elemental model, I would listen for the voices of cognitions, emotions, physicality, spirituality/philosophy and environmental/social in each story. I would be doing this to immerse myself into the participant story in a more detailed way. By listening for these voices in relationship to the phenomena being researched, I could bring a more specific focus to material that related to my topic across five different elements of human existence. These five
elements wouldn’t be used to analyse the transcripts, but would help me explore the stories in a holistic way, by bringing in a different focus to how I listened to the transcripts.

A template with five headings was developed with an added category labelled temporality – the voice of time, such as speaking of things happening earlier, later or perhaps over time. I then began working with the interview transcripts. In reading each transcript, if a sentence or paragraph spoke of emotions or an emotional state I would cut that out and paste it under the heading for the voice of emotions on the template. I would then continue through the transcript ‘listening’ for the voice of emotions. If I read a sentence or paragraph that spoke of thoughts, planning or problem solving then I would cut that out and paste it under the heading for the voice of cognitions. I would then continue through the transcript listening for the voice of cognitions. Sometimes it was hard to decide which voice heading to put some of the material into, so I needed a way to get a sense of where it seemed to fit best (I discuss how I did this in the following piece on tacit knowledge and focusing). The process of elemental listening went on with each transcript until I felt that I had all the elements of each person’s story that related to the topic.

There were some element headings that had many entries for particular transcripts and others that had few entries. This reflected the individual person in each story. Karla McLaren (2010) suggests that some people are more comfortable within certain elements of life and so they find themselves communicating in certain elements more than others. For example, there could be one person who is more comfortable with emotions and physicality, while another person may be more cognitive, physical and environmental/social in their approach to life. These are the voices that came through by doing this process, allowing me to get, what I felt was, a clearer sense of each person.

There was a specific focus on material from the transcripts that I felt related to the topic or said something about the person’s experience in relation to the phenomena.
It is also true that my judgement of what material went into which category was quite subjective, based on what I thought or felt fitted best under each elemental heading. This could be a flaw in the method, but I didn’t see this as a problem because I was not suggesting that there were strict definitions of how to identify certain elements in an individual story. What I see as an emotional experience, may be seen as a physical experience by someone else and so generalised definitions are not useful in this situation. This is where a type of inter-subjectivity came into play - bringing my subjective experience to the subjective experience of the participants. What was important was being able to look and listen to the stories in a way that called my attention to what was being said and how the person was describing their experience of what they were talking about. In this way, I was employing a phenomenological approach to the material - considering the ‘what’ of the story (the thing itself) and the ‘how’ of the story (the human experience of the thing itself) (Spinelli 2007).

**Tacit knowing, focusing, indwelling and intuition in an effort to illuminate and explicate the phenomena**

In making decisions about the application of the elemental listening towards each transcript, I applied tacit knowledge (Polanyi 1958) through the use of focusing (Gendlin 1981):

“Tacit knowledge comprises a range of conceptual and sensory information along with images that can be brought to bear in an attempt to make sense of something” (Hodgkin 1991 p15).

Tacit knowledge is the ability to sense the unity or wholeness of something from understanding the individual qualities and parts of that something. Polanyi (1964) offers the following example: knowledge of trunk, branches, leaves, flowers, sounds, shape and size enable a sense of the treeness of a tree and it’s wholeness as well. However, on most occasions we sense the treeness of the tree without needing to attend to all the different aspects that make it a tree. There is a relationship in Polanyi’s work with that of Martin Heidegger, who would say that we need to be concerned with the ‘being’ of the tree.
This knowledge of the essence of something involves engaging the qualities and parts, where vague and defined outlines move towards a sense of certainty, only to dissolve or change as we continue further experimental observations. Yet throughout the process, little visions of truth or a sense of truth appears and gains strength through ongoing reflection, further evidence and a sense of how something is in light of what we know, as well as an acceptance of what we don’t know. Tacit knowing is basically an integrated sense of knowing, where evidence on its own is not enough as we come to know something through a sense of the essence of that something. Tacit knowing has a close relationship to intuition:

“We know more than we can tell” (Polanyi 1967 p4).

Michael Polanyi (1967) calls researchers to consider their own personality, thoughts and feelings if they are to research a topic with a sense of exploration and discovery:

“We must conclude that the paradigmatic case of scientific knowledge, in which all faculties that are necessary for finding and holding scientific knowledge are fully developed, is the knowledge of discovery. To hold such knowledge is an act deeply committed to the conviction that there is something there to be discovered. It is personal, in the sense of involving the personality of him who holds it, and also the sense of being, as a rule, solitary; but there is no trace of self-indulgence. The discoverer is filled with a compelling sense of responsibility for the pursuit of a hidden truth, which demands his services for revealing it. His act of knowing exercises a personal judgement in relating evidence to an external reality, an aspect of which he is seeking to apprehend” (Polanyi 1967 p24-5).

When I engaged with listening for the five different elements of human existence within each participant story, I made use of tacit knowledge. There was a sense of selecting parts of the stories that had some relationship to the wholeness of what I was trying to discover, though at that early stage I still couldn’t name what I was to discover, but I could hold a sense of it. Indeed, there was a sense that there was a hidden truth amongst these stories and I was attempting to bring that to light through
exploring qualities and parts that I sensed had a relationship to the phenomena that I was yet to fully comprehend. What assisted me with applying tacit knowing was the complimentary skill of focusing, which Moustakas (1990) includes as one of the processes of heuristic enquiry.

**Focusing**

Focusing, applied to heuristic phenomenology, facilitates a relaxed and receptive state of being in the researcher. This enables perceptions and senses to have more definition and clarification. Focusing taps into the essence of what matters, setting aside peripheral feelings or distractions (Moustakas 1990). Focusing brings an inner attention that promotes a ‘staying with’ a sustained process of systematically coming into contact with central meanings of an experience or what Heidegger might call the ‘being’ of the experience (Miller 2008). It is about pausing long enough to examine and reflect upon the researcher’s experience of the phenomenon (Moustakas 1990). Eugene Gendlin (1981) who developed ideas around the concept of focusing describes focusing as both a mental and kinesthetic process that pays attention to what he calls a ‘felt sense’ that is in relationship to what is being experienced. It is a process that can bring forward subliminal knowledge to a situation, through connecting the stored knowledge of both body and mind. Gendlin points us back to how our bodies live ‘opened up to’ situations, especially other humans (Madison 2005).

Within the form of arts-based and presentational knowing discussed by Chris Seeley and Peter Reason (2008 pp. 30-31), they offer a similar approach to research which they describe as four states of being, while engaging with research –

- **Sensuous encountering** - uses all of our senses to bring a whole body experience to being curious.
- **Suspending** – setting aside quick intellectual responses to what is before us in order to have time to become more deeply acquainted with what we are experiencing.
- **Bodying forth** – Inviting imaginative impulses to express themselves through our bodies to avoid misplaced rationality or premature editing.
• Being in-formed – becoming a being whose living and actions are both formed and informed by rich experiences, surprises, provocations and evocations, both as perceiver and creator.

These ideas are like a conduit between arts-based presentational styles of research and use of the skill of focusing as a method of enacting these ideas in order to engage with the stories of participants.

Gendlin’s (1981) research on this topic of focusing over several decades demonstrates that all humans have and use what he call the ‘felt sense’ in everyday interactions and yet many are not aware of the process that takes place in order for this felt sense to be listened to and acted upon. Gendlin’s work, initially as a colleague of Carl Rogers, has been dedicated to unearthing the process and being able to teach people how to make more conscious use of this inherent skill. Firstly, it is understanding that a ‘felt sense’ is the body’s sense of a particular situation or problem. Then it is about pausing and leaving room for the felt sense to form fully within the body, before moving on to something else. Focusing is a form of indwelling or the turning of thoughts and feelings inward towards the core sense of self and what lies there, in order to reflect and know differently. When this occurs, the felt sense can impart information, though this information does not come in words, it comes in body sensations. By paying attention to these body sensations and connecting the mind to them through checking words or ideas against the sensations, the information can be made more tangible and clear (Gendlin 1981). It is basically an inquisitive sense of moving back and forth between body and mind in order to clarify a situation, experience or question. Without going into a long explanation of focusing as a skill here, I will instead give an example of how I applied it to my research illustrating the link that I see between tacit knowing (theory) and focusing (skill). Gendlin’s (1981) book on focusing, gives a more detailed explanation of the whole process of focusing and how to make use of it in lived experiences and I have included notes on the basic focusing process in the appendix (appendix f).
As I worked with the transcripts, I would use the skill of focusing to allow my tacit knowledge to come forward. For example, as I began reading each transcript I would listen for and notice which sentences or paragraphs seemed to have relevance to my topic. I would then highlight that sentence or paragraph and look at the sentence or paragraph again asking myself what makes this relevant to the topic? I might then get a sense that it’s because they are referring to their child in relation to a situation they faced. I would then pause for a moment and notice how my body felt. If there was a feeling of this sitting comfortably within my sense of the topic of my research I would then move to paying attention to which element I would paste this highlighted sentence or paragraph into on my template. Initially, I might say to myself: “It’s spiritual in nature” and then I would pause again and drop my awareness into my body and look for a body held sense of: ‘Is this spiritual?’ Sometimes my body sense would indicate: ‘Yes it is’ and at other times my body sense might shift slightly uncomfortably indicating: ‘Well no, it’s not so much spiritual for this person’. I might then feel that it’s perhaps more emotional in nature and I would check that against my body sense. If my sense was that ‘yes emotional fits better for this person’, then I would cut and paste it into the emotional aspect of the template. Often, I would do a final check of considering whether that sentence or paragraph sits well under the heading before moving on to the next paragraph or sentence.

Basically, this is the process of focusing that I applied. It takes a little more time, but for me it added both rigour and an ethic of respect to my process of working with the stories of the participants. In simple terms, based on the theory of focusing and tacit knowledge, what I was doing was checking any of my decisions in relation to a participant’s story, against my whole person memory and a sense of the individual participant rather than some objectively held principle which would be divorced from the actual individual. The research behind this approach indicates that our central nervous system perceives and processes a larger amount of information than that which is simply stored in our brains (Gendlin 1981; Damasio 2000). It is indeed our whole body that interacts, relates and stores information about our interactions with others and so by using focusing and tacit knowledge I was employing an embodied
awareness of each participant in order to assist me in working with the participant stories. There is an obvious link for me between tacit knowledge, ‘being’, intuition and the use of focusing, which has a relationship to indwelling, as described by Moustakas (1990).

**Bringing the pieces together to form stories with verisimilitude**

At the end of the process of elemental listening and getting a sense of temporality while drawing out information relevant to the topic, I was left with the question of how to bring these pieces together to form a whole coherent story. The story needed to be not only coherent, but also needed to reflect the voice of the participant and have a ring of truth (verisimilitude) about it that related to the original experience of the interview. Ideally, the reader should feel as if the participant is speaking to them.

I had already used and developed a range of skills that I trusted would allow me to do this. By holding close the methodological principles and using the methods that I had developed, I felt equipped and more confident in achieving the re-narration of the stories. As I faced each transcript within my template, there was a certain level of uncertainty related to wondering how I would ever piece it all back together to become a story with authenticity, but I set that aside and engaged in the process thinking of the following quote: “Creativity makes a leap, then looks to see where it is” (Andrews, Biggs & Seidel 1991 p. 58)

By applying the concepts of tacit knowledge and focusing, I was able to slowly and methodically re-narrate each story to form what I called a co-constructed narrative. In a similar process to listening for the five different elements within the transcripts, I was now re-positioning the words, phrases, sentences and paragraphs into a story that reflected the movement of time in each participants experience. So that the story read as a narrative telling of their experience from around the time of their child or children’s death through to current times.

By this stage of the research, it was clear that the something that felt ‘not right’ about the verbatim transcripts being used was the movement of time in the original
transcripts being disjointed. This disrupted the coherence of the overall story for the reader, making it less story like. Drawing on the work of Robert Neimeyer (2006) and ideas of constructivism, this process could be seen as the deconstruction and reconstruction of the participant narratives in order to more deeply understand, make meaning of and to clearly express the experience of the participants in a presentational form. By involving the participants in the co-construction of the narratives, I hope to have maintained the voice, meanings and intentions of each person as they explored the topic with me, while bringing in my own subjective experience of each person’s story through the re-narration process.

Co-constructed narratives
The term co-constructed narratives appears most often in ethnographic research and is not a fixed concept (Denzin & Lincoln 2008). Basically the ‘co’ stands for collaborative or co-operative, meaning that the construction of the narrative occurs between two or more people with each contributing something of their perspective to the story (Ellis 2004). Carolyn Ellis (2004) suggests that any relationship or interaction between people is jointly authored, incomplete and historically situated. Bochner and Riggs (2014) suggest that: “When people tell stories, they interpret and give meaning to the experiences depicted in their stories. The act of telling is always a performance, a process of interpretation and communication in which the teller and listener collaborate in sense-making.”

Based on these ideas, what I had in the original transcripts was already a co-constructed story of each participant’s experience because the participant had engaged in the interview due to my request for participants to talk about a particular aspect of their lives. In this way, I had already had input to the story being told by the participant in the interview because I had defined the topic and phenomena being explored and each participant responded to that in their own way. As Carolyn Ellis (2004) suggests, the story that unfolded during the interview was jointly authored, incomplete and reflected something of that particular moment in time.
There are many ways to co-construct narratives (Ellingson 2009; Ellis 2004) and in my case I chose a mediated and participatory method, utilizing the elemental listening process, noted above. In doing this, I was taking each participant’s words, phrases, sentences and paragraphs that were of relevance to the topic, out of the interview transcript. It was then a process of re-narrating the placement of those words, phrases, sentences and paragraphs into a story that expressed individual experiences relating to the phenomena. I focused on doing this in a way that reflected an overall sense of time, the original interview and the individual voice of the participant.

Using italics to illustrate the steps engaged with by participants, the steps involved in co-constructing the interview transcripts into participant stories are as follows –

- Define phenomena to be explored and invite participants as co-researchers
- *Participants offer an introduction to their story in response to me offering information about what style of introduction I was looking for.*
- I meet with participants and I offer the phenomena as a topic for an audio-recorded interview.
- *Participants tell their story in the interview in response to my presence, curiosity and questions.*
- I transcribe audio interviews into verbatim written transcripts.
- *Participants read the written verbatim transcript and check it through for accuracy.*
- I make any amendments to transcript based on participant feedback
- I trial methods of engaging with the verbatim transcripts and write some draft ‘I’ poems.
- *Some participants read and respond to this trial of methods.*
- I use an elemental listening and focusing process (described above) to extract words, phrases, sentences, and paragraphs that related to the phenomena being researched.
• I re-narrate/construct each participant’s words, phrases, sentences and paragraphs into a coherent story that I felt had verisimilitude in relation to the original interview and the voice of the participant.

• Placement of each participant’s pre-interview introduction (written by themselves), unchanged, at the beginning of each story.

• *Participants read the completed re-narrated story to check verisimilitude and to make any changes and adjustments as they see fit.*

• I offer each participant the opportunity to provide *their own written comments, reflections and thoughts about the experience they had described in the interview – from the perspective of four to five years post interview, as a conclusion to the story.* Some but not all participants take this opportunity and those that don’t are happy for the story to be presented as it is.

**Participatory research**

The above reflects the collaborative and participatory nature of the co-construction of the narratives presented in the research. Holman Jones (2008 p. 219) suggests “participation as reciprocity” is an important aspect of writing and presenting autoethnographic research and asks the question: ‘How well does the work construct participation of the author, participants and even readers?’ Participatory research doesn’t seek knowledge simply for the sake of knowledge and provides a more reflective knowledge that helps people to name certain experiences that can be of significance in their world and the world in general (Conrad and Campbell 2008). The approach I have used holds closely to the idea that my research is ‘for, with and by’ people who have experienced the phenomena that is the topic of the research and is not research ‘on’ these people, thereby developing a subject/subject relationship between myself and the participants rather than a subject/object relationship that can be common in some forms of research (Fals-Borda 1991).
**Creative synthesis: Creating an essence of each person’s story – poetic knowing**

I felt quite strongly that each participant’s story should be included in its entirety because the finished co-constructed narratives provide a presentation of and research about (through a reflection on) their individual experience of the phenomena being explored. By referring to Laurel Richardson’s (1996, 2006, 2008) concepts of seeing writing and story-telling as research rather than simply data, I could see more clearly that my engagement with the participants, the story-telling that happened during that engagement and the writing of these stories was indeed a significant part of the research in and of itself. All the way through, myself and the participants were exploring and responding to the questions of the research. In the end, I realised that the central section of the thesis – section two, actually comprised nearly everything I was seeking in the research. In the participant stories, there is the presentation of the phenomena being explored, the individual experience of the phenomena, an enquiry into the individual experience of the phenomena, a presentation of the individual meanings in relationship to the phenomena and subjective accounts of the significance of the experience of the phenomena for these eight bereaved parents. As discussed by Carolyn Ellis (2004 pp.195-196), telling and retelling a story is in many ways an analytic activity because it involves making connections between events and brings attempts to communicate meaning.

Much as the completion of these co-constructed narratives felt satisfying, there was, what felt like, a lose thread needing to be tied off or neatened up. This was to do with my role in the research and that fact that heuristic phenomenology ‘begins and ends with the researcher themselves’ (Moustakas 1990). While I had engaged in the co-construction of the stories, what was needed was the final step in the heuristic research process – a creative synthesis. Moustakas (1990) suggests that in creating the synthesis the researcher is entering the process thoroughly familiar with all the major themes, qualities, explication of meanings and details of experience as a whole. The creative synthesis relies on engagement with tacit and intuitive knowing and challenges the researcher to place core themes into a form that brings forward the
researchers own expression of the essences found in the phenomenon that has been explored. This synthesis can take varied forms including poetry, stories, drawing or some other creative form, often using verbatim material and examples from the research process.

Poetry had been a thread for me throughout the research process, with the poetic form assisting me to bring ideas into sharper focus (Schwartzman 2002; Chilton & Leavy 2014). It was here that I returned to aspects of the listening guide concept of ‘I’ poems, where the actual words of participants were selected chronologically from their stories and used to construct a poem. I found other referents in the work of Laura Ellingson (2009), Roy Schwartzman (2002) and Laurel Richardson (1992), who each make use of poetry as part of research and often use the actual words of participants to form poetic representations. Ellingson (2009) speaks of chronologically selecting excerpts from the interview, which were then condensed and physically arranged on the page. She suggests that poetry and poetic forms offer rich opportunities for highlighting larger segments of a participant’s story and reflect much of the artistic sensibility used in writing narratives. Laurel Richardson (1992 p126) suggests that “poetry commends itself to multiple and open readings in ways that conventional sociological prose does not”.

A referent for the use of poetry in a PhD thesis came to me via the work of Doris Brett (2003), who made use of poetry in her PhD thesis title *Eating the underworld*. Brett describes poetry as a condensed, intense form of communication, were words have freedom to become jumping off points into connections around a topic that are beyond the orderly, logical processing of the rational mind. She goes on to suggest that poetry demands a relationship with the reader through the use of language that is multi-layered, evocative and unsettling and in doing this new meanings can emerge in relationship to the phenomena explored in the poem. I was certainly wanting to engage the reader in considering key jumping off points for exploring meaning within the experiences of the participants and I wanted to stretch beyond rational and orderly ways of understanding the phenomena. Poetry gave me a creative and
interesting way to give a sense of summary to each of the participant stories while leaving openness to individual interpretation.

In keeping some consistency with my methods, I chose to use the now familiar approach of again reading through the co-constructed narratives and selecting short phrases that presented themselves to me as meaningful, based on my overall knowledge of and engagement with that participant and their story. I used the process of focusing (Gendlin 1981) to assist me in selecting these phrases and I then cut and pasted these phrases into a new document so I had space separate from the stories to create the poems in. I pasted these short phrases in chronological order, one on top of the other and blocked them into sections in unison with a particular section, paragraph or topic being spoken about within the co-constructed narrative. In this way, I ended up with drafts of poems. Only the main section of the story, which was created from the interview transcripts, was used for this process. I did not extract phrases from pieces that were written solely by the participants. I felt that these should remain intact as the participant intended.

Once I had gone through the co-constructed narrative and had chosen phrases for the poems, I turned my attention to the poems themselves. Working chronologically, I further condensed and re-arranged the words and phrases into a non-rhyming poem that each reflected my sense of that person’s experience of the phenomena. In doing this, I too was reflecting on and explicating my understanding of the phenomena and the participant’s experience of this. I also felt I was expressing something about the whole research process through the creation of these poems, by returning me to ideas about pieces of personal experience and life and how each of us continually look for ways to bring these pieces together in order to understand something.

I then placed each poem at the end of the corresponding co-constructed narrative, bringing a sense of completion to my engagement with each participant story. Even as I am writing this, the thought comes into my mind that these poems indeed completed a cycle for me. I began the research with my own experience and
wonderings about the phenomena and then turned to those beyond myself (the collective or the community) to enquire further and understand more about the phenomena. What followed was a somewhat closed intersubjective project where I worked with eight participants to explore and understand the phenomena in a collaborative way. In creating the poems, I moved these subjective experiences from the research project back into the collective or community, where they can be experienced and wondered about. The poems reflect my own highlighting of what appears to me as meaningful and significant in each participant’s experience. The poems further reflect my own clearer understanding and illumination of, the pieces of individual experience and meaning that come together to create the phenomena of spontaneous creativity in bereaved parents after the death of a child. There is a sense of completeness yet incompleteness that leaves the reader room to experience and understand the topic in their own subjective way. This leaves me with a sense of congruence in relation to myself, the methodology and methods I have applied.

Point of Return – Alternative reading of thesis

For those readers who decided on an alternative reading of this thesis and took the point of departure on page 47 in Chapter Three, then this is the time to consider returning to page 47 in Chapter Three in order to continue on with the thesis from there. Otherwise simply read on.
Chapter Sixteen – Bringing the stories to the literature

Blending the emergent understandings from the research with existing understandings in the field

By exploring general grief and bereavement theories in this chapter I aim to situate some of what has emerged from the participant stories. Here I will bring what I see as significant aspects of the participants’ stories and experiences into relationship with current grief, loss and bereavement theories and models. Through reflecting on the theoretical ideas in light of the participant stories, I can consider how the emergent understandings and meanings might articulate with current thinking in the field of grief and bereavement. I will then present my own theory building that has developed through my engagement with the participant stories, the literature, methodology and research topic. This is followed by considering the participant experiences in light of my theory building. Towards the conclusion, I will briefly reflect on the implications of this topic for future research in relationship to experiences of spontaneous creative activity amongst bereaved parents.

Grief: Pondered and theorised

Humans have pondered, wondered and found ways to understand and express the experience of death, loss and grief for thousands of years dating back to Neanderthal times (Tattersall 2002; Shaver and Tancredy 2001). It is widely acknowledged in the field of grief and bereavement research that Sigmund Freud (1917), initiated the concept of ‘grief work’, which suggests that after someone close dies, the surviving person must sort through their mental and emotional connections to the deceased person and then disconnect or detach from these connections in order to be able to have healthy and viable connections and relationships into the future. Part of this ‘grief work’ was expressing feelings and emotions about the deceased in order to ‘work through’ these connections and associated emotions and eventually detach
from them. Freud also suggested that unexpressed emotions were problematic in the human grief and bereavement experience (Shaver & Tancredy 2001 pp. 63-88).

This work by Freud was published at a time when the western world was grappling with the issues of grief and loss through the experience of World War One (Parkes 2001). These concepts and variations thereof continue to form a background understanding in the current field of grief and bereavement theories in our current western society. In the 1950s and 1960s, research into the grief and bereavement experiences of people began to increase significantly, with many of the studies relating to the experiences of people affected by world conflicts and losses caused by war (Parkes 2001).

**Ideas that attempt to explain grief and bereavement**

Three influential theorists in the field are Colin Murray Parkes, John Bowlby and Elisabeth Kubler-Ross, who emerged as significant researchers during the above-mentioned period (1950s to 1970s). The concepts and ideas they developed continue to be influential to date (Stroebe et al. 2001, Mikulincer 2008, Stroebe & Schut 2008, Prigerson et al 2008). Parkes initially focused on identifying that bereavement can lead to psychiatric/psychological problems, while Bowlby focused on attachment theory and how it can be used to explain grief and bereavement as a form of separation anxiety, with death bringing an irreversible form of separation. To me, there are links back to the work of Freud in evidence amongst the ideas they developed. Together in 1970, Parkes and Bowlby collaborated on a project, which provided a descriptive classification of, what they termed, the ‘phases of grief’ which were outlined as follows:

- Numbness
- Yearning and searching
- Disorganisation
- Despair and re-organisation

(Bowlby & Parkes 1970 pp197-216).
Around the same time Elisabeth Kubler-Ross (1969), who worked with the terminally ill in America, adopted her well known classification of what she termed the ‘five stages of grief’. –

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

What must be remembered is that although Kubler-Ross’s ‘stages of grief’ became widely accepted by both professionals and the general community, it was originally specifically developed in relation to those who were dying rather than those who were bereaved (Kubler-Ross 1969; Prigerson et al 2008). Certainly, I hear many people talk about Kubler-Ross or the ‘stages of grief’ and many popular writings on grief and loss are dominated by these ideas (Attig 1996). Many people see the stages as a linear progression and this can create expectations about how they should or shouldn’t be grieving. These expectations may limit the ability of a person to respond to intuition or emotions if they believe they are not responding to their grief appropriately according to dominant theories or stage models. It is perhaps more accurate to consider Kubler-Ross’s idea as simply five aspects of grief that are likely to be observed, often in a continually changing order or cycle.

I regard these theories as an important in relationship to this research, because they do form part of the current ‘taken for granted’ attitudes to grief and loss. These prevailing attitudes provide some understanding of grief, but also create limitations on how community members view what is and isn’t acceptable as part of the grief process. I see often that people will question themselves, when following hunches or intuition and wonder: Is it OK to feel the way I do? Am I normal for being the way I am? Should I do this or that? As can be seen from the participant stories presented in section two, hunches and intuition are quite an important aspect of these bereaved parents finding a way to live with the death of their child. There is clearly a need for
theories of grief to accommodate options for the following and consideration of hunches, wonderings and intuition. A common underlying assumption with many theories seems to be that it is necessary or desirable for a person in grief to move from distress to normality in a linear fashion, when, in fact, people may move about between the phases and steps and may re-visit any or all of the phases or tasks at any time in their life subsequent to the death or loss (Neimeyer 2000).

**Myths and assumptions**
Camille Wortman and Roxane Silver (2001) undertook a review of the dominant Western theories and models relating to bereavement and grief and found that there are many assumptions and myths about coping with loss, which are pervasive in society. Wortman and Silver (2001) suggest that some aspects of dominant theories perpetuate these ‘myths of coping with loss’, which can create confusion or distress for those experiencing loss. They argue for a questioning of current assumptions in Western society about the grief process in order to ascertain whether these assumptions are supported by research into the lived experiences of those individuals who have experienced a loss. Wortman and Silver (2001) also suggest that some of the currently accepted support and treatment approaches to loss and grief may be based on erroneous assumptions that are perpetuated by theories that are disconnected from the reality of lived experience. In this sense, it is likely that professionals and community members might simply accept that theories are reflective of lived experience for each individual, when in fact this may not always be the case. As discussed here, the need to connect theories or approaches to grief and loss into the lived experiences of people who are grieving gives adds credence to my chosen research approach that gives emphasis to the individual and subjective experiences of bereaved parents in relationship to things they have done since the death of a child or children.

Alongside the previously discussed psychological approaches to grief, during the period from 1940s to 1970s, there were some theorists who viewed grief in medical terms. Terms such as healing and recovery came to be some of the words used to describe grief and bereavement, likening grief to a wound or illness (Attig 1996)
Erich Lindemann (1944) introduced concepts such as the ‘symptomatology and management of acute grief’ and made links to psychiatric illness. George Engel (1964) viewed grief much like a disease and describes ‘symptoms and syndromes of grief’ which are part of a ‘healing process’. Therese Rando (1993) makes an argument that for some people grieving can become ‘complicated’ if ‘symptoms’ don’t resolve over a set period of time and that this calls for clinical attention. These definitions of ‘complicated or prolonged grief’ also rely on the stage models of grieving to define whether a person is progressing through the stages or phases in a healthy way. The concept of ‘complicated grief’ as a medically defined disorder has recently evolved into a proposed clinical definition titled ‘Prolonged Grief Disorder’ and there were calls for its inclusion in the internationally used DSM V (Diagnostic and Statistical Manual for Mental Health Issues) as a widely recognized mental health illness (Prigerson et al 2008). However, there are those researchers who suggest that grief as a normal process of adaptation to loss, is in no way analogous to disease, no matter what the course of an individual grief process (Klass, Silverman & Nickman 1996). So the debate continues, what is grief and is it a problem to be solved?

Thinking about the stories of the participants and the window they provide into some of their grief experiences, it seems to me that grief is the experience of being bereft of someone you care about. It may of course also be related to the loss of something you care about in a broader sense of grief. Love is certainly a significant part of the story for the participants. The feelings of love toward each child who had died can be sensed clearly within all the stories. Noted often in the parents’ stories was the feeling of needing to do something for their child and indeed it appears that for these parents love is not just a feeling, it involves actions that emerge from feelings of love. If grief has a close relationship to love then I doubt that it’s wise to see grief as a problem to be solved. Thomas Attig (2011) suggests that grief is not a problem to be solved but is instead a mystery that we should bring levels of personal understanding to.
What happens when people grieve?
Margaret Stroebe and Henk Schut (2008) developed what is known as the ‘Dual Process’ model of grief with a focus on addressing what they saw as the shortcomings of existing models of bereavement. Stroebe and Schut, agree that other models and theories have been highly influential and appealing, but there is always room for revision and new conceptualizations around any existing theoretical work in the field of grief and bereavement.

Briefly, the ‘Dual Process’ model of bereavement and adaptive coping after a grief experience, suggests that within everyday life, (after experiencing a loss or a death) people have two ‘orientations’ or ‘stressors’ (areas of focused attention), that need time and energy to attend to. One ‘orientation’ is towards the loss or death itself, involving the feelings, thoughts and experiences relating to the loss or death and the person or thing, which has now gone. The other ‘orientation’ is towards the stressors that are a consequence of the bereavement and form part of the struggle to re-orient oneself to a changed world in which the deceased person or thing is missing. The second orientation is about rethinking and re-planning a life in the face of the bereavement.

A feature of the Dual Process model is that it adds a dynamic element of what is termed ‘oscillation’, which occurs between the two ‘orientations’. This was added to address what Stroebe and Schut felt was a previously ignored aspect of grief, namely that a person in grief is not and cannot, continually be focused on grief, loss and sadness. There are times when a person in grief must attend to everyday life and the things that have changed since the loss. It is noted that ‘time out’ from the grief is necessary, and in the past this may have been seen as ‘denial’ rather than part of living with grief. The ‘oscillation’ is used to describe that fact that, in grief, people continually ‘oscillate’ or move between attending to what has been lost and what needs to be done now and into the future (Stroebe & Schut 2008 pp. 4-5). A diagram best illustrates this model:
The dual process model has usefulness in relation to child-bereaved families following emotional and intuitive drives to create things in their bereavement, where they are giving energy to both orientations – acknowledgement of the loss, while also living life as it is now. From the participant stories, it appears that as a parent is involved in the spontaneous creative process, they can be holding both feelings of the loss and their engagement with how life is now at the same time. This is a little different from oscillation between one state or another. Thomas Attig (2011) suggests that the concept of oscillation has limited application to lived experience, because grieving individuals can often be faced with situations that bring both the stressors of loss and restoration simultaneously and not always in isolation from each other. We can be confronted by our losses exactly in the moments that we are engaged in living a changed life.

A significant theory around grief and bereavement that has been adjusted over time is Bowlby’s (1973) ‘attachment’ theory, which I discussed earlier. The main thrust of this theory is that humans are born with an innate ‘attachment-behavioural system’ that calls them to seek closeness to significant others. Bowlby suggests that the goal of the system is to provide a means of security, protection and support. Because of this, the loss of a significant other to which one is attached, is experienced as a
devastating event that causes great distress, because it is hard to accept that the physical closeness we seek with the person who has died can no longer occur. In the past, there was the suggestion that one way of managing this situation and the emotions and thoughts that come with it, was to actively detach oneself from the person who had died, in order to allow energy for other living attachments. Bowlby referred to this as a process of de-activation of the attachment system towards that person. However, Bowlby noted that in the early stages of grief a person will often move into a hyperactivated attachment state, which calls them to yearn and search for ways to re-attach to the person who has died.

Mario Mikulincer (2008) elaborates on these concepts to suggest that what allows people to adjust to the death of a loved one are two major psychological tasks. Firstly, one needs to accept the loss and return to everyday activities while editing or re-arranging the hierarchy of attachment figures in one’s life. Secondly, and importantly for my research, one needs to maintain a symbolic relationship to the deceased person and integrate the lost relationship into everyday life. Mikulincer goes on to suggest that it is actually both ‘hyperactivation’ and ‘de-activation’ of the attachment system that allows people to achieve this adjustment to a death. Hyperactivation allows us, as humans, to experience the deep pain and re-activate memories of the deceased, providing a context for exploring the meaning of the lost relationship and thereby strengthening any symbolic bonds to the person who has died. Deactivation allows us to momentarily detach from thoughts of the deceased and the intrusion of painful thoughts and feelings, which then gives us emotional space to be connected to current daily reality and be open to re-organising or forming new attachments to other people in our lives. Mikulincer also cites the ‘dual process’ model of grief (Stroebe and Schut 2008) as a way of understanding that it is normal for people to ‘oscillate between a hyperactivated attachment system and a deactivated attachment system. By adding these concepts to the diagram of the ‘dual process’ diagram, it is easy to see the correlation:
Two Track Model
The Two-Track Model of Bereavement developed through the work of Simon Shimshon Rubin (1999) suggests that the bereavement response occurs along two main axes, each of which is multidimensional. The first axis or track is focused on how people function in their daily lives and how this functioning has been affected by the experiences of loss or a death. The second axis is concerned with how people maintain and change their relationship to the deceased or what has gone. Some people may not always appreciate or be aware of the detail of the nature of this relationship, their investment in it, or of the consequences. Nonetheless, this component is critical for understanding the human bereavement response (Rubin 1999).

In this model, it is suggested that grieving people grapple with the effects of grief to function on a daily basis and many areas of their lives can be impacted on. The model also suggests that the grieving person contends with finding ways to manage their now changed relationship to the person who has died. In both cases, the bereaved person moves between how life use to be and how life is now and needs to find ways to reconcile these factors within themselves. Within the stories of the
bereaved parents in this research, I can hear how their lives and daily functioning both changed and carried over aspects from before their child’s death. Of particular interest is that certainly the spontaneous creative things they did seemed connected to managing a changed relationship to their child. These activities allowed these parents to bring their relationship with their child into their current and ongoing daily lives, which in turn seemed to have an influence on the parent’s ability to function on a daily basis. Both tracks of this model seem entwined in the spontaneous creative processes described by the parents.

**What do people do when they grieve and mourn?**

Another theorist who is very influential in the field of grief and bereavement, particularly the area of grief and loss counselling practice, is William Worden. William Worden’s (2002) ‘Tasks of grief’ has some similarities to the ‘Phases of grief’ proposed by Parkes and Bowlby and discussed earlier. Worden suggests that there are four tasks to be addressed for those in grief -

- Accept the reality of the loss
- Experience the pain of grief
- Adjust to life without the deceased
- Re-locate the deceased emotionally and continue on with life

Worden changed the fourth task from its original form of “withdraw emotional energy from the deceased and invest in another relationship” (1991), to its current wording. This was done in response to the development of other theories such as ‘continuing bonds’ (Klass, Silverman & Nickman 1996), which will be discussed later. The relevance of Worden’s theory to my topic is that I can see that the creative activities that child bereaved families engage in, may allow them to address some or all of the ‘tasks’ suggested by Worden as they live with their grief. There is evidence of several of the participants coming to accept the reality of the death through the activities they have engaged in. For some, the spontaneous creative activities were in response to experiencing the pain of grief and I will talk later about the idea that perhaps the pain of grief is related to a feeling of love or longing that has nowhere to
be expressed. Certainly, all participants indicate that the things they did in relation to their child helped them to adjust to life without their child and then re-located the child emotionally in a way that allowed an ongoing connection within their lives.

It is significant that these more recent theoretical developments highlight that it is now widely accepted that developing and maintaining an ongoing connection to the person who has died is in fact a necessary aspect of grief and bereavement, rather than being problematic. Also, there is an indication that symbolism and meaning reconstruction after a death are of importance, which is where my particular interests lay with this topic. It is apparent that the spontaneous creative processes, engaged in by the bereaved parents in this research, attend to these symbolic and meaning-making ideas. Participants mention in their stories how they felt connected to their child in some way while engaged in these processes and this at times extended to some parents saying that they felt each time they engaged in the activity, they were spending time with their child. In the sense of meaning making one participant story had a theme of ‘making something out of nothing’ or ‘making some good come of what had happened’. The creative activities that child bereaved families engage in are an acknowledgement of the continued relationship with their child who has died and the meanings associated with that relationship. The spontaneous creative activities allow parents to express and perhaps give meaning to this relationship, both privately and for themselves as well as publicly, where they can share something of what they have done with others, such as family members and friends.

‘Continuing Bonds’ (Klass, Silverman & Nickman 1996), as a theory, is based on research that reflected the lived experiences of those living with different forms of grief. This concept suggests that ‘death ends a life but not a relationship’. By gathering research that reported on the lived experiences of bereaved and grieving people, Klass, Silverman and Nickman found that people do not and cannot forget or detach themselves from the person who has died, even if they tried to. We as humans do not have an ‘erase’ function in our minds to remove memories and experiences that we have had, especially those relating to another person who we have been
strongly attached to. Therefore, after a death, a significant part of the grief experience is to do with how we manage a radically changed relationship to a person who is no longer physically present. We continue to have thoughts and feelings about the person who has died. We see, hear, smell, touch and taste things that remind us of the person who has died, but the way we managed our relationship with them before their death is no longer viable. Over time, the relationship that we have to the person who has died takes on new meanings and we can eventually find ways to incorporate this relationship into our daily lives. Often a tension occurs when we live in a society that seems to tell us that death has ended a relationship, when we are still having thoughts and feelings about the deceased, therefore continuing a bond or relationship to them. I would suggest the continuing bond is an expression of love, care or significance.

The continued bond that people have to the deceased is tied up with the meanings attached to that person and relationship and this is an important element within the lives of bereaved parents. It can be said that humans are meaning seeking beings. The life of a human, when reduced to its most basic elements, is about making meaning out of what is experienced between birth and death (Yalom 2008). In spite of the efforts of scientists, philosophers, sages and the world’s many religious groups, to name only a few, there is no substantiated evidence of any intrinsic meaning or purpose for the existence of human beings. However, the history of human beings is marked by our continuing search for meaning and purpose in our existence. This is not to say that our lives have no meaning, but rather that any meaning or purpose is developed and constructed by each person as they live their lives. That is, we make meaning out of our lives and experiences.

At times, when people are faced with a major personal crisis, trauma and loss, it can seem that our personal meanings in life and our understanding of these meanings is challenged or feels as if it has been stripped away. People can find ourselves needing to ‘re-construct’ meaning for their lives after the previous meanings, ideals and ways of living have been challenged and sometimes pulled apart or ‘de-constructed’. This
is the ‘existential crisis’ I have referred to earlier (Denzin 1989, Klass 1999). The death of a child is an experience that severely disrupts previous assumptions and meanings, with bereaved parents vulnerable to loss of physical, cognitive and emotional mastery along with previously held goals and sense of purpose in life (Miles & Crandall 1983).

Robert Neimeyer has emerged as a key theorist in the field of meaning-reconstruction and grief. Neimeyer (2001; Neimeyer & Sands 2011) suggests that meaning reconstruction in response to loss and death is a central process in grieving. His interactions with the bereaved and his research in the field of loss and grief indicates that grieving requires people to engage with fundamental revisions in their assumptive world views, meaning systems and life narratives in an effort to restore some sense of coherence, hope and self-efficacy in the overall narratives of their lives (Neimeyer 2001; Neimeyer & Sands 2011). In his book Lessons of Loss: A guide to coping (2000), Neimeyer reflects on and summarises the concepts and theories about grief and emphasizes the importance of stories and narrative approaches in order to develop a sense of meaning within the grief experience. With what I see as influences of Thomas Attig and Klass, Silverman & Nickman, Robert Neimeyer reframes William Worden’s ‘tasks of grief’ as “challenges to the mourner” (ibid p40). Neimeyer’s ‘challenges to the mourner’ are:

- Acknowledge the reality of the loss
- Open yourself to the pain
- Revise your assumptive world
- Reconstruct your relationship to that which has been lost
- Reinvent yourself

Neimeyer (2000 p. 41) is quick to point out that these challenges are not to be accomplished in any given order and should never be considered over and done with in any final sense. As we go through life and our situation changes, we will often have to re-visit some or all of these challenges in different life contexts. I am
interested in Neimeyer’s (2000 p. 84) rejection of the implicit assumptions found in what might be termed ‘traditional grief theories’ (those discussed earlier in this section). Neimeyer adopts a constructivist/narrative approach that highlights the ways in which people uniquely re-construct meaning in their lives following a significant loss or death, while facing the challenges of mourning outlined above. All of the participant stories give evidence to each parent’s unique re-construction of meaning following the death of their child or children. There are of course many ways in which people try to reconcile the need to understand what has happened after a death, while also feeling a sense of connection to the person who has died. An example is the use of rituals around loss and death, which have been used for many hundreds and thousands of years to assist with this integrating the experience of loss and death into life. I want to explore this notion briefly in relation to the topic, because at times there is a sense of ritual around how the participants engaged with a sense of creativity in relationship to their child.

The role of ritual in meaning making
Rituals punctuate life, marking the significant points of transition for humans. Rituals can be seen as cultural devices that provide ways of comprehending some of the most complex aspects of human existence. Rituals are usually active in nature and can provide a structure for what might otherwise be emotional chaos, giving symbolic order to events and social construction of shared meanings. To me, I can see that the creative activities and process that family members engage in after the death of a child could be viewed as having a ritual aspect to them, such as the washing of a tattoo on an arm being the first part of the body to be washed in the shower each day. I have heard it said that rituals make meaning out of moments, which I feel is very apt.

One of the first opportunities for bereaved people to engage in creativity and ritual is through a funeral. Funerals serve these functions while reaffirming our communal bonds to others (Neimeyer 2000). The funeral rite constitutes an effective symbol of the acceptance and subsequent ordering of existential and emotional chaos. The ritual nature of a ceremony of farewell accompanied by the disposal of the body has
vital significance for the acceptance of reality and the eventual re-construction of meaning.

One of the participants talks about the importance of the funeral for her baby daughter and how it was so important for her to pay attention to detail and do the best she possibly could to make the funeral meaningful. This is an example of a funeral being one of the first activities after the death of a child where a bereaved parent creates something that has a relationship to the child and expresses something about this relationship. Sometimes, the need for unity between the dead and the living reaches an intolerable climax. People feel the need to build a bridge between the living and those who have died. Perhaps the gap between the living and the dead is most powerfully felt when the one who has died is a child. The funeral rite is often an early expression of this bridge building, where the life of a child or the meaning of the child’s life in the context of the family can be publicly aired, before farewelling the physicality of the child as they enter the realm of the dead. The funeral rite provides a tangible experience, from which understanding or knowledge may be acquired, allowing family members to begin re-constructing or making sense of their changed circumstances. Parents begin to consider the place of the deceased child as part of a family that will lives into the future.

**Personal note**

Writing and re-reading the above paragraph, I think about the time after my daughter died, when my partner and I thought long and hard about what to write on her plaque at the cemetery. We were struggling with the idea that she was our first born child and her birth marked a change from being a ‘couple’ to being a ‘family’ and even though she had died we still felt like a family, but our sense of how to be a family was not fully clear. So Madeleine’s plaque has this written on it – ‘A family now, we always will be, holding you in our hearts for eternity.’ For us, this was a final part of the burial ritual and the meaning of these words has simply grown more solid over the years.
**Back to the role of ritual in meaning making**

There is great difficulty for families of children who are stillborn or who die in the perinatal period, as people outside the family may consider the child has barely lived at all. Therefore, they may not see the full significance of the child’s death. It is here that the importance of public rituals can be seen. In the funeral ritual for a stillborn child, the child is acknowledged as a child and member of the family, therefore the child is given a place within the family and this in turn gives the opportunity for meaning to be constructed around this child’s role in the family history and the family can reconstruct meaning around any previous constructs that had related to what constitutes a ‘family’ (our western culture tends to view families as being made up of living people.) (Grainger.R 1998 p115-116)

These funeral rites assert the existential importance of another person and mark an event in time that relates to that person. It ‘locates’ the person as being dead and this is done in relation to the life of the person and what that life meant to those who remain living. In order to have a relationship with another person, you need to know who that person is and where to locate them. The person may be ‘somewhere else’ but at least they are somewhere, whether this be in eternity or time – for the past is a place also. Rites that allow this reality to be revealed then allow the living people, who knew the dead person, to have a relationship with that person, which in turn allows them to reconstruct meaning around the place of the deceased person in their lives. This can give a sense of comfort and a sense of some order being re-established in life (Grainger 1998 pp. 134-136).

There is some existing research that focuses on creative activity around the funeral rite and religious rituals (Grainger 1998). At times, mention is made of rituals and activities that are ongoing beyond the time of the funeral or activities that can occur at any time beyond the death of a person, but these are usually discussed in relation to semi-structured, socially and culturally driven practices that are accepted as part of the bereavement or mourning process. It appears to be a common theme across different cultures and ethnic groups that these activities, rituals and practices occur
during the first year after the death and thereafter may be linked to significant dates or the anniversary of the person’s death (Irish, Lundquist & Jenkins-Nelson 1993).

With the participants, I explored the more unique and individually specific activities and associated moments of ritual, with regard to the place they take in the individual lives of a bereaved parent. The activities appeared to not be driven by dogma or social/cultural sanctions, such as funerals, but were more individualistic and connected more closely to the lived experience of the particular parent and the ‘narrative’ or ‘story’ of their lives. As can be seen from the stories of the participants, these activities occur across varied time frames and not simply the first year, although it appears quite common for some spontaneous creative activity to emerge within the first months and within the first year.

The creative activities appear to be a public expression of not only the grief, but also the symbolic place of the deceased child in relationship to that child’s family of origin. It seems to be acknowledgment that this child remains a significant family member, although they are not physically present in human form (Klass, Silverman & Nickman 1996). Indeed, recent research in the field of grief and bereavement suggests that after the death of someone close, it is important for people to have a balance of a symbolic relationship to the person who has died while maintaining solid relationships to those in the current lived environment (Mikulincer 2008). The creative activities relate to the fact that the child remains a significant family member, although they are not physically present in human form (Klass, Silverman & Nickman 1996). Several of the participants speak of keeping their child as part of their family and that the spontaneous creative things they have done assist in maintaining a sense of that child’s presence in the life of the family. In some cases, other family members engaged in contributing to what was being created, while other situations family members engage in an ongoing way with the product of the parent’s creativity – a sense of the siblings in the family connecting with each other, whether living or not and at the very least acknowledging the presence of the deceased child within the family.
It appears that spontaneous creative/symbolic activity after the death of a child connects to a basic human need for a continued symbolic relationship to the child or children who are not physically present in the lives of bereaved parents. The research shows that this continued symbolic relationship is often based on feelings of love and connection to the child who has died, a love that continues to be felt beyond their death (Attig 2002). At the same time, some of the spontaneous creative activities engaged in by these bereaved parents seemed connected to an ongoing striving to understand what had happened and attempts to try and make some sense of the experience of having their child die. From reading the participant stories, the striving to understand and make sense of events and experiences seems connected to feelings of confusion, guilt and fear of living in a world with no meaning or sense of safety – a sense of ‘how could this could happen to me and my child’ and could it happen again? I’ve also realised that the spontaneous creative activities have a similar importance and a similarity to the socially sanctioned activities relating to the time of the funeral, it’s just that they occur over time and don’t have a socially sanctioned framework or ritual structure. This highlights the idea of these creative activities being spontaneous. As the participant stories illustrate repeatedly, the things that the parents have done are generally not guided by any external structure or frame of reference, they came more from the bereaved parent’s internal frame of reference – a sense that something feels right or a sense that ‘this is what I need to do’.

**Intuitive reasoning and know-how as possible pathways to the creative urge**

Current professional support systems, research and theories regarding child bereaved parents commonly have a more cognitive, psychological focus that may limit awareness of emotional, spiritual, physical and environmental/social factors. The intense meanings the bereaved parent feels regarding their dead child are quite apart from rational proof or disproof (Klass 1999) and their experiences merge across all aspects of their life. There is a tendency amongst professionals to give precedence to cognitive aspects of grief and bereavement, where thoughts and cognitive faculties are used to control and manipulate emotions that are often implied to be
many theories and practices relating to grief, bereavement and loss, tend to be overly focused on language and rational thought processes with a lesser regard for intuition, spontaneous creative responses and spirituality (Neimeyer 1999; Klass 1999; Attig 2011).

Anthropologist Ian Tattersall (2002) sheds some light on our human ability to use ‘symbolic processes’ to abstract elements of our experience and represent them with discrete mental symbols. It is thought that this trait is one of the defining features of ‘modern humans’. This ability allows human beings to constantly re-create the world and individual aspects of it. This is made possible by being able to form and manipulate mental symbols that correspond to things we perceive both within ourselves and also things beyond ourselves. It is argued that our ability to do this forms the foundation of our ‘creativity’ as a species. Tattersall (2002) goes on to remind us that contemporary human beings retain the fundamental processes of intuition which pre-dates modern humans and which Neanderthal humans used as their basis for living their lives.

Intuition allows us to respond and react to stimuli from the environment around us in quite complex ways. In fact, Tattersall argues that there is sound evidence that Neanderthals were able to live quite complex and successful lives, by using intuitive processes alone to respond to the world in which they lived. Antonio Damasio (2000) in his book The feeling of what happens uses recent psychological, biological and neurological research to argue that our whole body is our consciousness. Our brain is not the sole site of our conscious awareness and it’s perhaps more accurate to say that “the brain is truly the body’s captive audience” (p. 150). Damasio (2000) explores in detail what he calls the ‘internal milieu’ and ‘visceral division’ that involves the constant reading, mapping and producing of the experiences we have at a chemical and cellular level of ourselves as an organism. The internal milieu and visceral aspects of ourselves not only contain information, but have the ability to call the body to act, while the brain watches, monitors and perhaps adds something else. Eugene Gendlin’s (1981) concept of focusing (which I used as one of my methods) is
the practice of making a conscious connection to this internal milieu and visceral
division of the body and checking for information, while bringing in the brains ability
to interpret that information symbolically so that the information can be reflected
upon and utilised. Perhaps what Gendlin (1981) and Damasio (2000) are describing
is a scientific explanation of intuition? It’s likely that Neanderthals lived their lives
more from this internal milieu and visceral division, or intuition, while the brain at
that time was a less sophisticated audience to the body’s performance.

What we find in modern humans is that we have added the ability for symbolic
manipulation to our inherent intuition to develop ‘intuitive reasoning’; the ability of
the brain to hold, work with and interpret more complex understandings of
experiences. It is this combination that makes science, art and technology possible.
However, we do need to remember that our ‘intuition’ can take us a long way by
itself. Research has shown that even without the forms of symbolic language used by
modern humans, Neanderthals were able to use and pass on complex stone tool
making techniques (Tattersall 2002), making and wearing of body ornaments and
practiced forms of mortuary rituals which included interment of their dead. The
symbolic nature of this behaviour is debated because the burials lack grave goods and
even if they did we, as modern humans, would struggle to interpret the meaning of
these practices from the perspective of Neanderthals (Wong 2006). I would argue
that the above mentioned ability of Neanderthals to make objects and practice
mortuary rituals, indicates a creative ability through the use of intuition, albeit
without the use of language to explain the meaning behind these practices.

Based on the above ideas, the spontaneous creative activities of the bereaved parents
in this research could be seen as an application of intuitive reasoning. Several of the
parents described the experience of doing things because it felt right to them and not
because it was a planned cognitive process. It would seem that their whole being was
responding to an internally held and visceral response to their child’s death and then
as this unfolded, they connected to more cognitive aspects of themselves and were
able to plan and direct the activities, so that meaning and understanding was
enhanced. One participant, Tracey, gives a very pertinent example of this, with her description of her whole sense of self reeling from the experience of her daughter’s death and that same whole sense of self searching for a way to respond to what had happened. Tracey describes the writing of poems early in her grief, where she felt the poems wrote themselves with her breathing. My understanding of this now is that this experience was an expression of an internal milieu, a visceral response to what had happened seeking a way to reinstate some balance within Tracey’s whole being.

From my engagement with Tracey’s story, this certainly rings true with how Tracey describes her experience. Another participant, Jasper, talks of how he created paintings that seemingly flowed from his whole being and depicted graphic images that related to his son’s death. However, he only recognised this after he finished the painting, turned it to a different angle and engaged the cognitive part of himself. Jasper, also tells of how he did things because he had a sense it felt right to him and that things didn’t need to make sense to anyone else. This all encourages me to think that perhaps our whole beings have a way of responding to the death of a child, if we allow space for responding to the felt need of the body. Greg Madison (2005) suggests that the bereaved person not only metaphorically, but also literally has lost a part of their world. The grieving body of a bereaved parent will continue to ‘imply’ the deceased child in order to fill in their co-created interaction, the relationship within which they both lived prior to the death.

Through immersion in the stories of the participants, it has become clear that these spontaneous creative activities are a whole person response to the death of a child and certainly not something that is driven by rationally thinking about what to do in response to the child’s death. Of course, cognitions are part of this picture, but perhaps we get overly focused on using our cognitive faculties to lead or drive our grief response, rather than recognise that within our bodies at a visceral, chemical and cellular level, a response is underway that is individually tailored to suit each person. To draw on Antonio Damasio’s (2000) work, I sense that we, as professionals and community members, have become too focused on the ‘audience’ (brain and
cognitions) and pay less attention to the actors (internal milieu and visceral system) on the stage (all parts of the whole being).

At a simpler level of course, the spontaneous activities of bereaved parents could be also be viewed as being an application of ‘know how’ in living with the absence of the child, while still feeling a strong connection within themselves. Know-how uses skills and concepts learnt through lived experience, rather than applying rules or knowledge at a theoretical or socially sanctioned level. In their book, *Mind over Machine*, Hubert and Stuart Dreyfus (1986) discuss the concept of human understanding and applied knowledge as being able to reach a point where a person has ‘know how’. Using the ideas and thinking of Heidegger, Merleau-Ponty and Wittgenstein, they suggest that human beings acquire this ‘know how’ through lived experiences, but that this knowledge cannot be broken down into rational step by step instructions, which are learnt through knowing facts or rules (as in prevalent forms of professional training). They particularly note Merleau-Ponty’s claim that human perception and understanding are based in our capacity for picking up flexible styles of behavior and not necessarily rules. They suggest that it is more to do with knowing how to find your way about in the world, rather than knowing lots of facts and rules that relate to them. I don’t see these ideas as being too far removed from the above discussion on intuitive reasoning, it’s just a different way of expressing something similar I feel. The fluid and individual nature of grief after the death of a child calls for this type of ‘know-how’. In the stories of participants I can hear how they all were able to draw on aspects of previous experiences to experiment with finding ways to live with their grief and find ways to maintain a connection to their child. They were able to use their know-how to create something different with the existing skills they had, while adding new skills in the process of creating things.

In drawing this chapter to a close, I find it interesting that all of the grief and bereavement theories, models and concepts mentioned bring some understanding to the phenomena of spontaneous creative activity after the death of a child and yet for me there seems to be something missing. From my research, I feel there is something
other than bereaved parents adapting to life after their child’s death and while this something feels to me like it is related to meaning re-construction, there is something other than that present. Certainly these activities seem related to a continued bond with the child but I found myself wondering what the nature of this bond might be. This sense of there being something more to the phenomena led me to engage in my own reflecting and theorising, which of course emerges from my understanding of the existing ideas explored in this chapter. In the following chapter I develop my own changed understanding of both the phenomena itself and grief and bereavement, by blending together what has emerged for me from the research with existing theories, models and concepts in the literature.
Chapter Seventeen - Emergent ideas

My own emergent theory building blended with existing theories
Through engaging in the research, I have found myself re-conceptualising ideas about grief, loss, bereavement and ways of being with people after the death of someone they love. This was probably inevitable given I work as a grief and bereavement counsellor and educator. In keeping with the idea that heuristic research brings ‘eureka’ or ‘lightbulb’ moments that can transform the researchers understanding of the topic, I want to talk here about transformations to my practitioner self that have emerged as part of this research. The following can be seen as an open exploration of my own developing know-how in relation to the topic.

The work of Thomas Attig (2011) came to my attention some years ago through earlier editions of his books. I found his theories and approach to the topic of grief and bereavement enlightening. I felt a resonance with Thomas Attig’s work and understand this to be due to several things. Firstly, philosophy is his main reference point for thinking about grief and bereavement and this is my main reference point also. Secondly, much of Thomas Attig’s work is focused on understanding the lived experience of those who are bereaved and how the individual stories of those who are bereaved can provide us with greater insights to the nature of grief and bereavement in general. Again here, the connection is that I have a strong focus on working with the stories of bereaved people.

While engaging in my research, I found myself returning to some of the ways of approaching and considering grief and bereavement that Attig (2011) puts forward. Attig suggests that while many of the theorists in the field of grief and bereavement have provided useful information about the nature of grief and loss, many theorists have ignored the individual stories and lived experiences of those who are living with grief. Because grief and bereavement is acknowledged as such an individual experience, Attig suggests that the stories and experiences of bereaved are the ‘heart of the matter’ in researching and understanding grief and bereavement more fully.
He suggests that generalized theories and models around grief are only useful when and if they speak to or resonate with individuals and their life stories when living with grief. The preferred approach he describes asks for research that reflects, provides insight to and helps us understand the stories and lived experiences of the bereaved. While my actual methodology may be somewhat different from that applied by Attig, there is a great deal of congruence between his emphasis on stories and the similar emphasis within this research. I would like to utilise some of Thomas Attig’s ideas as a starting point to think some more about what might be involved in the participants urges to do something in response to the death of their child or children. I will then extend these ideas to build my own theorising around understanding the phenomena and grief and bereavement in general.

Thomas Attig (2011) talks of both a grieving reaction and grieving response, with the reaction being about noticing how we are affected by a death or loss. Reactions are experiences like sadness, helplessness, longing, disbelief, disturbing thoughts and feelings that come upon us. We have minimal control over our grieving reactions. The grief response is about what we do following a death or loss, the way in which we acknowledge the death or loss, the actions we take because the death or loss has happened and the ways in which we maintain or modify our daily lives to accommodate what has happened. Our grieving responses are where we can enact choice in response to the loss or death. Taking the idea of the grief response a little further, Attig (2011) describes grieving as an active process of relearning different aspects of life following a death or loss –

- Re-learning the world and how to live in it with our experiences
- Re-learning ourselves as multi-dimensional, changing and interdependent beings
- Re-learning our relationship with the person who has died as it is currently experienced

The participant stories in my research focus a great deal on the grief response and relearning how to be in the world while managing a changed relationship to their
child or children who have died. When I began the research, I knew that I wanted to focus on the things parents had done in response to their child’s death and less on their grief reaction. Consequently, my research would pay less attention to what it was like for these parents to have a child die. There has been, and continues to be, good research on this aspect of the topic, as I discussed in part one. For me, I felt there was less research relating to what bereaved parents do after a child has died; the grieving response. In each of the stories you can hear echoes of their grief reaction, but it is not a focus of the story they tell.

It is of interest to me to understand the link between the grieving reaction and the grieving response, and from my research activities, I now tend to think that this link is emotional. Attig (2011 p. xxxii) suggests that the word emotion means ‘without motion’, based on the idea that the prefix ‘e’ means without and therefore e-motion means without motion. I don’t believe that this is a clearly articulated concept and it is here that I turn to other ideas to understand the movement from grieving reaction to grieving response. Several sources note that the origins of the word ‘emotion’ are found in French and Latin with meanings more often given as ‘moving through and out’, ‘energy in motion’, ‘move out’ and ‘to stir up’ (Harper 2014, Merriam Webster 2015).

Grief reactions bring forward an emotional state and whereas Attig (2011) suggests that the emotions stop us and hold us motionless (p. xxxii), I think that emotions are more accurately characterised as being responsible for moving us ‘out and through’ in order to ‘stir up’ a grieving response – an action of some kind. I am uncertain whether Attig was attempting to impart the idea that if we simply have emotions and do not respond to them, then we indeed find ourselves ‘without motion’. I have a sense that he was alluding to this as his discussion moves to suggesting that emotions cry out for understanding rather than simply expression, because expression alone does not move anywhere, apart from perhaps to another emotion. Based on my understanding and drawing on some of the work of Antonio Damasio (2000) and Karla McLaren (2010), I would suggest that in fact emotions require both expression
to allow them to be present and understanding of what any particular emotion is moving us towards.

The emotional states of love and fear present themselves strongly after the death of a child (Klass 1999) and are certainly present amongst the stories of the eight bereaved parents. Some people argue that indeed there are only two basic emotional states – love and fear, and that all other emotions are variations of these two. There are implications for this research regarding how these emotions might play a role in the spontaneous creative activities of bereaved parents. As I have reflected on this, it seems that feelings of love drive bereaved parents to find ways to connect to their child and express their love for them while feelings of fear (guilt, confusion etc.) drive the parents to feel more safe and comfortable in the world, requiring them to understand and make some sense of what has happened. I would frame these two aspects as a need to integrate both the love for the child and an understanding of what has happened, into their lives as it is lived now and that these two aspects happen concurrently. The closest current model I’m aware of that relates to this is Rubin’s Two Track Model (1999).

From my engagement with the stories of participants, it is clear that all of the parents were driven to respond to their child’s death by feelings of love, care and connection for that child. Some of the participant stories, however, illustrated that both feelings of fear (less safe and comfortable) and love were driving the parent to respond by seeking to understand and make sense of what had happened (seeking more certainty and safety), while expressing feelings of love, care and connection to the child. The feelings of fear seemed more prominent for situations where trauma had been present in relation to the child’s death.

**Creatively synthesised theory building**
By immersing myself in, and reflecting on, the above ideas, other literature relating to grief and loss and also by connecting myself to my experience with the participant stories, several significant concepts and ideas kept emerging for me as I have written my way through and described experiences related to my research. By drawing on
methodological concepts and other related theoretical concepts, I will frame some of my thoughts here, because I used many of the following ideas to reflect on my engagement with the stories of the participants in the research.

The following section is drawn from my own reflections and while I know I am connecting to a wide range of philosophical and theoretical ideas that I have absorbed over time, I did not refer to any specific texts while drafting and writing this section. This section simply came forward and presented itself. It is rather philosophical and abstract in nature and a contrast to other more poetic or storied pieces that have emerged for me in relation to the research. However, I imagine this is because the voice of myself I’m bringing forward here in this section is more academic or theoretical. Where I am aware of places of influence I will reference them.

**Love and fear**

As human beings, we are programmed towards life, living and survival and this is a primary drive for most beings. The drive to connect, love and be loved is directly related to our drive to survive and live, because loving and solid connections to people and places increases our safety and sense of security, thereby enhancing our survival. When someone we love dies, our sense of security and safety in the world is disrupted and we can question our survival, feeling disconnected and alone. Bereavement brings the linked confrontation of two fundamental existential givens; death and relatedness (Madison 2005). Love is associated with relatedness - connection, attachment and relationships (Bowlby & Parkes 1970, Parkes 2006) and fear is associated with death - survival and living in the face of death (Levine 1997). Based on this, it is possible to consider that the core emotions of grief are love and fear (Lewis 1961). By exploring the idea that the purpose of emotions is to move us through experiences; emotions are energy in motion (McLaren 2010), we can see the movement of the emotions of love and fear.

Love – moves towards – connection and attachment – moves towards – relationships

Fear – moves towards – survival and safety – moves towards – living/survival
By moving towards connection and attachment, love inevitably makes us aware of disconnection and detachment. By moving towards survival and safety, fear inevitably makes us aware of death and danger.

**Cycle of opposites: Yin and Yang**

Ancient Chinese philosophy proposes that all things exist through the interplay of complimentary but opposing energies - night and day, heavy and light, soft and hard, male and female, etc. We also know that for every action there is a reaction; one thing cannot exist without reference to another. There are infinite variations on the interplay of these opposite energies, bringing infinite manifestations of phenomena. Exploring the idea of grief and its relationship to love and fear and using my familiarity with the Chinese philosophical concept of Yin and Yang (concept of dynamics and balance in life), the following emerges –

Grief consists of - Yin – Fear. Yang - Love

Love – Yin – being in awareness of disconnection from a loved one. Yang – being in awareness of connection with a loved one.

Fear – Yin – being in awareness of death or possibility of death. Yang – being in awareness of life or the possibility of life. (Blofield 1979)

I have depicted this idea as follows –
Grief, love and fear are experienced across all five elements of life – physically, emotionally, cognitively, environmentally/socially and spiritually/philosophically, with the balancing between yin and yang varying across each element. I will note here that an influence on the above is an awareness of what I see as the appearance of the concepts Yin and Yang in Margaret Stroebe and Henk Schut’s (2008) Dual Process Model. Loss orientation is Yin and Restoration orientation is Yang.

Thomas Attig (2011) tells us that following a death or loss we have both a grieving reaction (affect) and a grieving response (action). Death or loss brings a grieving reaction (affect) and we are thrown into a confrontation with life/death, connection/disconnection, bringing emotions of love and fear. These emotions signal a movement towards connection and survival in the face of disconnection and death. At this point a choice presents itself (action). Some say we are condemned to choose, because to not choose is a choice (Sartre 2007).

One choice is: accept the change, which brings a grieving response (action). We focus on our awareness of life and connection, bringing the emotion of love which moves us to seeking connection. This requires creativity or experimentation in finding pathways to connect (Klass, Silverman & Nickman 1996). This embraces what has changed with a focus on life and connection in the midst of death and potential disconnection; it is here that meaning re-construction occurs (Neimeyer 2001, Neimeyer and Sands 2011).

Another choice is – reject the change, which returns us to a grieving reaction (affect). We are taken in to awareness of death/life and disconnection/connection, bringing the emotion of fear, which moves us to survival. This requires endurance where we wrestle with or reject what has changed and focus more on death and disconnection in the midst of life that has potential for connection.
What this might mean for those that are living with grief

- For life to be experienced as complete there needs to be both awareness and acceptance of and engagement with, the reality of existence or what might be termed the ‘givens of life’.
- Both life/death and connection/disconnection are givens in life – both are realities that we cannot change. We can only be aware of them and accept them while also engaging with them and understanding our choices in engaging with them (Yalom 2008).
- Problems arise when we only accept and engage with one half of each of these realities. If we wish to live fully we need to be aware of and accept death and if we wish to connect fully we need to be aware of and accept disconnection.
- A focus on only life and connection can exhaust us and a focus on only death and disconnection can bring stagnation to our lives (Lao Tzu).

Functionality of Grief

Grief is functional in nature; its powerful effect is calling us to slow down or stop whatever we were doing in our lives, so that we have time to fully recognise the significance of what has gone and then make adjustments and changes to our lives in response to the death or loss that has occurred. Grief takes us out of commission with life, while we mourn the death or loss (honour the significance) and give our energy to the necessary change processes that will allow us to continue living life (Jeffreys 2011). Lowered mood states such as sadness and feeling melancholy bring us into a heightened state of awareness relating to the details of life bringing an intense engagement with the realities of life (Wilson 2008). Far from being a completely negative aspect of life, grief and grieving can help us to change and open up to new possibilities, bringing the seeds of adaptation and creativity in the face of adversity. Through engaging with the research and writing this thesis, I can see that grief has the potential to continue acting upon our whole being to slow us down or stop us until we -

- Recognise what we previously had, its significance and how this influenced our lives.
• Identify which aspects of what we previously had can be retained and which aspects must be relinquished.
• Adjust and change our lives in response to the death or loss to suit our own individual needs and current life situation, retaining what we can and relinquishing what we must.

**Functional Grief Model**

![Functional Grief Model Diagram]

The arrows in the above model suggest that there is always potential for constant movement between any of these aspects of grieving. It was created to illustrate the open-ended and back and forth movement of the human experience of grieving, within the concept of grief being functional. What I noticed in the participant stories is that the spontaneous creative activities were functional within each person’s grief experience and that led me to conceptualise the idea that grief is functional if we approach it on its own terms, rather than problematising it. Of course there is always the potential for us to not understand the functionality of grief for each person, because it is so subjectively experienced, but I think it bears thinking about that we can approach grief with a view to seeking the function of an individual’s grieving reactions and responses.
Facilitators of grieving

A final aspect of my theorising about grief and loss in relation to my research comes more directly from the participants themselves; although all of the above emerged from my thinking about, living with and reflecting on their stories also. Amongst the stories of participants, there were indications of things that helped facilitate the functionality of their grief. So I want to condense a sense of these facilitators of grief into point form, reflecting my understanding of what the participants felt facilitated their grieving after their child died.

- Slowing things down to allow time to notice significant things connected to their child.
- Gathering landmarks or signposts – sights, sounds, sensations, experiences and memories.
- Connecting to people, places, things and experiences that resonate with and amplify the love for their child.
- Doing things that bring the deceased child into life as it is now.
- Taking notice of intuition, hunches, guesses and any felt need as you live with your grief,
- Find or create tangible things that evoke the presence of the deceased child.
- Continue to give time and energy to the child who has died.
- Find a place and expression for the love and care felt towards the deceased child.

While perhaps considered somewhat esoteric, all of the above provide me with a new frame of reference for exploring, contemplating and engaging with death, grief and loss. It has changed for me the way in which I think about, and practice counselling in the area of grief, bereavement and trauma and will continue to do so. The ideas certainly provided me with a way of attempting to bring together my thoughts, feelings, hunches and beliefs about bereaved parents’ experiences of spontaneous creative activity following the death of a child. Specifically, the above ideas allow me to have a way to summarise the research undertaken with the eight bereaved parents who participated and shared their experiences and stories. In many ways, the
above ideas and theory building were generated through my immersion in the experiences of these eight people. From a validity perspective, this brings a particular verisimilitude to my final interpretation of the emergent understandings and meaning found through the research project and through the writing of the thesis.

**Emergent understandings and meanings in relation to the topic**

I want to conclude with an exploration of the significant things that emerged for me at the level of understanding and meaning in relation to bereaved parents’ experiences of spontaneous creative activity after the death of a child. My research did not have a hypothesis that I was trying to prove or disprove. There was only an assumption that through exploring bereaved parents’ experiences of spontaneous creative activity, that there would be things to learn and a development of understanding relating to the topic. The participant stories were explored and worked with in such a way that the stories themselves brought an emergent understanding of the phenomena, as both myself and the participants sought to explicate the experiences of the phenomena and any associated meanings. In this way, part two of the thesis is a combination of the phenomena, an exploration of it and an explication of meanings and significance. There is of course then my own reflecting on the participant stories as a whole and the research as a whole.

The theory building that I have written about in the previous chapter developed from noticing and becoming more aware of certain things as I reflected on the participant stories. Firstly, by using Thomas Attig’s (2011) concept of the difference between a grieving response and grieving reaction, I could see that what I’m describing as the spontaneous aspect of the creative activity could be in fact the movement from a grieving reaction to a grieving response. I still feel that the process is intuitive and feels spontaneous, but can see the likelihood that the movement from a reaction to a response occurs within the body and eventually registers with the mind. As Damasio (2000) and Gendlin (2000) suggest, this occurs outside conscious awareness and so feels intuitive and spontaneous. An implication of more clearly realising this means that by considering a whole body/person understanding of grieving we may be able to
bring forward more personally situated information that can assist grieving individuals.

Another realisation that occurred for me in working with the participants was that through engaging with a spontaneous creative urge, they each entered a process of more clearly identifying what was significant and important for them in regard to their child and their child’s death. In each case participant’s describe (in different ways of course) a sort of sifting and refining process of reconnecting to the child’s life and noticed the things that were special, significant and important. Where there were higher levels of trauma, the creative process seemed to provide a way for the person to also sift and sort through events that had happened around the child’s death, mingled with a movement towards a connection to the child themselves.

What followed in my reflecting on the client stories was that as the parents engaged in this sifting and sorting through their own experiences of and with the child, they were able to see both what they could build on and remain connected to and also recognised those things that had changed forever. For example, in Carol’s story, over time she can connect to her son as the only son in the family and make a sampler that represents the fact that her son remains in the family in some form. However, there is also a recognition of his physical absence and that the milestones in his life will not be directly viewed by Carol and her family. Nevertheless, they can recognise and celebrate his milestones in his absence. In this way, the creative process allows these bereaved parents to consider what can be retained as well as understanding what must be relinquished. Then in addition to this, those things that are relinquished are able to be honoured and memorialized in a tangible way allowing an ongoing connection.

As was made clear by all the participant stories, engaging in these spontaneous creative acts assisted them in adjusting to the devastating death of their child or children. Through engaging in the activities and following their intuition, the parents felt better able to acknowledge what had changed and to make changes to their own lives. In some cases, they did things they had never done before, like getting a tattoo
or starting a philanthropic trust fund. So in noticing all these different processes, I
came up with functional grief model as a way of depicting what I saw occurring for
these bereaved parents. Of course, when I worked on explaining and depicting the
model, it called me to reflect further on the participant stories. Again, I can’t help but
see the process of creativity at work within my own theory building and I find myself
somewhat pleased that there has been a type of parallel process between the topic of
the research and the way in which the research process has unfolded for me.

**What the five elements revealed**

During the immersion process involving the participant stories, I developed a five
element listening device in order to consider five different facets of life that were
embedded within the stories. I did not intend for this listening device to be anything
more than that and certainly it was never intended to be a device of categorization or
analysis. These five elements gave me focus points to listen for in the stories of the
participants and I was listening for the expression of these five elements of life
amongst the story; thoughts, sensations, emotions, spirituality/philosophy and
environmental/social. I was aware that I used my subjective judgement as to which
parts of the story I thought or felt were aligned to particular elements and that this
could be seen by others as problematic. However, the emphasis was on wanting to
have a way to immerse myself in the stories while considering different aspects of
human existence. The intention was to have a device to shift and change how I might
tune into the stories and pay attention to what was being expressed. This elemental
approach called me to question my thoughts and feelings as I worked through the
transcripts. For example, I might feel that an aspect of a transcript was emotionally
focused, but in considering the other possible elements I might find that the language
used was more about thoughts or cognitively trying to understand something. In
many ways, this process assisted me to more deeply consider the stories and also
helped me to find ways to identify the different elements of life through the types of
language used and what was being talked about. Deciding to differentiate between
sensations (physical) and feelings (emotional) is one example of how I learnt to think
differently about the use of language and how the word feelings can often be used
with regard to physical sensations, mood and emotional states. They are in fact different things albeit with a relationship to each other.

While I was not focused on finding themes through the use of the five elements, I can’t deny that part of me expected themes to emerge in these elements across all the parents. However, this wasn’t the case. In the stories of some parents, I could hear the emotional elements coming through very strongly and so would find more material that seemed to fit within the emotional element. For others, the cognitive element would emerge as a strong element, or the physical element would emerge in other cases. Several stories would have two or three elements that seemed to be represented more than the other elements.

With each transcript, all the elements could be heard. However, for each parent, certain elements would seem to be stronger than others. This is of course not at all unexpected, given we know how every each person experiences grief differently, based on their own personality and a range of other mediating factors. It does, however, reveal to me that it is so important to understand these five elements and pay some attention to all of them. There would be difficulty if we were to always focus on cognitive ways of working with people, given that some of them may live their lives more from a physical or emotional basis and others may live life more within the spiritual or social elements. Of course, all elements are present for each of us, but as individuals we can have different ways of being that are reflected in the elements we feel drawn towards. This was a significant learning for me.

**Inspirational Music**

Before continuing on to the final chapter I invite the reader to listen to the following piece of music. Simply click on the link below or paste the link into a web browser.

https://www.youtube.com/watch?v=xDqO_yUOpAM
Chapter Eighteen – Concluding with love

Love is the bridge

In addition to the content of the previous chapter there was another significant aspect of the participant stories that emerged. It could be debated as to whether it fits within any of the five elements, though some may say it related to emotions. From my perspective, what emerged is present in all of the elements, just expressed in different ways within each element. Love is this something else and I found that it emerged very strongly in all of the participant stories. I feel this is the most significant learning from the research. Love is experienced in all parts of ourselves, much like grief also is experienced in all parts of ourselves. It seems that love is the likely catalyst for the urges, hunches and drive that sparked spontaneous creative acts within the eight bereaved parents and these acts of creativity were all in some relationship to the child who had died. There was something both obvious and surprising in realising this. It was obvious in that of course these parents had such a strong love for their child or children and of course this would drive a parent to act or feel like they need to act in some way after the child dies. It is surprising, because it’s common for people to think that feelings of grief can drive us into action.

It seems we are more inclined to see love as something shared between living beings or towards tangible things. It’s as if after death, love is only seen in the context of grief, which assumes that feelings of love are something other than they were when the person was alive. The stories and experiences shared by the participants in the research have opened to me a clearer sense that love is love, both in life and death. The love itself does not change greatly, but by necessity how this love is then expressed must change following a death. When I return to my daughter’s death to consider this idea from a personal perspective, I can recall how my love for her in life, turned into grief. The grief was like this inwardly turned, powerful love that could no longer be directed towards my baby daughter.
‘Our hearts ache when we experience the death of someone we love and our love for them feels as if it is suspended in mid-air with no place to land’ (Attig 2002 p10).

The power of the love felt so large that it threatened to tear me apart. The love rippled inside me, confused, trapped and wanting to burst forward. I struggled to hold it, experience it and understand it. It was painful and it was called grief at that time. Now I can more easily see that it was love I was experiencing and it was just being expressed in a different way. So a significant emergent understanding for me is that grief can be the experience of having powerful feelings of love for that child, but not having anywhere to express or place those feelings.

If I also return to the moment where I wrote a poem for my daughter, I can still sense the feeling of love. It burst forth and spilled onto the page and for a moment my grief could be felt as love. I felt better briefly, as my grieving reaction became a grieving response. In that moment I stepped into an awareness of life, while confronted with death and I sought to make a connection, while confronted with the awful sense of disconnection from her. My emotions of love and fear moved me towards the possibility of living and being in relationship to her through the creative medium of poetry and words. It is perhaps best described as a form of alchemy; a melding of grief, love, despair and hope that brings something new into existence.

Time and again, as I return to the stories of the parents who participated in the research, I hear and sense the process of this type of alchemy, where grief melds into love and love melds into grief as part of an ongoing fluid and dynamic process. Grief is love’s struggle to find new pathways for expression, stretching outward towards the child who has died, seeking connection and relationship; love being expressed in the face of death.

Gary Schwartz (2002) offers the “living soul hypothesis” which posits the idea that the energies associated with living beings, continue to exist beyond death. Basically,
it is the concept that there is some form of ‘life after death’. Gary Schwartz (2002) suggests that there is evidence that those who have died remain connected to those they love after death and that the key energy/emotion that connects humans is love, with love extending beyond the physical relationship. There is some suggestion that the greater the love connection felt, then the greater the likelihood of a more tangible connection with the loved person beyond death. The love connection experienced between a parent and child is often argued to be the most significant love connection experienced in life. This could go some way to explaining the significance of creative meaning re-construction after the death of a child and the feeling that this process is somewhat ‘guided’. It seems that this idea has congruence with existing theories of grief and bereavement such as the continued symbolic bonds to the deceased (Klass, Silverman & Nickman 1996). I think it’s clearly expressed in the stories of the research participants, that this creative process changes how they are experiencing their grief and helps them to begin building a meaningful relationship with the child. Attig (2002) suggests that loving give and take can and does continue after another dies. He suggests that the deceased can be given places in our hearts, the vital centres of our lives, alongside everyone and everything else that we hold there.

**The pull of love**

Colin Murray-Parkes (2006), a highly regarded practitioner and academic in the field of grief and bereavement, suggests that for many people, love is the most profound source of pleasure in life and that the loss or death of those we love is the most profound source of pain. Murray-Parkes then concludes that love and loss are two sides of the same coin and while he doesn’t make this clear, I presume that the coin he speaks of is life? Based on these ideas, I suggest that one basic aspect of life is loving and grieving, or in simple terms, a constant dance of being with and being without. That is, spending time with ones we love and then being away from them and then returning to them because we love them. When someone close to us dies, it can seem that the dance has stopped. This is because we notice mostly the ‘being without’ and many bereaved people say that it feels like life has stopped (Attig 2011).
It is here that we notice a sense of disconnection or being out of relationship with our loved one.

However, Colin Murray-Parkes (2006) refers to love as being a bond or tie between people; that is, like an elastic band. The greater the distance we are from those we love, the more strongly we feel the pull of the elastic band calling us to return closer to our loved one. Therefore, after the death of a child (which could be thought of as the greatest distance of all), we feel a strong force pulling us back towards the loved child who has died. I would see the difficulty here is that the child is no longer physically present and so there seems to be no place for the love to be expressed and therefore the feeling of distance and the tension of love remains. This is grief as I see it; the tension of love pulling us towards someone or something that is no longer physically there in our world. We feel ourselves being pulled or drawn towards the child, but remain unsure how to recognize where we are being drawn to and are also uncertain about what to do with our feelings of love. This is because the sense of the child is not tangible in the same ways that they were when the child was alive.

Attig (2002) urges the exploration of ways in which connections to the deceased can be sustained, embracing their legacies so that they play active roles in our everyday and inner lives. He goes on to say that we can give places in our hearts to those that have died and as we do we experience lasting love. We continue to love them and sense that they still love us. Murray-Parkes notes that love is also tied to keeping ourselves and our loved ones safe and secure, otherwise we can feel endangered and unsafe in the world, therefore a permanent or pro-longed absence from the loved person brings feelings of anxiety and fear, which as I’ve mentioned, are also features of grief. Irvin Yalom (2008) would suggest that this fear is related to awareness of death. Yalom’s view is that loss and bereavement can cause a rip in the fabric of our assumed world, exposing unwelcome existential realities (Madison 2005).

As I theorised earlier, the sphere of fear is about both life and death. In particular, fear is connected to moving us towards survival and life and it is a grieving reaction
that needs a grieving response. In the case of the parents engaged in this research, their fears that they were or could lose their connection to their child or children led to a response of creating things through which they could maintain a connection to their child. The connection to the child occurred through both the process of creating and whatever was eventually created. Many of the parents described the creative activity as being able to do something for their child and that it gave them a sense of giving time to their child, much as they might have done were their child alive.

Murray-Parkes mentions Bowlby’s (1958) concept which suggests that a key feature of love is its ‘monotropy’ or specialized characteristics associated with each person or object that the love is felt towards. This means that the love felt toward a child that has died cannot simply be re-directed to another child or someone else, because this would then be a different love and would change the ‘elastic band’ effect being experienced in relation to the child who has died.

In keeping with this idea, it is useful to note the story of ‘Steffie’s Gift’. Philip and his family created a whole sense of his daughter Steffie around a trust fund that was basically initially funded by her money and placed this money as a resource, back into a particular sector of support work, where Steffie herself had worked and wanted to work in the future. As a family, they created an activity that in several ways meant that Steffie was involved in an area of her life that had been important to her while she was alive. The expression of love in this activity was particular to Stephanie and it wouldn’t have been possible for Philip to simply place his love for her with another of his children. The initial spontaneous creative urge to begin the activity was driven by a particular experience of Steffie visiting Philip through a dream and connecting to him in the dream in a way that held special characteristics of her as a person.

This is also a good example of emotions moving a bereaved parent from a grief reaction into a grief response where a choice is made to be in an awareness of life, connection and relationship, while also living with the awareness of death and disconnection. If Philip had ignored the urge to respond to Steffie’s voice in the
dream, due to waking and realising she is not alive and therefore the dream was not real, then he may have remained within his grieving reaction, noticing mostly his sense of disconnection from her because of her death.

“The purpose of the process of grieving is to incorporate the fact of bereavement and the significance of the person who has died, into the ongoing living awareness of the bereaved person” (Grainger 1998 p130).

The urges or drives of the eight bereaved parents and the desire to connect or reach out to their child is a result of the ‘elastic band’ effect of continued loving of that child with intensity after their death. It seems that the spontaneous creative activity emerges from these intense feelings of love for the child and the products of this creative activity then offer tangible and concrete ways to give some expression to the feelings of love for that particular child, in the absence of the child themselves. In reflecting on the work of Colin Murray-Parkes, all the stories of the spontaneous creative activities and the products of them, include things that symbolise many of the key characteristics of the child who has died. A child who wanted to be a youth worker, the little boy who loved dolphins, a man who loved his mother’s creativity and wanted her to make something good from her experience of his death, the little boy who was the only son in the family, just to name a few. Therefore, these activities are individualised and personalised around the child who has died, making the child easier to identify and locate and offer love to in the mysterious world between the living and the dead.

It would seem, from the description of the parents in this research, that this then allows the tension of the ‘elastic band’ effect to ease slightly, because the parent experiences a sense of closeness to the child and their characteristics that are loved. When Kate talks about sitting and working on a quilt that is both for and about her daughter who died, she comments about feeling close to her daughter. Here the elastic band feels less stretched. Likewise, Jasper who goes for a walk by the trees where his son and daughter’s ashes are and sits near them or runs his hands through
the leaves as he passes by. Here the distance between Jasper and his children doesn’t seem as vast as it might otherwise and the tension of the elastic band reduces somewhat and some sense of the comfort, safety and security that comes within a loving relationship is experienced. In this experience, the bereaved parents move from an awareness of disconnection and death to awareness of connectedness and life.

Participants in the research express feelings of comfort and solace, when engaged in activities that allow them to express their love for the child bringing a sense of connection between parent and child (Klass 2012). Key features of the activities are that they become personally held, reliable, symbolic ways of expressing feelings of love and connection to the deceased child. The spontaneous creative activities appear to have been born from intense feelings of love for the child that led to intuitive experimentation (Heaton 2002) around ‘doing’ something in relationship with the child while expressing their love for the child in a tangible and living way.

Reflecting on my initial curiosity
As I began my research eight years ago, I was curious about the personally held significance of spontaneous creative activity in relationship to a child who has died and wondered in what ways were these creative activities experienced as significant, over time, in allowing bereaved family members to grieve and maintain a symbolic connection with their deceased child. This curiosity emerged as the primary question over the first years of engaging in the research and other questions emerged around this. I wondered how these activities might influence the grieving process of bereaved parents in making sense of or finding meaning in, the experience of having a child die? As a practitioner in this field I wanted to consider what might be the implications of this thesis for researchers, professionals or others who have contact with or support/assist parents after the death of a child? I was also eager to explore how subjective-intersubjective knowledge of these activities and experiences could inform future research and practice in the field of grief, bereavement and trauma. As
the research progressed I tended to hold these questions less tightly and worked more with a felt sense (Gendlin 1981) of what the research was about.

Towards the end of the research I realised I was not so concerned with specifically answering what might be seen as the research questions. The curiosity and questions that I began with came from a desire to explore, experience and enhance my understanding of this topic and while I feel that these closing chapters of the thesis have indeed addressed my curiosity and questions, I don’t believe that I could ever definitively answer a question that is about the personally held significance of spontaneous creativity for bereaved parents. I can only conclude with my personally held understanding, based on my experience of the research, the participants and their stories, in other words, my subjective and intersubjective understanding in relation to the topic.

Through this research, I’ve come to what feels like a significant realisation: Death may take the life from a child, but it does not take a child from the life of the parent. For me, this is a major part of the personally held significance of spontaneous creative activity in relationship to a child who has died. As shown through the stories of the bereaved parents presented in this research, these activities emerge as the parents search to find ways to continue loving their child after they have died. The significance of these activities and the products of them, seems to remain constant over time in as much as they allow the parent to continue to express their love for the child, through symbolic connectedness that acts as a conduit for expressing love in physical the absence of the child.

This research indicates a need for further research and exploration across the areas of grief as an expression of love and care that initially, after death or loss, seems to have no physical place for expression. Related to this is the idea that grief is a functional, because the feelings of grief call people to pause and re-configure the ways in which they express the connection they have to the person who has died or what has now gone. From engaging in the research I see great potential in the use of focusing (Gendlin 1981) in developing a whole person response to grief as it offers a pathway
to active, conscious engagement with intuition and spontaneous creativity following a death or a loss. In a broader sense, the research indicates that many responses to death and loss are in perhaps expressions of love and fear, with love seeking a reliable pathway towards what is absent and fear seeking a reliable pathway towards safety. The learning from this research suggests that those who counsel, support or engage with bereaved parents turn their attention to expressions of love in the face of grief and loss in order to move beyond ideas of simply alleviating distress and discomfort.

**The Mystical Quilt of Love**

I will conclude my thesis by returning to the metaphor developed in part one, that being the metaphor of a patchwork quilt, put together by a bricoleur who uses whatever falls to hand in order to create a montage or representation of whatever he is focused on. It seems to me that all of the bereaved parents who participated with me in the research are also bricoleurs, each using whatever would fall to their hand in order to create something that represents both their child who has died and their love for them.

I also wrote in part one about my thoughts that life is made up of pieces and that we are continually made aware of all the different pieces that make up our lives. As we live, we find ways to bring these pieces of our lives together in forms that make some sense to us. Each time we create something a little different from infinite combinations of the pieces that are ourselves and our lives.

In part two I offered a fable about a quilt-maker who sought to find and create a patchwork quilt from a precious material (stories) that held pieces of experiences from parents who had lived through the death of their child. It seems to me that all of the participants are quilt-makers, searching through the precious material of their child’s life to find the pieces of experiences that they stitch together in order to create patchwork quilts that both radiate the essence of that child and create a space for that child.
As a potter in my early years, I have always remembered an ancient quote from Lao Tzi: ‘The shape, colour and texture of any pottery vessel may give it apparent beauty, but it is the space within the vessel that makes it useful’. I will adapt that to the idea of a quilt: ‘The shape, colours, placement of patches and stitching on a quilt may make it look beautiful, but it is the warmth and comfort it provides when you wrap it around you, or over you, that makes it useful.’ I conclude my research with a creative writing piece, which written I am sure with assistance from my twenty year old daughter who dwells in the vast empty somethingness and visits me often.

**Maddum and the Mystical Quilt of Love : A fable**

Maddum stares in sorrow at what seems to be a vast emptiness. Maddum’s thoughts seem fast yet empty. Her heart feels full yet empty. Her body is churning yet empty. Everything around is noisy yet empty and the flame of the spirit is low. Only yesterday, Maddum’s child was there, filling all this space and emptiness, calling out, moving past and giving hugs. Then, life had meaning. Now, meaning has no life.

All of Maddum senses that memory of the child, but it floats away. Instinctively Maddum reaches out and grasps the piece of memory, before it is gone. Then holding it gently but firmly, Maddum places this precious piece, the memory of the child, in a pocket. Maddum’s heart stirs and then eases briefly. Days pass in the vast fulsome emptiness. A brightly coloured bird lands on the window sill and Maddum recalls how the child loved to place some food on the sill, then watch the bird and hear it sing in the trees nearby. Maddum’s hand instinctively reaches into the pocket and notices several precious pieces now resting there, waiting.

One day, when the vast fulsome emptiness seemed too much to bear, Maddum reaches into the pocket and casts the contents onto the table. Multiple precious pieces of the child’s life shine, sparkle and float before the bereft Maddum’s eyes. Quickly, Maddum realises that they may float away or fall from the table and be lost in the dirt on the floor. So gathering and scooping them together the precious pieces are returned to the pocket. Maddum’s body relaxes a little; the heart urges and the mind responds with a thought: “Stitch the pieces on to fabric, so they can’t be lost or
float away and then you can take the pieces out to view and hold whenever you like”. Where was that voice coming from? Maddum doesn’t quite recognise its tone. It is an insistent, gentle and kind voice; a voice that calls and entices.

With some searching, Maddum finds a piece of fabric. It’s a piece of cloth that Maddum and the child had sat on when they went to the beach. Maddum notices the pocket is now almost spilling over with precious pieces of memory of the child. Just then, while sitting at the table and spreading out the cloth, a precious piece falls out of the pocket onto the cloth. Maddum holds the piece in place, takes a needle and thread and quietly stitches the precious piece to the cloth. The cloth and the precious piece feel soothing in Maddum’s hands. The bird sings outside the window; the heart leaps for a moment and the body finishes the stitching. That day, some pieces were stitched into place; some were pinned in position and the pocket had room for more precious pieces.

Over time, this ebb and flow of daily life went on for Maddum. The cloth is taken out, pieces are unpinned, then moved and stitched, and the larger pieces sometimes have smaller pieces stitched on top, which adds texture. With every stitch and movement, Maddum’s heart reaches out. The body sits more comfortably, the mind watches dutifully and the vast fulsome emptiness begins to change into vast patches of emptiness, mixed with somethingness. The bird sings outside the window and Maddum places food on the sill for it occasionally. Maddum decides to stitch the outline of the little bird into the cloth.

Around this time, Autumn arrives and as the days passed with Maddum stitching the precious pieces to the cloth, the weather grows slowly colder. One day Maddum takes the cloth and drapes most of it over shoulders, back and arms to keep out the cold while working on the stitching. The cloth on the body, is like a warm hug and Maddum’s body sinks into comfort, a vast somethingness mingled with the vast emptiness and the mind asks a question. “Is it you?” Clearly and strongly the heart replies. “Yes!”

An end and a beginning............
Appendices

Appendix a - Poem

Madeleine

Madeleine, such a lovely name
Our love for you will never leave us
We search every day
The space that you left in our lives
Cannot be fathomed, but is special
You completed our family

We long to take you in our arms
Wherever we go, we wish you were with us
Life continues outside unknowingly
There is a place in our lives that is special
An empty space that is filled with you
You are always with us and we are with you

As the days and weeks stretch before us
We imagine our life with you here
Wondering why each day
You only needed three weeks of life
To give us a lifetime of love and lessons
Madeleine, such a lovely daughter
Appendix b – Plain language statement

DEAKIN UNIVERSITY
PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: Participant

Plain Language Statement

Date: 31st July 2009.

Full Project Title: Into The Mystic – Emotions, Intuition and Creativity after the Death of a Child or Sibling

Principal Researcher: Professor Bob Pease

Student Researcher: Greg Roberts

Associate Researcher(s):

This Plain Language Statement and Consent Form is 8 pages long. Please make sure you have all the pages.

1. Your Consent

You are invited to take part in this research project. This Plain Language Statement contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project so that you can make a fully informed decision whether you are going to participate.

Please read this Plain Language Statement carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or someone else. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Plain Language Statement and Consent Form to keep as a record.

2. Purpose and Background

The purpose of this project is to investigate the significance of the things people do or make, following the death of a child. I would like to work with you, as a bereaved parent or sibling, in this research to investigate the significance and meaning of these activities that may allow bereaved family members to maintain a connection or bond, be it emotional or spiritual, with the deceased child. I’m interested in exploring how these activities might assist bereaved
family members in living with the death of a child and may assist with the grieving process. Overall this research project will explore these activities as a process, where something different or new is brought into existence after a bereaved family member follows their instinct or gut feeling. I specifically want to include the experiences of both bereaved parents and siblings in order to address the significance of these issues for parents, young people and children (as siblings). I wish to consider the place of these activities within family relationships after the death of a child. Finally I want to consider whether these activities might be useful in decreasing the feelings of social isolation that are experienced by many bereaved family members after the death of a child. Deakin University has certain expectations and guidelines about what is considered an acceptable research process. This will have an influence, on both myself and the research, by virtue of the fact that this is a formal piece of research that needs to meet formal requirements for the award of PhD at Deakin University.

A maximum of ten (10) people will participate in this project.

Previous experience has shown that many people experience the death of a child as a crisis, a time of social disengagement, physical illness and emotional turmoil, born from a grief that is more intense and prolonged than other losses (Raphael 2006, Stebbins & Batrouney 2007). In my professional experience as a bereavement counsellor/educator I have found that, when grieving a child or children who have died, many bereaved family members do a range of things as a way of expressing their grief, for example, artwork, music, construction/invention, gardening, writing books/poetry and so on. Much of the existing research in this field, to date, focuses only on the funeral rite.

You are invited to participate in this research project because I want to investigate the significance of the things people do or make, following the death of a child that allows bereaved family members to maintain a connection or bond, be it emotional or spiritual, with their deceased child. I’m interested in exploring how these activities might assist bereaved family members in living with the death of a child and may assist with the grieving process and perhaps decrease feelings of social isolation. Overall this research project will explore these activities as a creative process where a bereaved family member follows their instinct or gut feeling. I think that the word creative applies just as much to people who build something or restore a car as much as someone who writes poetry, paints or makes a garden. I’m keen to make this piece of research something that is useful not only to professionals, but also the people who participate in the project and other people who have had a child die. I believe that the voices and stories of bereaved family members are not heard often enough in research and that every individual has a story to tell that perhaps can make a difference to others. As a bereaved parent myself, it is important for me that I work closely with other bereaved parents in order to conduct research that is not only about bereaved family members, but is written by bereaved people. To this end I advertised the research in places that would find child bereaved family members, such as newsletters and amongst support networks for people who have had a child die. You will have voluntarily responded to one of these advertisements.

The results of this research may be used to help researcher Greg Roberts to obtain a PhD through Deakin University.

3. Funding

This research is totally funded by Greg Roberts and Deakin University.
4. Procedures

Participation in this project will involve several steps over a period of time. Firstly, you will be invited to an informal one-hour information session to hear about the research and summary of the information gathered up until that time. I will discuss the research in more detail, answer questions and invite you to formally agree to participate in the research. You will be given a week from the information session to formally agree to participate. The initial session will be held at a place that is easy to travel to for those who wish to attend. Each potential participant will be asked to consider and ask questions about this plain language statement before formally agreeing to participate in the research.

You will be required to have access to personal support that relates to your individual situation, which may or may not include independent counselling and professional support. For those that do not have access to this support, but would like to participate, assistance will be given in locating appropriate and acceptable support services that you can easily access.

When you agree to participate in the research, you will be asked to provide something that expresses, or gives an example of, the thing or things that you have done or made since the death of the child or children in your family. This can be written, photographic, drawn or painted, but needs to be able to be included in a paper-based thesis. You can provide this anytime during the first month after agreeing to participate and will be encouraged to simply provide what you are comfortable with and whatever seems meaningful to you.

When I collect this from you, I will audio-record an interview, of up to one hour’s duration, which will begin with the question—“What part does this creative process play in your life and what does it mean to you?” The interview will take place at a location mutually agreed upon by yourself and myself bearing in mind personal comfort and safety. You will be able to end the interview at any point if you wish.

I will then write-up the complete interview and note my own thoughts. You will also be given the complete written interview and asked to read it and note your thoughts and feelings about what you had to say along with any thoughts or meanings that emerge for you. You will then be asked to advise me on how you would like me to include the interview notes, my notes and your notes in the research.

You will be asked if you would like to participate in a two hour group meeting with other participants to discuss the research thus far and how it might best progress, bearing in mind the needs of the researcher and the participants. The reason for this is that I would like you to have as much control as possible over how I present information that relates to you and your family. You will be offered the option of having this discussion on an individual basis, with a view to me distributing any agreed comments amongst the other participants for reflection and input if you wish.

Eighteen months to two years after this initial contact, I will contact you again to repeat the above process. However you will be given to option to contact me at anytime over this
period to add to or reflect on matters relating to the topic. You will have the option to withdraw from the research at any time, without question, while understanding my wish to have you offer any final comments for inclusion in the thesis before you withdraw. You can ask for any material from the research process that relates to yourself to be removed, returned or destroyed. All participants will be given a copy of the entire completed research.

I will also be seeking input from my supervisors at Deakin University who will advise me on the academic and professional aspects of this research. So the information I collect will be shared with them from time to time to help me monitor my progress.

5. Possible Benefits
Participating in the research may possibly provide further insight into your own grief experience. Your individual story and examples of what you have done will perhaps assist and encourage other bereaved individuals who are living with grief after the death of a child. The final thesis will be given to you as a document that records and expresses the things you have done that relate to your child/children. Some people find it beneficial to have the opportunity to share their stories/experiences with others through participating in the research.

I cannot guarantee or promise that you will receive any benefits from this project.

6. Possible Risks
Possible risks, side effects and discomforts may include mixed emotions that may at times be intense or unsettling when talking about things that relate to the child who has died. However, the focus of this research is on the things you have done, made, etc, since the death of the child rather than a specific focus on the death itself. Also, I have many years of experience (as a social worker, counsellor and professional educator) in this specific field and before we discuss topics that may be uncomfortable we will agree on strategies to manage this. It is a requirement of participating that you have access to support and I will assist you in identifying and accessing this support. You will be able to interrupt or end any of the conversations or interviews involved in this research. It will be understood that you can do so without having to give a reason. You will be encouraged to indicate to me if you begin to feel distressed and we will stop the interview/session. Also if I sense that you are becoming distressed I will stop the interview/session and check on your wellbeing, in order to decide whether to continue. You will have the final say on whether the interview/session continues for you as an individual.

There may be additional unforeseen or unknown risks.

7. Privacy, Confidentiality and Disclosure of Information
All information relating to this research will either be stored on a password protected computer or on paper and electronic storage devices, which when not under the direct control of the researcher, will be stored in a secure filing cabinet in locked premises. Any information obtained in connection with this project and that can identify you will remain confidential. It will only be disclosed with your permission, subject to legal requirements. If you give us your permission by signing the Consent Form, I plan to publish the results in a written thesis with Deakin University. During the course of the research I may also publish or discuss examples from the research through professional articles and seminars/workshops that relate to the topic.
In any publication, information will be provided in such a way that you cannot be identified if that is what you wish. Likewise you can choose to be identified if that is important to you. You will be given the opportunity to choose how you wish yourself, or any information you give, to be represented to others. Because this research involves me contacting you over a eighteen month to two year period, your contact details will need to be kept up to date over that time and will be stored securely.

Upon completion of this research project materials relating to this research will be stored in a locked filing cabinet at Deakin University for a period of six years, after which time it will be destroyed in line with University policy.

8. **New Information Arising During the Project**
During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information so you can consider whether it affects your continued involvement in the research.

9. **Results of Project**
I will regularly inform you of the progress of the research and any outcomes. As a participant you will be informed of any results and given a copy of the completed thesis to peruse prior to it being submitted for examination. After the examination and publication of the thesis you will be given a bound copy of the completed research for your records.

10. **Participation is Voluntary**
Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Any information obtained from you to date will not be used and will be returned to you or destroyed. There may be some non-identifiable information that relates generally to the topic or group process that cannot be removed. You will be advised of this should you withdraw and offer to negotiate on its inclusion or removal. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship to support services you have accessed or their staff.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify me personally or complete and return the Revocation of Consent Form attached.

11. **Ethical Guidelines**
This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethics aspects of this research project have been approved by the Human Research Ethics Committee of Deakin University.
12. Complaints
If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

The Executive Officer, Human Research Ethics Committee, Deakin University, 221 Burwood Highway, Burwood Victoria 3125, Telephone: 9251 7123, Facsimile: 9244 6581; research-ethics@deakin.edu.au.

Please quote project number EC 78 - 2009.

13. Reimbursement for your costs
You will not be paid for your participation in this project.

14. Further Information, Queries or Any Problems
If you require further information, wish to withdraw your participation or if you have any problems concerning this project (for example, any side effects), you can contact the principal researcher or members of the researcher’s supervisory panel. The researchers responsible for this project are:

Greg Roberts – Student Researcher
P.O. Box 533 Colac 3250
Phone Greg – 0415 132 302 (all hours) – Email – gpro@deakin.edu.au

Bob Pease– Principal Supervisor/Researcher
Deakin University
Waterfront Campus – Gheringhap St Geelong 3220
Faculty of Health Medicine, Nursing and Behavioural Sciences
School of Health and Social Development
Phone Bob 5227 8445 (BH) – Email bob.pease@deakin.edu.au
DEAKIN UNIVERSITY
PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: Participants

Consent Form

Date:

Full Project Title: Into The Mystic – Emotions, Intuition and Creativity after the Death of a Child or Sibling

I have read, and I understand the attached Plain Language Statement.

I freely agree to participate in this project according to the conditions in the Plain Language Statement.

I have been given a copy of the Plain Language Statement and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details, including where information about this project is published, or presented in any public form, unless I specifically request to be identified.

Participant’s Name (printed) …………………………………………………………………………

Signature ……………………………………………… Date …………………

Greg Roberts – Student Researcher
P.O. Box 533 Colac 3250
Phone Greg – 0415 132 302 (all hours) – Email – gpro@deakin.edu.au

Bob Pease – Principal Supervisor/Researcher
Deakin University
Waterfront Campus – Gheringhap St Geelong 3220
Faculty of Health Medicine, Nursing and Behavioural Sciences
School of Health and Social Development
Phone Bob 5227 8445 (BH) – Email bob.pease@deakin.edu.au
DEAKIN UNIVERSITY

PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: Parent/Guardian

Third Party Consent Form

(To be used by parents/guardians of minor children, or carers/guardians consenting on behalf of adult participants who do not have the capacity to give informed consent)

Date:

Full Project Title: Into The Mystic – Emotions, Intuition and Creativity after the Death of a Child or Sibling

I have read, and I understand the attached Plain Language Statement.

I give my permission for .............................................................(name of participant) to participate in this project according to the conditions in the Plain Language Statement.

I have been given a copy of Plain Language Statement and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details, including where information about this project is published, or presented in any public form.

Participant’s Name (printed) ........................................................

Name of Person giving Consent (printed) ...........................................

Relationship to Participant: ..........................................................

Signature ................................................................. Date

Greg Roberts – Student Researcher
P.O. Box 533 Colac 3250
Phone Greg – 0415 132 302 (all hours) – Email – gpro@deakin.edu.au

Bob Pease – Principal Supervisor/Researcher
Deakin University
Waterfront Campus – Gheringhap St Geelong 3220
Faculty of Health Medicine, Nursing and Behavioural Sciences
School of Health and Social Development
Phone Bob 5227 8445 (BH) – Email bob.pease@deakin.edu.au
**Revocation of Consent Form**

*(To be used for participants who wish to withdraw from the project)*

Date;

**Full Project Title:** Into The Mystic – Emotions, Intuition and Creativity after the Death of a Child or Sibling

I hereby wish to WITHDRAW my consent to participate in the above research project and understand that such withdrawal WILL NOT jeopardise my relationship with Deakin University or any support agencies that I access.

Participant’s Name (printed) .................................................................

Signature ...................................................................................................  Date
  ................................................................

Please mail or fax this form to:

**Greg Roberts – Student Researcher**
P.O. Box 533 Colac 3250
Phone Greg – 0415 132 302 (all hours) – Email – gpro@deakin.edu.au

**Bob Pease – Principal Supervisor/Researcher**
Deakin University
Waterfront Campus – Gheringhap St Geelong 3220
Faculty of Health Medicine, Nursing and Behavioural Sciences
School of Health and Social Development
Phone Bob 5227 8445 (BH) – Email bob.pease@deakin.edu.au
DEAKIN UNIVERSITY
PLAIN LANGUAGE STATEMENT AND ACKNOWLEDGEMENT FORM

TO: Parent/Guardian

Acknowledgement Form for Participants Aged Under 18 years of age, but over 16 years

(To be used by parents/guardians of young people aged between 16 years and 18 years of age. Deakin University requires that people in this age group have their parent or guardian acknowledge that they are participating in the research.)

Date:

Full Project Title: Into The Mystic – Emotions, Intuition and Creativity after the Death of a Child or Sibling

I have read, and I understand the attached Plain Language Statement.

I acknowledge that .................................................................(name of participant) will participate in this project according to the conditions in the Plain Language Statement.

They have been given a copy of Plain Language Statement and Consent Form to keep and I have sighted these.

The researcher has agreed not to reveal my identity and personal details, or those of the above named participant, including where information about this project is published, or presented in any public form.

Participant’s Name (printed) ..........................................................

Name of Person acknowledging the participation(printed)..........................................................

Relationship to Participant: ..........................................................

Signature .......................................................... Date

Greg Roberts – Student Researcher
P.O. Box 533 Colac 3250
Phone Greg – 0415 132 302 (all hours) – Email – gpro@deakin.edu.au

Bob Pease – Principal Supervisor/Researcher - Deakin University
Waterfront Campus – Gheringhap St Geelong 3220
Faculty of Health Medicine, Nursing and Behavioural Sciences
School of Health and Social Development
Phone Bob 5227 8445(BH) – Email bob.pease@deakin.edu.au
Appendix c – Instructions for participants

Instructions for participants

The first step of the research –

"Initially I will ask you to provide one or more representations of the activities you have engaged in since the death of the child (written, photographic or other ways of describing or showing these activities)."

OK, I imagine you might think, “what does he mean by this?” This sheet will hopefully guide you a bit with what I think is the best first step into the topic. But at the end of the day, just offer me whatever you feel comfortable with in whatever way makes sense to you. Take this information as a guide rather than as a strict step-by-step process. Follow your instinct on what works best for you. I might get a bit repetitive about the word *describe* in what follows, but that’s because I think it’s really important to this first step.

If we are going to talk about the things you have done or made since your child died and have other people understand this, then I think it’s going to be important to include a couple of things. For the first part, you don’t have to go into lots of detail, but I think it’s important to introduce your situation, by giving a brief description. Here’s my example –

“At the end of July 1995, my first born child, Madeleine, entered the world after an event free pregnancy. In the days after her birth, she was diagnosed with a severe congenital heart condition related to Down’s Syndrome. Madeleine died at 25 days of age after having heart surgery. My wife and I had also experienced a miscarriage just over a year before Madeleine was born”

This is just an example and you can write yours in any way you wish to, but I suggest you keep it brief and just give a very short description. If you find this difficult to do then please don’t push yourself, just leave this bit and come back to it or give me a call and we can have a chat about it. Later on you can decide whether you want to use real names or change the names used to protect your identity. At this early stage no-one else will see it apart from you, and me unless you give me permission to share it with anyone else.

The next part is the main focus of the research. I would like you to simply describe the ‘things you have done or made’ since the death of your child/sibling. You may have one key thing that stands out for you, or you may have several things. I would ask that you try to go with the thing or things that are really significant to you and just *describe* or show what it is, by either writing down a description, draw it, photograph it or give an example. **Most importantly at this stage, I only want you to describe or show what it is that you have done or made**, I don’t want you to say anything about how you feel about it, or to even say what makes it special to you, just *describe* it. (We will get into how you feel about it and what is special about it later on when I meet to interview you). By just describing what you’ve done or made, you
may notice things you haven’t noticed before, so that’s why I’m asking you to do this. Here are some hints to help you describe what you have done or made. You may like to use some of these as a guide, all of them or none. It’s just to give you some ideas if you need them.

**HINTS FOR DESCRIBING**

What is it that you have done or made?
How would you describe it so that someone else could get a picture of what it is?
Could a photograph or a drawing help represent it? (If so include one)
Does it have a shape, colour, texture, size etc?
Is it part of you or separate from you?
If it’s part of you, how is it part of you and which part of you is it connected to?
If it’s not part of you where is it located in relation to you (eg – In your garden or on you car, etc)?
Is it something permanent or temporary?
Depending on what it is, use some or all of your senses to describe it, for example – What can you see? What can you hear? What can you touch? What can you smell? What can you taste?

So, I’m asking you to use these questions to help you provide me with something that represents what you have done or made since the death of your child/sibling. But again please give me whatever you think helps me get an idea or a picture of what you have done. Just keep it simple and straight-forward. Some of you have already given me some of this basic information, when you emailed me, so all you have to do is give a little more detail. It’s a bit like thinking about or looking at what you have done or made with fresh eyes, like you are seeing it or thinking about it for the first time ever. Just describe what you have done or made.

I’d really appreciate it if you could do both of these things and either send or email what you have ended up with within a month of reading this. It may be just an introduction of your situation with a few photos and a description. Or you may just write down an introduction with a description and send that. Whatever is easiest for you. Try not to labour over it and just offer what you feel comfortable with. This is only the first step, so it’s not meant to be a huge task. Simple and straight-forward is good.

After I have this from you I will be in touch with each of you to arrange to meet for an interview on an individual basis.

As always, if you have any questions just give me a call or email me.
Email – gpro@deakin.edu.au or Mobile 0415 132 302
Appendix d – Eight moments of qualitative research

The eight moments in qualitative research identified by Denzin & Lincoln (2008).

First moment
The traditional phase (1900-1940s)
Accounts of field experiences, including classic ethnographies, try to reflect the positivist scientific paradigm.

Second moment
The modernist phase (1950s-1970s)
Accounts of work in the field and in practice draw on marginalised and other voices in society, while seeking rigour in similar ways to quantitative approaches.

Third moment
Blurred genres (1970-1986)
Naturalistic, postpositivist and constructivist paradigms emerge that blur the boundaries between the social sciences and the humanities, providing researchers with diverse strategies and techniques, including narrative, phenomenology, feminism and hermeneutic approaches. The researcher becomes a bricoleur borrowing from many disciplines.

Fourth moment
Crises of representation (mid-1980s-1990)
The blurring of genres problematises the writing of research. The researcher’s identity and power as constructor of the text is acknowledged, so the direct link between lived experience and the text is opened to challenge. In turn, issues of validity, reliability and generalisability arise, so that research becomes hard to evaluate and its authority to improve practice is challenged.

Fifth moment
The postmodern period of experimental ethnography (1990-1995)
Researchers try to grapple with the crises of the postmodern era, searching for different ways to represent the “other”. Grand narratives and “distant observers” are abandoned in favour of action-based and activist research and local, small-scale
theories. Other evaluative criteria are sought, including moral and critical perspectives.

**Sixth moment**

Postexperimental inquiry 1995-2000)

New ways of expressing lived experience are taken up, including poetry, literary forms, autobiography, visual and performative approaches.

**Seventh moment**

The methodologically contested present (2000-2004)

The value of qualitative research is contested by demands for evidence-based approaches to practice and knowledge, using objectivist models and experimental techniques. This can be seen as a backlash to the growth of qualitative research, or to the extreme postmodernist positions, and as an expression of more contemporary conservatism.

**Eighth moment**

The fractured future (2005-)

Qualitative researchers confront the methodological backlash, and revisit the demands of moral discourse, the sacred, and critical conversations about the diversity of human life, including experiences of freedom and control in a global society.
Appendix e – Ethics approval

Research Services

Office of the Deputy Vice-Chancellor (Research) (Melbourne Campus)

MEMORANDUM

TO: Dr Heather D'Cruz - School of Health and Social Development, Geelong Waterfront

FROM: Deakin University Human Research Ethics Committee (DU-HREC)

DATE: 9th July 2009

SUBJECT: EC 78-2009 (Please quote this project number in future communication.)

Into the mystic - emotions, intuition, spirituality and creativity after the death of a child

The application for this project was considered at the DU-HREC meeting held on 22 June 2009.

Approval has been given for Greg Roberts, under the supervision of Dr Heather D'Cruz, School of Health and Social Development, to undertake this project.

The approval given by the Deakin University Human Research Ethics Committee is given only for the project as stated in the approval. It is your responsibility to contact the Executive Officer immediately should any of the following occur:

• Serious or unexpected adverse effects on the participants

• Any proposed changes in the protocol, including extensions of time.

• Any events which might affect the continuing ethical acceptability of the project.

• The project is discontinued before the expected date of completion.

• Modifications are requested by other HREC’s.

In addition you will be required to report on the progress of your project at least once every year and at the conclusion of the project. Failure to report as required will result in suspension of your approval to proceed with the project.
DU-HREC may need to audit this project as part of the requirements for monitoring set out in

the *National Statement on Ethical Conduct in Human Research (2007).*

On behalf of DU-HREC

Vicky Bates, Secretary

03 9251 7123
Appendix f – Focusing example


1. Clear a space

How are you? Don’t answer; let what comes in your body do the answering. Don’t go into anything. Greet each sensation that comes. Put each aside for a while.

2. Felt Sense

Pick something to focus on. Don’t go into it. What do you sense in your body when you sense the whole of that something? Sense all of that, the sense of the whole thing, the murky discomfort or the unclear body-sense of it.

3. Get a handle

What is the quality of the felt sense? What one word, phrase, or image comes out of this felt sense? What quality-word would fit it best?

4. Resonate

Go back and forth between word (or image) and the felt sense. Is that right? If they match, have the sensation of matching several times. If the felt sense changes, follow it with your attention. When you get a perfect match, the words (images) being just right for this feeling, let yourself feel that for a minute.

5. Ask

What is it, about this, that makes me so ________? When stuck, ask questions: What is this feeling about? What does it need? What should happen? Don’t answer; wait for the feeling to stir and give you an answer. What would it feel like if it was all OK? Let the body answer.

6. Receive

Welcome what came. Be glad it spoke. It is only one step, not the last. Now that you know where it is, you can leave it and come back to it later. Protect it from critical voices that interrupt. Does your body want another round of focusing, or is this a good stopping place?
References


Sartre, J.P. 2007. (trs Macomber. C.) Existentialism is a humanism. Yale University Press, Yale


Wong, K. 2006. The morning of the modern mind. *Scientific American*, sp, 16(2) pp74-83


I am the author of the thesis entitled

Into the Mystic - Bereaved parents, love and spontaneous creativity.

submitted for the degree of Doctor of Philosophy

This thesis may be made available for consultation, loan and limited copying in accordance with the Copyright Act 1968.

‘I certify that I am the student named below and that the information provided in the form is correct’

Full Name: Gregory Paul Roberts

Signed:

Date: 30th November 2015