This is the published version:

Cummins, Robert A., Campbell, Peter, Rechner, Ruth and Hammond, Thomas 2011, *Carers counselling intervention study* Deakin University, Geelong, Vic.

Available from Deakin Research Online:

http://hdl.handle.net/10536/DRO/DU:30042969

Reproduced with the kind permission of the copyright owner.

Copyright: 2011, The Authors
Carers Counselling Intervention Study

2011

Robert A. Cummins
School of Psychology, Deakin University

Peter Campbell
Carers Australia

Ruth Rechner
Carers Victoria

and

Thomas Hammond
School of Psychology, Deakin University

Australian Centre on Quality of Life
Deakin University, 221 Burwood Highway
Melbourne, Victoria 3125, Australia

Published by Deakin University, Geelong, Victoria 3217, Australia

First published 2011

© Deakin University and Carers Australia


This is a joint publication of:

The School of Psychology, Deakin University
Carers Australia
Carers Victoria
The Australian Centre on Quality of Life, Deakin University

Correspondence should be directed to:

Professor Robert A. Cummins
Deakin University
Geelong, Victoria 3217
Australia

Email: cummins@deakin.edu.au
Website: acqol.deakin.edu.au

Acknowledgements

We thank the Expert Panel for the National Carers Counselling Program Review Implementation for their advice in the development of this evaluation protocol and questionnaire items. The members are: Paul Gibney, Alison Strasser, Mal McKissock, Bob Cummins and Peter Campbell.

We thank Ann-Marie James for her assistance in the preparation of this report.

Carers Report July 2011
Index of Tables

Table A 1: Personal Wellbeing Index ................................................................................................................... 13
Table A 2: Carer life ............................................................................................................................................... 13
Table A 3: The correlation between average life as a carer during the past few weeks and wellbeing .......... 13
Table A 4: Life Events and Wellbeing ................................................................................................................ 14
Table A 5: Support and resources in carer life and PWI ..................................................................................... 14
Table A 6: Survey 1 Regression of carer life over the past few weeks on PWI .................................................. 15
Table A 7: Survey 2 Regression of carer life over the past few weeks on PWI .................................................. 15
Table A 8: Survey 1 Regression of kind of help received on PWI ....................................................................... 15
Table A 9: Survey 2 Regression of carer kind of help received on PWI ............................................................. 16
Table A 10: Survey statistics November 2010 to May 2011 ................................................................................. 16
Index of Figures

Figure 3.1: Acceptance rates for involvement in the study.................................................................6
Figure 3.2: Baseline and post-counselling wellbeing against the normal range (Personal Wellbeing Index)......6
Figure 3.3: Carers evaluation of key life areas ..................................................................................7
Figure 3.4: Correlation between the average of the key life area evaluations and personal wellbeing..........8
Figure 3.5: Frequency of life events .....................................................................................................8
Figure 3.6: Perceived strength of life events .........................................................................................9
Figure 3.7: Personal Wellbeing Index vs life events.............................................................................9
Figure 3.8: Types of regular help............................................................................................................10
1. Introduction

The National Evaluation of the National Carer Counselling Program (NCCP) conducted in 2009 (by Alt Beattie) recommended a greater focus on outcome measures to demonstrate the impact of carer counseling. Given the 2007 collaborative research between Australian Unity, Deakin and Carers Australia: Cummins et al., 2007b) which had demonstrated the lowest personal wellbeing of carers against any category yet surveyed by these authors (Cummins et al., 2007a), this same study methodology was selected to provide a longitudinal perspective on the impact of counselling for carers. Carers Victoria offered and was selected in 2010 to implement the initial pilot study, prior to its proposed national roll-out across the NCCP.

This report details the procedures and findings from a pilot study conducted by Carers Victoria in collaboration with Carers Australia and Deakin University. The aim of this study is to determine the feasibility and effectiveness of the standard 6-week counselling intervention offered by Carers Victoria.

The details of this pilot study are provided in appendices. Appendix 1 provides the tables of data analysis, Appendix 2 the questionnaires, Appendix 3 the experiences of Carers Victoria staff and feedback from carers relating to their involvement in the study, Appendix 4 logistics and flow chart, and Appendix 5 the statement of ethical approval and standard correspondence with carers. Appendix 3 includes recommendations regarding the procedures used in the study.

1.1. Understanding Personal Wellbeing

The major measurement instrument used in our surveys is the Personal Wellbeing Index (PWI). This is designed as the first level deconstruction of ‘Life as a Whole’ and the manual can be found at http://www.deakin.edu.au/research/acqol/instruments/wellbeing-index/. It comprises seven questions relating to satisfaction with life domains, such as ‘health’ and ‘standard of living’. Each question is answered on a 0-10 scale of satisfaction. The scores are then combined across the seven domains to yield an overall Index score, which is adjusted to have a range of 0-100.

On a population basis the scores that we derive from this PWI are quite remarkably stable. A total of 25 surveys have been conducted over the period 2001 – 2011, each comprising a fresh geographically representative sample of 2,000 randomly selected adults across Australia. These survey means range from 73.7 to 76.7, a fluctuation of only 3.0 points. These survey means are used to construct normal ranges, which are incorporated into the description of results shown in the next section. So, how can such stability be achieved?

We hypothesize that personal wellbeing is not simply free to vary over the theoretical 0-100 range. Rather, it is held fairly constant for each individual in a manner analogous to blood pressure or body temperature. This implies an active management system for personal wellbeing that has the task of maintaining wellbeing, on average, at about 75 points. We call this process Subjective Wellbeing Homeostasis.

The proper functioning of this homeostatic system is essential to life. At normal levels of wellbeing, which for group average scores lies in the range 73.7 to 76.7 points, people feel good about themselves, are well motivated to conduct their lives, and have a strong sense of optimism. When this homeostatic system fails, however, these essential qualities are severely compromised, and people are at risk of depression. This can come about through such circumstances as exposure to chronic stress, chronic pain, failed personal relationships, etc.

Fortunately for us, the homeostatic system is remarkably robust. Many people live in difficult personal circumstances which may involve low income or medical problems, and yet manage to maintain normal levels of wellbeing. This is why the Index is so stable when averaged across the population. However, homeostasis can fail when placed under too much challenge from the circumstances of
living. When this occurs, people lose their normal positive sense of wellbeing and become prone to depression. Such people need additional resources in order to regain homeostatic control and normal levels of wellbeing.
2. Method

2.1. Operational issues

The Team at Carers Victoria incorporated the study within its existing processes. It is likely that these will vary from state to state. These processes were then slightly modified, particularly after the early carer feedback canvassed after the first quarter. In particular, we moved from ‘asking for consent’ at Intake to send the Survey, to ‘mentioning the study and survey’ which they would receive and could then decide to participate in. We also simplified the covering letters and attachments sent to carers with their referral details. In March 2011 we focused on raising the awareness of Contracted Counsellors (CCs) regarding this study at our Annual CC Network Forum. Professor Bob Cummins presented the Well-being study at this forum and received an enthusiastic response.

The implications for CCs practice (i.e. returning paperwork quickly after case closure etc) has also been conveyed through our regular CC E-Bulletins. It has also been important to raise awareness of the study amongst Carer Support Workers and CRCCs through the Victorian Carer Services Network, as many carers ‘mention’ the study to their other workers.

2.2. The initial six months 16/11/2010 – 31/5/2011

The initial 3 months of this pilot coincided with the Christmas and New Year period which is typically a time when counselling referrals drop overall. Furthermore, it took some time initially for all staff to become familiar and comfortable with the delivery of the study, so there was an inevitable progressive build-up in the initial rate of implementation (Table 1). During the initial 6 month period, 70.3% of all allocated counselling cases agreed to participate in the Study. Only 6.7% declined, though in the latter 3 month period we did not specifically ‘invited’ participants at Intake. 9.3% were not eligible (due to language or age), and 13.6% were not specifically asked (based on Intake worker’s judgment). At the end of this initial 6 months we had sent out 385 Survey 1s, 53 Survey 2s, and 5 Survey 3s.

2.3. Resource implications

Carers Victoria’s implementation of this initial pilot has had inevitable resource implications, though these are difficult to separate precisely from the routine Intake and Administration processes in relation to counselling referrals.

• Over the initial 6 month period, in addition to the initial planning discussions and agreed processes, it is estimated that an additional 30 minutes per referral is involved across Intake and Administration at Survey 1, then an additional 30 minutes per referral across Surveys 2 & 3. On average this is an estimated additional 1 hour per referral.

• Carers Australia provided an initial contribution of $3,000 to support additional resource costs in Administration, then a further $2,000 towards carer follow-up which has assisted in the fine-tuning of processes.

• An additional specific resource of $3,000 was also provided to source the purchase of $20 vouchers to recipients of Survey 2 at the end of their counselling. This was identified as an acknowledgement of carer time, irrespective of whether or not they chose to complete the surveys.

• There has also been some additional postage costs incurred for the additional mail-out of Survey 3, and if Survey 1 and 2 were sent separately (as recommended below) this would also involve increased postage costs.
2.4. **Carer feedback**

Carers Victoria advocated quite strongly for some resource provision to support some random carer feedback as part of the initial pilot. Carers Australia supported this through an additional $2,000 (as outlined above), which has been further supplemented by Carers Victoria in matching a further $2,000. One of Carers Victoria's locum staff and a very experienced counsellor, Lisa Burke, has undertaken focused conversations with 19 random carers regarding their experience with the NCCP and the Deakin Study. 10 of these had received Survey 1 and 9 had received Survey 2.

These semi-structured telephone interviews provided initial feedback in February 2011 which resulted in some early procedural changes, followed up in May 2011 with Survey 2 recipients which have identified further recommendations for consideration.

- All carers contacted were very willing to provide their feedback and most spontaneously acknowledged the importance of research both to Carers Victoria and themselves.
- Many of the carers contacted proactively offered positive feedback about their experience of counselling and particularly the value of talking to qualified professionals who really understood the carer experience.
- Most carers also identified the importance of Carer Counsellors also being registered with Medicare, as an additional avenue for support, given the inadequacy of 6 sessions to address complex caring issues which in turn impact on their own mental health.
- Importantly, these telephone interviews also resulted in the provision of additional support, referrals or crisis management as appropriate.
- The 'recall' capacity at Intake was a significant finding during the early carer feedback. Very few (6/19) could recall their consent to participate in the Deakin Study in the midst of presenting their primary concerns. This feedback resulted in a change to our processes where we now only mention the Deakin Study at Intake, indicating that they can decide if they wish to participate when they receive the Survey.
- While most could then recall receiving the actual Survey 1 (17/19), this declined to the recall of receiving Survey 2 (3/9). At least half reported completing Survey 1 (10/19), but this declined further for returning Survey 2 (2/9).
- Most carers contacted highlighted a confusion regarding the period of reporting on their 'mood' and indicated that their response could easily be influenced by their state on the day of completing the Survey, rather than reflecting on a period of time since the counselling etc.
- A comprehensive summary of all this carer feedback forms Appendix 3 of this report.

2.5. **Recommendations**

1. Carers Victoria fully supports the national roll-out of this study in order to provide an evidence-base to demonstrate the impact of counselling on the well-being of carers.

2. Carers Victoria suggests that processes be reviewed to simplify the process for carers, including correspondence and attachments, and separate mailings between the Carers Victoria and Deakin Study correspondence and documentation.

3. Carers Victoria strongly recommends that the survey instructions be modified to emphasize capturing the carers' mood 'over the last few weeks' (see A3.5 for further details).
4. Carers Victoria also supports the value of identifying Carer Counsellors who can also provide further counselling support through Medicare where appropriate at reduced rates (see A3.6 for further details).

2.6. Data Analysis

Once the surveys were received at Deakin University, the data was entered into the statistical program SPSS (Statistical Package for the Social Sciences) for analysis. Responses were then standardized into units of a 0 to 100 point distribution. This was achieved by shifting the decimal point one step to the right. For example, a response of 5.0 on the 0 – 10 scale becomes 50 points. Once the responses were standardized, all data was checked for response sets. A response set is evident when the participant scores at the top or the bottom of the scale for all items. This type of data may indicate a response set due to either acquiescence or a lack of understanding. Therefore, data sets from participants that consistently displayed maximum or minimum scores on all 8 domains of the Personal Wellbeing Index or on all 6 domains of the Carer’s Evaluation of Key Life Areas were eliminated prior to data analysis. This procedure was undertaken as the lack of variation may distort the data analysis. In total, one participant in the second survey was removed from the analysis as a result of a response set.
3. Results

3.1. Response rate

The uptake and retention statistics are provided in Table A10 and in the Figure below.

Figure 3.1: Acceptance rates for involvement in the study

The initial 3 months of this pilot coincided with the Christmas and New Year period which is typically a time when counselling referrals drop overall. Furthermore, it took some time initially for all staff to become familiar and comfortable with the delivery of the study, so there was an inevitable progressive build-up in the initial rate of implementation. Five months into the project, the acceptance rate reached over 90% and seems to have stabilized.

3.2. Counselling program effectiveness

The values in Figure 3.2 show the initial data coming from this project as at 24th June 2011. The number of returns for the baseline measurement (Time 1) is N=178 and the number for the immediate follow-up is N=31. The latter number is too small to be reliable, so the results are indicative only.

Figure 3.2: Baseline and post-counselling wellbeing against the normal range (Personal Wellbeing Index)

In Figure 3.2, the baseline indicates the summary measure of wellbeing (PWI) followed by the seven ‘domains’ that combine to yield the total measure of wellbeing. The vertical axis shows the level of wellbeing on a 0-100 scale. The vertical arrows in the figure show the normal ranges for each of the 8 measures – so responses should fall within these ranges. The Time 1 measures were made before counselling, and the Time 2 immediately after.
The Time 1 measures are quite shocking. The value of 54.7 is lowest group mean score on record. While the Time 2 measures show that the counselling has been effective in raising wellbeing by 10.8 points (Table A1; p=.02), it remains 8.0 points below the bottom of the normal range.

In terms of the domains, the three showing the greatest degree of rise are Connection to community (+13.9 points), Health (+13.4 points, and Future security (+13.2 points). The domains that showed no significant rise were Standard of Living, Safety and Spiritual/religious.

3.3. **Carers' evaluation of key life areas**

Carers were asked their level of agreement with each of the following statement:

a. As a carer my life is getting easier
b. When an unexpected difficulty happens I can deal with it
c. In an emergency I can find help
d. It is easy for me to leave home and go shopping
e. I have enough time for myself
f. As a carer I feel I am doing enough

The changes in responses are shown in Figure 3.3. Higher values shows a more positive assessment.

All of these positive changes are significant except for ‘Easy to leave home to go shopping’, which is non-significant. It is interesting that this is the only objective variable in the list and so it is not surprising that it has shown the least change.

Table A6 shows the results of a multiple regression, which shows the relative power of each of these 6 areas to predict wellbeing. The data only come from Survey 1, since the number of respondents for survey 2 is insufficient to support this type of analysis. The results show that the power of these areas to predict wellbeing is modest, with the areas together accounting for 34.3% of the variation in wellbeing. Only one item 'When an unexpected difficulty happens I can deal with it' has a unique ability to predict wellbeing.

The relationship between personal wellbeing and the average of the key life areas is shown in Table A3 and Figure 3.4.
There is, as expected, a highly significant relationship, which appears to be high following counselling. Whether this strong relationship remains as the sample size for Survey 2 increases remains to be seen.

### 3.4. Life events

Carers are asked “Has anything happened to you recently causing you to feel happier or sadder than normal?” If they answer ‘Yes’, they are then asked whether this was a happy or a sad event, and to ‘rate its influence on a 0 to 10 scale, from very weak to very strong’.

If people were to be severely interrogated along these line virtually everybody would recall an event of some kind that made them happier or sadder than normal. The time frame is loose (‘recently’) and the point of reference (‘normal’) is open to interpretation. But respondents are not interrogated, and if they answer that they have experienced no such event, the interviewer proceeds to the next item. Because of this, the item is either measuring people’s sensitivity to the positive and negative events in their lives, or the extent to which people are willing to identify such events. In either case it is measuring the direction of people’s attention to the positive or negative side of their life. The results are shown in Table A4 and Figure 3.5. The normal values are drawn from Table A9.4 in Australian Unity report 25.0 (Cummins et al, 2011)

These results show a remarkable degree of change in Carers’ perception of the events in their lives. Relative to normal values, prior to counselling the proportion of Carers reporting a happy event was very low, and the proportion reporting a sad event was very high. Following the counselling, this pattern completely reversed, with Carers actually more like than normal to report a happy event and less likely to report a sad event. However, the number of carers in Survey 2 is as yet too low for these results to be regarded as reliable.

The felt strength of recalled life events is shown in Table A4 and shown in Figure 3.6.
For Survey 2, there are only 14 ‘Happy’ and 4 ‘Sad’, so these numbers are too small to be reliable.

The normal link between life events and wellbeing is that they follow one another. Thus, people who report a happy event also report higher wellbeing. It can be seen that, prior to the intervention, this linkage was not present, which is a response typical of people who are depressed. They have lost the capacity to experience positive emotion. Following the intervention their affective response looks much more normal.

3.5. **Help received on a regular basis**

Carers were asked to check (yes/no) whether they received the following kinds of help ‘in your caring role on a regular basis’

a) Help from family or friends  
b) Someone to help you in your home  
 c) A professional person you talk to  
d) Someone to help with shopping or transport  
e) Someone paid to help look after the person you care for  
f) Someone to help you be healthy  
g) Additional income
Section 3: Results continued

h) Contact with people in the same situation

i) Information or education

These results are found in Table A5 and Figure 3.8 shows the percentage ‘yes’ responses for each item.

<table>
<thead>
<tr>
<th></th>
<th>Survey 1</th>
<th>Survey 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family/ friends</td>
<td>46.0</td>
<td></td>
</tr>
<tr>
<td>Help in home</td>
<td>24.5</td>
<td>24.1</td>
</tr>
<tr>
<td>Talk to professional</td>
<td>35.6</td>
<td></td>
</tr>
<tr>
<td>Shopping/ transport</td>
<td>7.4</td>
<td>6.9</td>
</tr>
<tr>
<td>Paid care</td>
<td>28.2</td>
<td>20.7</td>
</tr>
<tr>
<td>Help being healthy</td>
<td>16.6</td>
<td></td>
</tr>
<tr>
<td>Additional income</td>
<td>22.1</td>
<td></td>
</tr>
<tr>
<td>Contact similar others</td>
<td>30.1</td>
<td>27.6</td>
</tr>
<tr>
<td>Information/ education</td>
<td>30.7</td>
<td>58.6</td>
</tr>
</tbody>
</table>

Figure 3.8: Types of regular help

The * at the top of columns indicates a significant difference between the wellbeing for people answering ‘yes’ between the two surveys. It is, thus, an indication of the relevance of the percentage changes to changed wellbeing. Notably, even though ‘Information/education’ showed a big rise in the percentage of people saying ‘yes’, this was not significantly linked to increased wellbeing. The two that are significant both involve interpersonal relationships.

However, a more rigorous test of the linkage between these areas and wellbeing is provided in Table A8 where, for Survey 1 data, the 9 types of help are regressed against the PWI. This shows a very weak relationship, with the types of help together accounting for only 4.5% of the variation in wellbeing. Moreover, not one of the types shows a significant unique relationship with wellbeing.

3.6. Summary

The results of this pilot study can be summarised as follows:

1. The acceptance rates appear to have stabilized at over 90%.

2. Prior to counselling, the wellbeing of the 178 carers was at the lowest value recorded in the history of the Personal Wellbeing Index, at 54.7 points. This signals the desperate situation these people are in, and the certainty of high levels of depression.

3. While the immediate post-counselling measures showed a significant 10.8 point rise in wellbeing, this still remained 8.0 points below the normal range.

4. In terms of the domains, the three showing the greatest degree of rise are Connection to community (+13.9 points), Health (+13.4 points, and Future security (+13.2 points). The domains that showed no significant rise were Standard of Living, Safety and Spiritual/religious.

5. Following counselling, satisfaction with all 6 key life areas rose significantly except for ‘Easy to leave home to go shopping’, which is non-significant. This is the only objective variable in the list and so it is not surprising that it has shown the least change.
Section 3: Results continued

6. The power of these key life areas to predict wellbeing is modest, with the areas together accounting for 34.3% of the variation in wellbeing. Only one item 'When an unexpected difficulty happens I can deal with it' has a unique ability to predict wellbeing.

7. In terms of the experience of life events, relative to normal values, before counselling the proportion of Carers reporting a happy event was very low, and the proportion reporting a sad event was very high. Following the counselling, this pattern completely reversed, with Carers actually more like than normal to report a happy event and less likely to report a sad event.

8. Of the 8 types of help received on a regular basis, two types as help from family and friends, and talk to professionals, were associated with increased wellbeing following counselling. However, the power of these areas of help to predict wellbeing is very weak.
4. References


## Appendix A1. Tables

### Table A 1: Personal Wellbeing Index

<table>
<thead>
<tr>
<th>Item</th>
<th>Survey 1</th>
<th></th>
<th></th>
<th>Survey 2</th>
<th></th>
<th></th>
<th>Mean S1-S2</th>
<th>PWI Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whole</td>
<td>175</td>
<td>48.34</td>
<td>25.12</td>
<td>30</td>
<td>61.67</td>
<td>22.76</td>
<td>13.33</td>
<td>F(1,118) = 5.74, p=0.02</td>
</tr>
<tr>
<td>Living</td>
<td>176</td>
<td>61.87</td>
<td>23.33</td>
<td>30</td>
<td>68.00</td>
<td>24.41</td>
<td>6.13</td>
<td>F(1,118) = 3.08, p=0.08</td>
</tr>
<tr>
<td>Health</td>
<td>173</td>
<td>51.27</td>
<td>25.21</td>
<td>30</td>
<td>64.67</td>
<td>25.56</td>
<td>13.4</td>
<td>F(1,118) = 11.30, p&lt;0.01</td>
</tr>
<tr>
<td>Achieving</td>
<td>176</td>
<td>48.47</td>
<td>26.73</td>
<td>30</td>
<td>60.67</td>
<td>24.34</td>
<td>12.2</td>
<td>F(1,118) = 6.68, p=0.01</td>
</tr>
<tr>
<td>Relationships</td>
<td>175</td>
<td>53.20</td>
<td>23.91</td>
<td>30</td>
<td>64.14</td>
<td>27.71</td>
<td>10.94</td>
<td>F(1,118) = 4.63, p=0.03</td>
</tr>
<tr>
<td>Safe</td>
<td>173</td>
<td>56.01</td>
<td>23.91</td>
<td>30</td>
<td>64.00</td>
<td>26.70</td>
<td>5.99</td>
<td>F(1,118) = 2.30, p=0.13</td>
</tr>
<tr>
<td>Community</td>
<td>175</td>
<td>51.77</td>
<td>27.91</td>
<td>30</td>
<td>64.67</td>
<td>27.88</td>
<td>13.9</td>
<td>F(1,118) = 7.76, p&lt;0.01</td>
</tr>
<tr>
<td>Security</td>
<td>172</td>
<td>50.76</td>
<td>28.63</td>
<td>30</td>
<td>64.00</td>
<td>26.73</td>
<td>13.24</td>
<td>F(1,118) = 4.79, p=0.03</td>
</tr>
<tr>
<td>Religion</td>
<td>105</td>
<td>66.00</td>
<td>27.23</td>
<td>20</td>
<td>74.50</td>
<td>24.60</td>
<td>8.5</td>
<td>F(1,118) = 1.48, p=0.23</td>
</tr>
<tr>
<td>PWI</td>
<td>163</td>
<td>54.72</td>
<td>19.94</td>
<td>29</td>
<td>65.27</td>
<td>24.09</td>
<td>10.55</td>
<td>F(1,192) = 6.45, p=0.02</td>
</tr>
</tbody>
</table>

Table 1: This table provides the descriptive statistics for each item of carer wellbeing as well as their Personal Wellbeing Index (PWI). PWI was determined by calculating the average of responses to items 2 to 6. This table also displays the results of the univariate analysis of personal wellbeing between survey 1 and survey 2. Results demonstrate that there is a significant difference (p<0.01) in carer wellbeing from survey 1 to survey 2.

### Table A 2: Carer life

<table>
<thead>
<tr>
<th>Item</th>
<th>Survey 1</th>
<th></th>
<th></th>
<th>Survey 2</th>
<th></th>
<th></th>
<th>Mean S1-S2</th>
<th>Carer Life Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life getting easier</td>
<td>165</td>
<td>26.85</td>
<td>20.65</td>
<td>28</td>
<td>50.00</td>
<td>26.53</td>
<td>32.15</td>
<td>F(1,185) = 27.51, p&lt;0.01</td>
</tr>
<tr>
<td>Can deal with difficulty</td>
<td>163</td>
<td>48.65</td>
<td>25.20</td>
<td>27</td>
<td>61.11</td>
<td>21.90</td>
<td>12.46</td>
<td>F(1,185) = 5.86, p=0.02</td>
</tr>
<tr>
<td>Can find help in emergency</td>
<td>166</td>
<td>60.60</td>
<td>26.94</td>
<td>28</td>
<td>75.00</td>
<td>23.17</td>
<td>14.4</td>
<td>F(1,185) = 9.00, p&lt;0.01</td>
</tr>
<tr>
<td>Easy to leave home to go shopping</td>
<td>168</td>
<td>53.99</td>
<td>30.64</td>
<td>28</td>
<td>63.93</td>
<td>33.37</td>
<td>9.94</td>
<td>F(1,185) = 2.07, p=0.15</td>
</tr>
<tr>
<td>Enough time for self</td>
<td>169</td>
<td>36.39</td>
<td>28.48</td>
<td>28</td>
<td>58.57</td>
<td>29.15</td>
<td>22.18</td>
<td>F(1,185) = 12.73, p&lt;0.01</td>
</tr>
<tr>
<td>Feel i am doing enough</td>
<td>165</td>
<td>58.85</td>
<td>30.19</td>
<td>28</td>
<td>71.43</td>
<td>25.92</td>
<td>12.58</td>
<td>F(1,185) = 3.58, p&lt;0.01</td>
</tr>
<tr>
<td>Careraverage</td>
<td>158</td>
<td>47.29</td>
<td>16.35</td>
<td>27</td>
<td>63.15</td>
<td>18.33</td>
<td>15.86</td>
<td>F(1,185) = 17.22, p&lt;0.01</td>
</tr>
</tbody>
</table>

Table 2: This table provides the descriptive statistics for how much a carer agrees with each item relating to their life in the past few weeks. Their average agreement is represented by "careraverage", that was determined by calculating the average response. This table also displays the results of the univariate analysis of carer life between survey 1 and survey 2. Results demonstrate that there is a significant difference (p<0.01) in carer's life from survey 1 to survey 2.

### Table A 3: The correlation between average life as a carer during the past few weeks and wellbeing

<table>
<thead>
<tr>
<th>Survey 1</th>
<th>Survey 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>PWI</td>
<td>.585**</td>
</tr>
<tr>
<td>N</td>
<td>147</td>
</tr>
</tbody>
</table>

**. Correlation is significant at the 0.01 level (2-tailed).

Table 3: This table illustrates the relationship between the carer's wellbeing (PWI) and their life in the last few weeks (careraverage). The results demonstrate their is a significant relationship between wellbeing and recent carer life.
### Table A 4: Life Events and Wellbeing

<table>
<thead>
<tr>
<th>Anything happened Recently</th>
<th>Survey 1</th>
<th>Survey 2</th>
<th>PWI Difference</th>
<th>Strength Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N 1</td>
<td>% N 1</td>
<td>Event Strength</td>
<td>PWI Std. Deviation</td>
</tr>
<tr>
<td>No event</td>
<td>34</td>
<td>22.52</td>
<td>N/A</td>
<td>55.29</td>
</tr>
<tr>
<td>Yes sadder</td>
<td>100</td>
<td>66.23</td>
<td>70.38</td>
<td>53.41</td>
</tr>
<tr>
<td>Yes happier</td>
<td>17</td>
<td>11.25</td>
<td>70.50</td>
<td>55.21</td>
</tr>
<tr>
<td>Total</td>
<td>151</td>
<td>100%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 4: This table indicates if a recent life event occurred in the carer’s life making them feel either sadder or happier and on average how strong this event was. The wellbeing of each group was calculated.

### Table A 5: Support and resources in carer life and PWI

<table>
<thead>
<tr>
<th>Resource</th>
<th>Survey 1</th>
<th>Survey 2</th>
<th>PWI Difference</th>
<th>Strength Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N 1</td>
<td>% N 1</td>
<td>PWI Std. Deviation</td>
<td>N 2</td>
</tr>
<tr>
<td>Family/ friends</td>
<td>88</td>
<td>53.99</td>
<td>50.28</td>
<td>20.22</td>
</tr>
<tr>
<td>Family/ friends</td>
<td>Yes</td>
<td>75</td>
<td>46.01</td>
<td>59.94</td>
</tr>
<tr>
<td>Total</td>
<td>163</td>
<td>100%</td>
<td>Total</td>
<td>100%</td>
</tr>
<tr>
<td>Help in home</td>
<td>123</td>
<td>75.46</td>
<td>54.67</td>
<td>19.66</td>
</tr>
<tr>
<td>Help in home</td>
<td>Yes</td>
<td>40</td>
<td>24.54</td>
<td>54.89</td>
</tr>
<tr>
<td>Total</td>
<td>163</td>
<td>100%</td>
<td>Total</td>
<td>100%</td>
</tr>
<tr>
<td>Professional help to talk to</td>
<td>105</td>
<td>64.42</td>
<td>53.63</td>
<td>20.39</td>
</tr>
<tr>
<td>Professional help to talk to</td>
<td>Yes</td>
<td>58</td>
<td>35.58</td>
<td>56.70</td>
</tr>
<tr>
<td>Total</td>
<td>163</td>
<td>100%</td>
<td>Total</td>
<td>100%</td>
</tr>
<tr>
<td>Help with shopping</td>
<td>151</td>
<td>92.64</td>
<td>54.66</td>
<td>20.09</td>
</tr>
<tr>
<td>Help with shopping</td>
<td>Yes</td>
<td>12</td>
<td>7.36</td>
<td>55.48</td>
</tr>
<tr>
<td>Total</td>
<td>163</td>
<td>100%</td>
<td>Total</td>
<td>100%</td>
</tr>
<tr>
<td>Some to help look after</td>
<td>117</td>
<td>71.78</td>
<td>53.60</td>
<td>20.01</td>
</tr>
<tr>
<td>Some to help look after</td>
<td>Yes</td>
<td>46</td>
<td>28.22</td>
<td>57.58</td>
</tr>
<tr>
<td>Total</td>
<td>163</td>
<td>100%</td>
<td>Total</td>
<td>100%</td>
</tr>
<tr>
<td>Help to be healthy</td>
<td>136</td>
<td>83.43</td>
<td>52.84</td>
<td>19.63</td>
</tr>
<tr>
<td>Help to be healthy</td>
<td>Yes</td>
<td>27</td>
<td>16.57</td>
<td>64.23</td>
</tr>
<tr>
<td>Total</td>
<td>163</td>
<td>100%</td>
<td>Total</td>
<td>100%</td>
</tr>
<tr>
<td>Additional Income</td>
<td>127</td>
<td>77.91</td>
<td>54.30</td>
<td>20.74</td>
</tr>
<tr>
<td>Additional Income</td>
<td>Yes</td>
<td>36</td>
<td>22.09</td>
<td>56.23</td>
</tr>
<tr>
<td>Total</td>
<td>163</td>
<td>100%</td>
<td>Total</td>
<td>100%</td>
</tr>
<tr>
<td>Contact with people in similar situation</td>
<td>114</td>
<td>69.94</td>
<td>53.71</td>
<td>20.14</td>
</tr>
<tr>
<td>Contact with people in similar situation</td>
<td>Yes</td>
<td>49</td>
<td>30.06</td>
<td>57.06</td>
</tr>
<tr>
<td>Total</td>
<td>163</td>
<td>100%</td>
<td>Total</td>
<td>100%</td>
</tr>
<tr>
<td>Information education</td>
<td>113</td>
<td>69.32</td>
<td>52.97</td>
<td>20.52</td>
</tr>
<tr>
<td>Information education</td>
<td>Yes</td>
<td>50</td>
<td>30.68</td>
<td>58.69</td>
</tr>
<tr>
<td>Total</td>
<td>163</td>
<td>100%</td>
<td>Total</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 5: This table displays the wellbeing score of carers who do or do not receive resource support in their life.
### Table A 6: Survey 1 Regression of carer life over the past few weeks on PWI

<table>
<thead>
<tr>
<th>Variable</th>
<th>PWI</th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>B</th>
<th>β</th>
<th>sr² x100</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life getting easier</td>
<td>.37</td>
<td>.11</td>
<td>.11</td>
<td></td>
<td>.941</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deal with difficulty</td>
<td>.49</td>
<td>.19</td>
<td>.25</td>
<td></td>
<td>3.69</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help in emergency</td>
<td>.46</td>
<td>.13</td>
<td>.17</td>
<td></td>
<td>1.72</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>leave home</td>
<td>.35</td>
<td>.05</td>
<td>.07</td>
<td></td>
<td>0.31</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time for self</td>
<td>.42</td>
<td>.13</td>
<td>.19</td>
<td></td>
<td>1.90</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doing enough</td>
<td>.33</td>
<td>.13</td>
<td>.06</td>
<td></td>
<td>0.32</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* p<.01

Unique variance = 8.88%; Shared variance = 28.12%

R² = .370

Table 6: The sr² statistic represents the proportion of unique variance contributed by each domain. It is calculated as the square of the ‘Part’ statistic that can be requested from SPSS in association with a multiple regression. When this value is multiplied by 100 it gives the percentage of unique variance contributed by the item. Thus, Life is getting easier contributes 0.941% of unique variance within the total 37.0% explained variance for this sample.

### Table A 7: Survey 2 Regression of carer life over the past few weeks on PWI

<table>
<thead>
<tr>
<th>Variable</th>
<th>PWI</th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>B</th>
<th>β</th>
<th>sr² x100</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life getting easier</td>
<td>.72</td>
<td>.29</td>
<td>.45</td>
<td></td>
<td>8.58</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deal with difficulty</td>
<td>.81</td>
<td>.28</td>
<td>.25</td>
<td></td>
<td>1.54</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help in emergency</td>
<td>.43</td>
<td>.36</td>
<td>.33</td>
<td></td>
<td>4.28</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>leave home</td>
<td>.55</td>
<td>.20</td>
<td>.28</td>
<td></td>
<td>2.69</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time for self</td>
<td>.18</td>
<td>.34</td>
<td>.42</td>
<td></td>
<td>6.76</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doing enough</td>
<td>.39</td>
<td>.12</td>
<td>.13</td>
<td></td>
<td>1.17</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* p<.01

Unique variance = 25.02%; Shared variance = 54.88%

R² = .799

Adjusted R² = .735

Table 7: The sr² statistic represents the proportion of unique variance contributed by each domain. It is calculated as the square of the ‘Part’ statistic that can be requested from SPSS in association with a multiple regression. When this value is multiplied by 100 it gives the percentage of unique variance contributed by the item. Thus, Life is getting easier contributes 8.58% of unique variance within the total 79.90% explained variance for this sample.

### Table A 8: Survey 1 Regression of kind of help received on PWI

<table>
<thead>
<tr>
<th>Variable</th>
<th>PWI</th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
<th>7.</th>
<th>8.</th>
<th>9.</th>
<th>10.</th>
<th>B</th>
<th>β</th>
<th>sr² x100</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family/Friends</td>
<td>.24</td>
<td>.04</td>
<td></td>
<td>.05</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3.76</td>
</tr>
<tr>
<td>Help in home</td>
<td>.005</td>
<td>.04</td>
<td></td>
<td>.05</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.05</td>
</tr>
<tr>
<td>Person to talk to</td>
<td>.07</td>
<td>.05</td>
<td></td>
<td>.05</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.23</td>
</tr>
<tr>
<td>Help shopping/trans.</td>
<td>.01</td>
<td>.03</td>
<td>.01</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.05</td>
</tr>
<tr>
<td>Someone paid to help</td>
<td>.09</td>
<td>.15</td>
<td>.12</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.77</td>
</tr>
<tr>
<td>Help to be healthy</td>
<td>.21</td>
<td>.13</td>
<td>.12</td>
<td>.05</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.98</td>
</tr>
<tr>
<td>Additional income</td>
<td>.04</td>
<td>.18</td>
<td>.06</td>
<td>.08</td>
<td>.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.13</td>
</tr>
<tr>
<td>Contact w/people</td>
<td>.08</td>
<td>.10</td>
<td>.07</td>
<td>.12</td>
<td>.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.0001</td>
</tr>
<tr>
<td>Info/Education</td>
<td>.13</td>
<td>.16</td>
<td>.08</td>
<td>.07</td>
<td>.06</td>
<td>.34</td>
<td>.16</td>
<td>.40</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.04</td>
</tr>
</tbody>
</table>

* p<.01

Unique variance = 7.37%; Shared variance = 2.43%

R² = .098

Adjusted R² = .045

Table 8: The sr² statistic represents the proportion of unique variance contributed by each domain. It is calculated as the square of the ‘Part’ statistic that can be requested from SPSS in association with a multiple regression. When this value is multiplied by 100 it gives the percentage of unique variance contributed by the item. Thus, Life is getting easier contributes 8.58% of unique variance within the total 79.90% explained variance for this sample.
### Table A 9: Survey 2 Regression of carer kind of help received on PWI

<table>
<thead>
<tr>
<th>Variable</th>
<th>PWI</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>B</th>
<th>β</th>
<th>sr² x100</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Family/Friends</td>
<td>.25</td>
<td>.22</td>
<td>.22</td>
<td>.22</td>
<td>.22</td>
<td>.22</td>
<td>.22</td>
<td>.22</td>
<td>.22</td>
<td>.48</td>
<td>15.13</td>
</tr>
<tr>
<td>2. Hel in home</td>
<td>-.35</td>
<td>-.35</td>
<td>-.35</td>
<td>-.35</td>
<td>-.35</td>
<td>-.35</td>
<td>-.35</td>
<td>-.35</td>
<td>-.35</td>
<td>-.41</td>
<td>13.40</td>
</tr>
<tr>
<td>3. Person to talk to</td>
<td>.10</td>
<td>.10</td>
<td>.10</td>
<td>.10</td>
<td>.10</td>
<td>.10</td>
<td>.10</td>
<td>.10</td>
<td>.10</td>
<td>.45</td>
<td>0.45</td>
</tr>
<tr>
<td>4. Help shopping/trans.</td>
<td>.038</td>
<td>.038</td>
<td>.038</td>
<td>.038</td>
<td>.038</td>
<td>.038</td>
<td>.038</td>
<td>.038</td>
<td>.038</td>
<td>.17</td>
<td>1.77</td>
</tr>
<tr>
<td>5. Someone paid to help</td>
<td>-.03</td>
<td>-.03</td>
<td>-.03</td>
<td>-.03</td>
<td>-.03</td>
<td>-.03</td>
<td>-.03</td>
<td>-.03</td>
<td>-.03</td>
<td>.07</td>
<td>0.50</td>
</tr>
<tr>
<td>7. Additional income</td>
<td>-.24</td>
<td>-.24</td>
<td>-.24</td>
<td>-.24</td>
<td>-.24</td>
<td>-.24</td>
<td>-.24</td>
<td>-.24</td>
<td>-.24</td>
<td>-.62</td>
<td>23.52</td>
</tr>
<tr>
<td>8. Contact w/people</td>
<td>.11</td>
<td>.11</td>
<td>.11</td>
<td>.11</td>
<td>.11</td>
<td>.11</td>
<td>.11</td>
<td>.11</td>
<td>.11</td>
<td>.07</td>
<td>0.32</td>
</tr>
<tr>
<td>9. Info/Education</td>
<td>.06</td>
<td>.06</td>
<td>.06</td>
<td>.06</td>
<td>.06</td>
<td>.06</td>
<td>.06</td>
<td>.06</td>
<td>.06</td>
<td>.30</td>
<td>0.01</td>
</tr>
</tbody>
</table>

* p<.01

R² = .459

Unique variance = 61.04%; Shared variance = -15.14% Adjusted R² = .202

Table 9: The sr² statistic represents the proportion of unique variance contributed by each domain. It is calculated as the square of the 'Part' statistic that can be requested from SPSS in association with a multiple regression. When this value is multiplied by 100 it gives the percentage of unique variance contributed by the item. Thus, Life is getting easier contributes 15.13% of unique variance within the total 45.90% explained variance for this sample.

### Table A 10: Survey statistics November 2010 to May 2011

<table>
<thead>
<tr>
<th>Month</th>
<th>Total allocations</th>
<th>Accepted</th>
<th>Declined</th>
<th>Not eligible</th>
<th>Not asked</th>
</tr>
</thead>
<tbody>
<tr>
<td>November</td>
<td>42</td>
<td>29</td>
<td>3</td>
<td>7.1%</td>
<td>7</td>
</tr>
<tr>
<td>December</td>
<td>72</td>
<td>43</td>
<td>10</td>
<td>13.8%</td>
<td>45</td>
</tr>
<tr>
<td>January</td>
<td>76</td>
<td>43</td>
<td>6</td>
<td>7.8%</td>
<td>22</td>
</tr>
<tr>
<td>February</td>
<td>69</td>
<td>43</td>
<td>11</td>
<td>12.8%</td>
<td>4</td>
</tr>
<tr>
<td>March</td>
<td>112</td>
<td>91</td>
<td>9</td>
<td>8%</td>
<td>7</td>
</tr>
<tr>
<td>April</td>
<td>76</td>
<td>57</td>
<td>1</td>
<td>1.72%</td>
<td>6</td>
</tr>
<tr>
<td>May</td>
<td>99</td>
<td>91</td>
<td>0</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Totals</td>
<td>568</td>
<td>405</td>
<td>36</td>
<td>6.3%</td>
<td>48</td>
</tr>
</tbody>
</table>

Number of Surveys sent as per Excel Nov-May: 385
Number of 2nd Surveys sent: 53
Number of 3rd Surveys sent: 5
Appendix A2. Carers Questionnaires

National Carer Counselling Program

Longitudinal evaluation of carers' subjective wellbeing – survey questions

September 2010
**Initial well being assessment**

**Form One**

1. Thinking about your own life and personal circumstances please circle the number that best represents how satisfied you feel with your life.

**How satisfied are you with...**

<table>
<thead>
<tr>
<th>Question</th>
<th>very dissatisfied</th>
<th>neutral</th>
<th>completely satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>your life as a whole</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your standard of living</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your health</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>what you are achieving in life</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your personal relationships</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>how safe you feel</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>feeling part of your community</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your future security</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your spirituality or religion (if not applicable)</td>
<td>N/A 0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
2. Over the past few weeks how much do you agree with the following?

<table>
<thead>
<tr>
<th>Statement</th>
<th>completely disagree</th>
<th>neutral</th>
<th>completely agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>As a carer my life is getting easier</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>When an unexpected difficulty happens I can deal with it</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In an emergency I can find help</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is easy for me to leave home and go shopping</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have enough time for myself</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>As a carer I feel I am doing enough</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. Other than you joining the counselling program, has anything else happened to you recently causing you to feel happier or sadder than normal?

Yes happier □ go to question 4

Yes sadder □ go to question 4

No □ go to question 5

4. On a scale from 0 to 10, how strong would you rate this influence?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>
5. Please tick any of the following kinds of help you receive in your caring role on a regular basis

(Tick your choice)

- Help from family or friends
- Someone to help you in your home
- A professional person you talk to
- Someone to help with shopping or transport
- Someone paid to help look after the person you care for
- Someone to help you be healthy
- Additional income
- Contact with people in the same situation
- Information or education

Thank you for your participation. Please return your form in the envelope provided.
Appendix A2: Carers Questionnaire continued

National Carer Counselling Program
An Australian Government Initiative

Second well being assessment Form Two

Thank you for participating in this survey. This is the second wellbeing assessment form of three.

1. Thinking about your own life and personal circumstances please circle the number that best represents how satisfied you feel with your life

<table>
<thead>
<tr>
<th>How satisfied are you with...</th>
<th>very dissatisfied</th>
<th>neutral</th>
<th>completely satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>your life as a whole</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your standard of living</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your health</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>what you are achieving in life</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your personal relationships</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>how safe you feel</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>feeling part of your community</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your future security</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your spirituality or religion (if not applicable circle N/A))</td>
<td>N/A</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>
Appendix A2: Carers Questionnaire continued

2. Over the past few weeks how much do you agree with the following?

<table>
<thead>
<tr>
<th>Statement</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>As a carer my life is getting easier</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When an unexpected difficulty happens I can deal with it</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In an emergency I can find help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is easy for me to leave home and go shopping</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have enough time for myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>As a carer I feel I am doing enough</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. Has anything happened to you recently causing you to feel happier or sadder than normal?

   Yes happier
   □

   Yes sadder
   □

   No
   □

   (if you answered No, you have now finished this item. Please go to question 5)

4. If you answered 'yes' to the last question, on a scale from 0 to 10, how strong would you rate this influence?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>
5. Please tick any of the following which have helped you in your caring role since you started counselling

(Tick your choice)

- Help from family or friends
- Someone to help you in your home
- A professional person you talk to
- Someone to help with shopping or transport
- Someone paid to help look after the person you care for
- Someone to help you be healthy
- Additional income
- Contact with people in the same situation
- Information or education

Thank you for your participation
Please return your form in the envelope provided
Appendix A2: Carers Questionnaire continued

National Carer Counselling Program  
An Australian Government Initiative

Final well being assessment  
Form Three

This is the third and final wellbeing assessment form. Thank you very much for giving us your time to fill in the three forms.

1. Thinking about your own life and personal circumstances please circle the number that best represents how satisfied you feel with your life

<table>
<thead>
<tr>
<th>How satisfied are you with...</th>
<th>very dissatisfied</th>
<th>neutral</th>
<th>completely satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>your life as a whole</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your standard of living</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your health</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>what you are achieving in life</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your personal relationships</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>how safe you feel</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>feeling part of your community</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your future security</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| your spirituality or religion (if not applicable circle N/A) | 0 1 2 3 4 5 6 7 8 9 10 | N/A
2. Over the past few weeks how much do you agree with the following?

<table>
<thead>
<tr>
<th>Statement</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>As a carer my life is getting easier</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When an unexpected difficulty happens I can deal with it</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In an emergency I can find help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is easy for me to leave home and go shopping</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have enough time for myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>As a carer I feel I am doing enough</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. Has anything happened to you recently causing you to feel happier or sadder than normal?

- Yes happier  
- Yes sadder
- No

(if you answered No, you have now finished this item. Please go to question 5)

4. If you answered 'yes' to the last question, on a scale from 0 to 10, how strong would you rate this influence?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>
5. Please tick any of the following which have helped you in your caring role since you ended the counselling

(Tick your choice)

- Help from family or friends
- Someone to help you in your home
- A professional person you talk to
- Someone to help with shopping or transport
- Someone paid to help look after the person you care for
- Someone to help you be healthy
- Additional income
- Contact with people in the same situation
- Information or education

Thank you for your participation
Please return your form in the envelope provided

Carer Feedback Responses
Calls to carers made in Feb 2011 and May 2011.
Calls conducted by: Lisa Burke (Social Worker, Carers Vic.).

A3.1 Preamble

- A random selection of carers who sought counselling from the CVic NCCP, and also consented to participate in the Deakin Carer Wellbeing Survey, were contacted by phone to discuss their experience of the study overall.
- An initial 6 carers were contacted in Feb. 2011, and the remaining 13 in May 2011.
- A total of 21 carers were contacted – of whom all but two consented to provide non-identifying feedback to their experience of the Deakin Study.
- The two carers who declined to respond noted they would be open to participating, but at the time of contact they were very busy, and did not have the time to be involved. They were thanked for their consideration. (one of these two carers requested a call-back, attempting to find time to give feedback – but was again busy in her caring role at the time of the second call.)
- Feedback calls were completed with 10 carers who had commenced counselling, and had received Deakin Study One. ie these carers were spoken to whilst they were still receiving counselling.
- Feedback calls were completed with 9 carers who had completed counselling, and had been sent Deakin Study Two (together with the CVic Counselling Feedback Form). These forms were sent approx. 3 weeks after their final counselling session.
- ie A total of 19 carers have provided feedback to their perception and experience of the Deakin Carer Wellbeing Survey.
- At the time of this survey review being documented, only 3 carers have reached the three month post counselling point (at which Deakin Survey No. 3 is issued). All three only reached this period in May 2011. None have been contacted as yet for their feedback. It may be beneficial to review a number of carers who have been sent DS 3, being 3 months post their last counselling session – to identify if their impressions and feedback are similar or different to that noted todate.

A3.2 Core Data - as an aid to summarising trends.

Carers who recalled discussing the Deakin Study at the time of their Counselling Intake discussion with the CCAS at CVic:
DS Recalled: 6
DS Not Recalled: 10 (one carer stated he felt 'too traumatised' by his life issues, to remember the conversation at all).
Preferred to discuss Counselling related issues: 2
Not sure: 1

Carers who recalled giving verbal consent to participating in Deakin Survey:
Recalled given consent: 6
No recall of giving consent: 9
Not sure: 1
Not discussed: 3 (generally as wishing to discuss counselling related matters).
Appendix A3: Review of Victorian Pilot study: 30/5/2011 continued

Carer’s experience of receiving DS 1 (sent to all 19 carers)
Carer recalls receiving Deakin Study One: 17
Carer does not recall receiving Deakin Study One: 1
Not sure: 1

Carers who stated they have completed and returned DS 1:
Yes: 10
No: 4 (1 – lost survey; 1 – moved home; 1 – ‘too traumatised’ to focus on; 1 – DNA first appt; )
Not sure or not open (or timely) to discuss: 5

Carer’s experience of receiving DS 2

Note: only applicable to 9 respondents.

Carer recalls receiving Deakin Study Two: 3
Carer does not recall receiving Deakin Study Two: 5
Not sure / not known: 1
(Note: 5 carers requested CVic re-send DS 2 – due to a wish to participate in the study. Only one carer stated he did not wish it resent, as his life was too busy.)

Carers who stated they have completed and returned DS 2:
Carer stated they completed and returned DS 2: 2
Carer stated they did not complete and return DS 2: 4
Carer advised survey still to be completed and returned: 1 (carer stated he wished to reflect more on his experience, before sending the survey back).
Not stated/ Not known: 2

CVic Counselling Feedback Form (CFF)

Note: only applicable to 9 respondents (as CFF sent with DS 2)

Carers who stated they have received the CFF: 3
Carers who stated they have not received the CFF: 3
Not sure: 3

Carers who stated they completed and returned the CFF: 2
Carers who stated they did not complete and return the CFF: 3
Not yet completed, but planning to: 1 (carer: ‘I wish to think more about it’.)
Not stated / not known: 3

Note: the apparent low return rate of the CFF may be overcome if it is sent separately to the carer (rather than in the same mail as DS 2).

Consideration of Inclusion of a Voucher with mailed surveys:
Exploring carer perception of if / how this may impact on their response to the survey/s.
Note: This question was not asked of the 6 carers in Feb 2011 feedback calls.

Carer states a ‘gift voucher’ would motivate them to complete and return surveys: 3 *
Carer states a ‘gift voucher’ would be appreciated very much, but not likely to influence whether they completed the survey/s: 3 **
Carer states a ‘gift voucher’ would have no impact on them: 2 ***
Appendix A3: Review of Victorian Pilot study: 30/5/2011 continued

* One carer stated: “We all like something for free … yep, that would be good.”
Another said: “Yes, that would be good. People enjoy those things.”
A further carer noted: “Yes, an excellent idea” – both as an ‘incentive’ to completing surveys; but also emphasising he would experience it as an ‘acknowledgement’ to carers of the help they provide, as well as being a reminder of the importance to look after their own needs (not solely focusing on the CR.)

**
One carer suggested that a ‘gift voucher’ could help carers who are ‘time poor’ to ‘prioritise’ making time to participate in the survey.
Another stated: “I’m all for giving feedback for programs, so wouldn’t be influenced by a voucher… but I wouldn’t knock it back either.”

***
One carer stated: “No, I would not want any form of encouragement; carers will respond because they want to help CVic to improve their service and its quality – and wouldn’t be enticed by anything.” She further stated: “.. the survey is a chance to say ‘thank you’ if the help has been valued; or to try and suggest ways to improve the service.”
Another proactively stated she would ‘love to be part of our research’.

Additional Data Relating to the Deakin Study and Carer Response Trends

DS 1 – 10 respondents
DS 2 – 9 respondents

**Respondents who sought telephone counselling support at time of feedback call:**
Carers who had been sent DS 1: 6
Carers who had been sent DS 2 (and CVic CFF): 2
Total number of carers who sought telephone counselling support: 8

Note: it is suggested that carers – whilst in the process of receiving counselling – are often in a state of stress/crisis in their lives: and therefore any contact made needs to respect and be able to respond to this in a timely and professional manner.

**Respondents who sought services/information at time of feedback call:**
Carers who had been sent DS 1: 7
Carers who had been sent DS 2: 4
Total Number of carers seeking telephone support relating to services/info – 11

**Respondents who sought both Counselling and services/information at time of feedback call:**
Carers who had been sent DS 1: 6
Carers who had been sent DS 2: 2
Total number of Carers who proactively sought guidance on services/information: 8
A3.3 Responses and recommendations

- It is noted that all carers contacted as part of this review were very willing and positive in offering their time and feedback to CVic. Several commented that they viewed this type of research as very important to organisations such as CVic and also to themselves (ie by providing data to funding bodies, the carer sees they are able to have direct input to the needs of carers, including someone in their own situation.)

- It is also noted that, whilst carers in this review tended to have a low recall of discussing the Deakin Study, the actual stated recall of return rates for DS 1 was very high (17 of 19 carers).

- No carers conveyed any negativity to being asked for their thoughts and opinions – despite our knowing that carers are often overwhelmed with multiple life pressures.

- Note: the initial cover letter sent to carers with DS 1 was modified after the first set of feedback calls in Feb 2011 – to assist with a more succinct and clear message.

- Several carers commented that their responses – be it to DS 1, 2 or the CVic CFF – could be easily influenced by their ‘mood’ on the day of completing the form. It is noted that this could be potentially distorting of any data which seeks to gain a perspective of change in carer wellbeing, per counselling, ‘over a period of time’. See * below for comments and suggestions in relation to this.

- One carer requested less response options, stating 0 -10 allowed for too many choices. Her stated preference was for three choices of response: poor, satisfactory, or excellent.

- The response rates of DS 2, and the CFF, appear overall lower than those of DS 1. A number of carers had no recall of both surveys (ie DS 2 and CFF) being received together – suggesting that one option would be to forward them independently, to ensure a clearer understanding that they are each part of a different survey / review process.

- In contacting carers, particularly on matters that invite them to reflect on a research study relating to their personal wellbeing, it is essential the person initiating the call has the time, sensitivity and professional orientation to ensure a compassionate, appropriate and clinically supportive response to whatever issues are raised by the carer. ie.it would be unethical to open such discussions, without at the same time offering the carer an option to be supported at that time in the way most appropriate to their expressed needs. This can often mean that questions about the survey process need to be ‘put aside’, so that a ‘counselling’ conversation can be prioritised (at times, this can also require crisis counselling, where the carer or CR is highly distressed and/or at risk to self or others.) . This point particularly applies to contact calls made to carers who are still in the counselling process – given that many of their concerns are still very ‘active’ and ‘raw’.

- Further, the caller needs to be able to respond with both a counselling perspective and an understanding of the core services and resources that may be important to carers should they be in need of them.

* As one carer said, are you wanting my response ‘at the time of completing the survey’, ‘or overall how I am feeling’?

Note: Recommended changes to DS cover letters, and the Deakin Survey are detailed in: Appendix A: Recommendations for Changes to Deakin Study cover letters.
A3.4 Counselling Process – Responses and Recommendations

(as arising via the DS Carer Feedback Process)

Carer Appreciation of the NCCP

Many carers proactively offered positive feedback about their experience of counselling, including the following:

- One carer stated that 'I got my confidence (as a carer) back' and 'came to understand the need for a respite plan'.
- Another volunteered that 'the counselling was great ... just wonderful. They (the C/C's) do their job unbelievably well.' She later added: 'I don't know what I would have done without it.'
- One male carer noted that he had previously attended a number of counsellors seeking help – prior to contact with the NCCP – and had never before felt understood and assisted as he did with the CVic program. As he stated, he felt strongly 'validated' – for the first time – in his role as a carer to his wife /CR (who has a severe mental health condition). He further noted that, via the counselling process, he was able to reach an understanding that the behaviours he experienced being subjected to by the CR were 'abusive', and that it was 'legitimate' to make significant life changes as a result – without guilt or a sense that he was in any way doing 'the wrong thing'.
- Another carer, whose CR had died resulting in the carer now living an isolated life, commented that the contact from CVic (in following up re the DS) showed him a sense of caring: “I'm not alone: someone is thinking of me.” He added that this particularly mattered, given that 'the counselling has finished'.

Carer Feedback on the NCCP

- Strongly positive feedback was received by most carers spoken to, emphasising how important it is for them to speak with qualified counsellors who understand their needs from the carer perspective. Many also wished to convey to CVic that this is a rare experience (ie to be understood as a carer). Others noted it enabled them to adjust to their carer challenges, in ways that had not previously been possible when consulting with 'non-carer' specialised counsellors.
- A request was made by some carers that CVic seek to further 'educate' other counselling agencies to support them in bringing a more defined 'carer perspective' to their work. (eg another telephone help line was mentioned – whereby the carer mentioned not being acknowledged by the counsellor as a 'carer' when he called, and thus not responding to him with a carer perspective that enabled him to be supported in his carer concerns – despite his clear wish / intent in calling that this be provided ).
- Whilst all carers spoken with were firmly appreciative of the free, 6 session counselling sessions provided by CVic, many noted that they felt a definite need for the program to be extended as needed to allow for further sessions. Two principal examples were given: firstly, that six sessions is not sufficient *; and secondly, that the requirement to access the allocated six sessions within a 6 month time frame is not viable for all carers (some preferring to spread the sessions further across time, thus using a counselling appointment on an 'as needed' basis).
- Another carer noted that she had responsibility for two CR's, each generating different demands upon her as a carer – and asked in such situations if it would be an option to 'allocate' two sets of counselling to the carer, given she was dealing with two caring relationship concerns.
* One Carer volunteered that the NCCP was ‘very good’ – but qualified it by saying that ‘it was just a start ... more of an introduction.’ She stated that through the six sessions, she was able ‘for the first time, to realise others (ie other carers) have similar issues.”. She also noted that the NCCP highlighted for her that there are specific problems in caring for an elderly person (as she is): ‘you tend to lose yourself’. She emphasised that she saw this as significant risk factor for carers such as herself: if all one’s time is spent caring, and the CR dies. ‘you’ll end up with no life, no sense of self.’ ‘This would be terrible – I can’t let it happen.’ Her concluding comments were that the NCCP assisted her to begin this establishing of a more sustainable perspective, but did not provide the number of sessions needed to anchor it for her.

• Whilst many carers noted that they were able to obtain some ‘ongoing’ counselling by consulting with medicare registered counsellors (including a number who are also contract counsellors with CVic), it was noted that the process of obtaining counselling support per CVic was much more accessible than that of the medicare counselling program. As one carer indicated: the CVic counselling program is free; easy to be assessed for; and quick to access the first consultation – with the special benefit of counsellors being ‘carer educated’ in their understandings and recommended interventions. By comparison, she noted the medicare system is problematic – needing to see a doctor; complete a health care plan; often wait several weeks for an appointment; incur a gap fee; – and most critically (unless the counsellor is carer educated) to receive counselling that is not necessarily aligned to or understanding of the carer perspective. ie Are we using another service (medicare counselling) as a default service – which may in a number of instances lack the professional orientation / knowledge base needed to respond to carer focused counselling.

• At this time, with the NCCP limited to 6 consultations, many carers expressly noted the benefits (where CVic could not offer further sessions) of being able to see a Contract Counsellor who is medicare registered. There was a clear recognition that the caring journey is often a stressful, lengthy and complex one – and that longer term counselling is needed. Given this, where a relationship of trust and ‘carer understanding’ has been created within the six sessions of the NCCP, many carers felt that the medicare option with a C/C enabled them to maintain the benefits of a valued relationship – and not need to ‘begin all over again’ with another counsellor.

• Whilst noting the benefits of C/C’s with medicare registration, a number of carers remained ambivalent about accessing this option – due to lack of knowledge and/or concerns about the cost of the service: and particularly the cost they may incur in the ‘gap fee’ between the C/C fee and the rebate per medicare. (See section below titled: Appendix B: Recommendations for Contract Counsellors and Medicare Registration.) Other carers expressed ambivalence about asking the C/C about their fee structure; if they were eligible for any fee reduction; and if ‘fee gap’ was negotiable. In a number of instances, CVic (per the DS feedback process) provided ‘coaching’ to carers on how to explore this conversation with their C/C (rather than letting counselling lapse – as was occurring in a number of instances).

Eligibility for the NCCP

• It appeared that there is some variation of understanding within CVic as the ‘service provider’ for the NCCP in terms of carer eligibility for receiving counselling – when the carer is concurrently receiving other counselling.

• More specifically; if a carer is concurrently receiving counselling, are they eligible for the NCCP? Various thoughts within the team have been expressed: no, not if other counselling is currently being provided to the carer at the same time; yes, if the concurrent counselling is not carer oriented.

• One carer noted that she chose not to tell CVic (at the time of the counselling intake process) that she was currently receiving counselling (which has been long term, and ongoing) from a psychiatrist – as she did not wish to be precluded from the NCCP. As she stated: ‘I didn’t let on that I have a regular psychiatrist that I have been seeing for several years ... as I wanted to
Appendix A3: Review of Victorian Pilot study: 30/5/2011 continued

gain a different point of view.” She further noted that her experience of the NCCP did provide her with her hoped for alternate ‘carer focused’ perspective – and that she now felt able to continue with her psychiatrist with a more comprehensive perspective on dealing with her life as a carer.

NCCP - and - Post Counselling Carer Review

• In a number of DS feedback calls, it was noted that carers appeared to benefit from being able to reflect/review any current or ongoing concerns they had – both during the counselling process and after the NCCP sessions had concluded. This particularly appeared to apply to information and services that are available to support carers – including core service such as respite services; the medicare counselling program; condition specific supports (for both the carer and the CR) *

* One carer noted she suffered from severe chronic pain – but had no recall of discussing this within counselling as a need to be addressed (eg per a referral to a Pain Management Centre, if appropriate, per her GP). Another carer spoke of having no informal support to help him with the CR, from extended family – due to their stigmatising beliefs around the mental health condition of the CR. Despite this, the carer had no knowledge of any support services (eg AREFEMI) that may benefit both the carer and the extended family in gaining knowledge that could potentially overcome both information and attitudinal barriers - thus opening the door to generating enhanced ‘informal supports’ for the CR and the carer.

• More specifically: in conversation with carers it appeared that many had either utilised the NCCP to focus primarily on emotional issues (and not explore complimentary services / support options that may assist them to ‘anchor’ their counselling goals); or had forgotten ideas / suggestions raised in counselling for them (as carers) to action post counselling. * In other instances, cares spoke of not feeling a sense of ‘entitlement’ to access further support (beyond the NCCP); whilst many others were very unclear about their personal eligibility for various services. **

* It is recommended that some process of review be considered, to ensure that core ideas and plans are implemented – rather than ‘lost’ in the often overwhelming busyness of carer’s lives. (see below for Contract Counsellor feedback comments).

** It appeared that many carers could benefit from a brief ‘coaching’ / ‘case management’ / ‘carer support worker’ review process at the end of their NCCP – to review services / actions that the carer views as beneficial (whether such ideas were raised by the C/C or not); and to support the carer to implement such actions (with a focus on ‘coaching’ the carer to support an ‘empowered’ approach to service entitlement; together with ‘advocacy’ as needed where the situation warranted such intervention.).

Contract Counsellor – Role Clarification.

• Whilst C/C’s will understand that a first counselling session primarily involves ‘assessment’ (rather than ‘intervention’), a number of carers were confused that ‘things were no different’ after the first appointment. It may be helpful for C/C’s to help explain to carers the process of assessment, intervention, and closure (the latter preferably including some level of action plan, as appropriate to the carers needs and identified issues, which with consent could be integrated into a carer review process.).

• In speaking with many carers, it appeared that there was a perceived variation in the ‘role’ taken by Contract Counsellors in their counselling sessions with carers.

• More specifically: it seems that C/C’s vary – from those who appear to see their role as primarily focusing on the provision of emotional support to the carer (an acknowledged core
Appendix A3: Review of Victorian Pilot study: 30/5/2011 continued

role) – through to C/C’s who (in addition to the former) proactively recommend services, engage in advocacy as needed, and where appropriate liaise with CVic for case review to ensure optimal outcomes for the carer.

Nb: it is noted that the above comments are based on carer perception – and may vary from the C/C recall of the counselling process and their role within this.

• It is also noted that a number of C/C’s appear unclear of their agreement with CVic to provide direct feedback to the CVic Program Manager of specific changes in carer situations: including FTA first appointment; or discontinuation of counselling (after commencement).

(see CC Induction Document: “NCCP (CVic): Procedure Manual for Accredited Counsellors. Pg. 2. ‘Standards’: “If for any reason a carer decides not to proceed with counselling, or the designated counsellor cannot follow through with a referral, it is the contracted counsellor’s responsibility to inform the Program Manager and return paperwork within seven days so that, where appropriate, the carer may be re-referred to an alternative provider within the program.”

A reminder to C/C’s of this agreement is recommended.

Early feedback by the C/C to CVic likely would have benefited one carer who moved from one regional town to another in Victoria, after her first counselling appointment. Her understanding was that the C/C suggested that the carer (not the C/C) phone CVic to enquire if she could be re-referred to another C/C in her new home town. However, the carer was overwhelmed by the stress of moving home, and also unclear if she was eligible to see another CVic C/C (ie unclear about program eligibility; ), so took no action.

The outcome of this was that CVic had no knowledge of this change of circumstances for the carer – with the outcome that the carer was not re-allocated in a timely manner (despite proactively indicating in the DS feedback conversation that her need for carer counselling support remained at a high level.)

Note: Following this review, the CCAS arranged a new allocation as a matter of urgency.

In another instance, a carer FTA her first appointment – due to a series of significant misunderstandings at a range of levels. No notification of this was provided by the C/C to the CVic Program Manager - until the return of the ‘Case Closure’ form (nor was any direct phone liaison initiated between the C/C and the carer – which raises concerns where carers may FTA for reasons such as an increase in the level of stress / trauma they are experiencing, and the potential ‘duty of care’ in at least clarifying if the carer does / not require counselling assistance.

Note: Following this review, the CCAS re-allocated this carer for counselling.

A3.5: Recommendations for Changes to the Communication Processes

For Consideration

• It is noted that the initial cover letter from Deakin / CVic– with DS 1 - states as follows: “You will be asked to answer some questions such as how satisfied you are with your health, your life as a whole and your standard of living.” Whilst implied, it does not include words such as: ‘over the last few weeks, prior to when you commenced your first counselling appointment from Carers Victoria’. Even the term ‘your life as a whole’ has the potential to be interpreted by some carers to mean ‘how I am feeling about my life as a whole at this moment’.

• Following through with this concern, it is noted that Question 1 of the actual DS survey form does not include any wording such as ‘in the few weeks prior to commencing counselling’. It is quite plausible that respondents may therefore be pre-disposed to answering questions 2-5 of the Deakin Survey (of which all questions do make reference to responses across a period of time) with a ‘preset state of mind’ by responding ‘in the here and now’ – and thus possibly prejudice the accuracy of their responses. (eg if they answer some / all of the
questions according to the ‘mood of the moment’ – which may be positive or negative – rather than a more representational response of how they are feeling over a period of weeks.)

- Further addressing this issue, the DS 2 Cover Letter, which also includes the CVic Carer Feedback Form, has very limited reference to the underlying principles of the Deakin Study. The cover letter solely states: ‘If you have agreed to participate in the Carers Australia and Deakin University survey: the second part of the survey is enclosed for you to complete and return directly to Deakin in the reply paid envelope.” (no further reference is made to the DS, or its protocols in this letter). The following points are noted:

- An additional statement in the cover letter to DS 2 may be useful, such as: “This Second Carers Wellbeing Survey is being sent to you, now that you have completed your counselling sessions provided by Carers Victoria.” (ie putting some context around the survey and its timing in relation to the counselling process.)

- An optional further sentence to consider for inclusion in the DS 2 cover letter is: “Please answer each question, in terms of how you are now experiencing your life in the few weeks since your counselling sessions have finished. This allows for a comparison of how your life is overall now for you, as compared to prior to when you commenced attending counselling sessions from Carers Victoria.”

- A further optional sentence to include in the DS 2 Cover letter is: “Thank you for taking the time to complete and return this second Carer Wellbeing Survey. As you will be aware, you will receive a third and final Carer Wellbeing Survey – in approximately three months time from when you attended your final counselling session. We appreciate if you are able to likewise complete this survey - again from the perspective of how your life is overall, reflecting on how things were for you before you commenced counselling with Carers Victoria, to how you are now overall experiencing your level of wellbeing as a carer.”

- And, as above, with Deakin Survey 3 – whilst the cover letter is more comprehensive, there is no reference / reinforcement of the key message: to please respond ‘according to how your life has been, overall, in the few months since your last counselling session’. This could potentially be reinforced by noting: “Please ensure each question is answered from this broader perspective: ie – How your life is overall, in the months since counselling ended.” (It is suggested that a second sentence – if valid in terms of research methodology – would help ‘anchor’ the principle the DS is trying to convey. Often, in reading something twice – ie the same concept, stated slightly differently – the thought seems to become more strongly embedded in our mind.)

A3.6: Recommendations for Contract Counsellors and Medicare Registration.

It is noted above that many carers seek to access – given the current limitation of 6 counselling sessions per the NCCP – the medicare counselling program as the next preferred option for ongoing counselling support.

Given this, it is suggested that CVic CCAS may benefit in obtaining the following information from C/C’s – with the understanding that they consent for such information to in turn be made available as requested to carers (both at the time of allocation; and after they have utilised their 6 NCCP sessions and are seeking further support):

- Is the C/C medicare registered? If not, are they open to obtaining this registration?
- If medicare registered, what is the cost under this program of a private counselling appointment with the C/C – for a carer who previously been referred to the C/C per the CVic NCCP and also for carers who are ineligible for the NCCP (but would benefit from a carer orientated C/C)?
- Where the carer is seeking to have ongoing counselling with the CVic referred C/C, and is experiencing financial hardship (including but not limited to being a CentreLink recipient) – does the C/C offer a ‘no-gap fee service’ (ie the equivalent of bulk billing). If not, does the
C/C offer a scaling of fees according to the carers ability to pay – and if so, details of the fee schedule.

- Does the C/C consent for CVic to record the above on CASSI – so that this information can be made available to carers on an as needed basis (thus removing the necessity for the carer to negotiate personally with the C/C on a case by case basis)?
Appendix A4. Logistics

Action flow chart

Carers Association distributes survey and maintains participants records

Carers send survey to Deakin Uni

Deakin University sends analyses to Carers Australia

Carers Australia analyses data

Analyses returned to Carers Association

Co-publish

Australian Government Department of Health and Ageing

Local feedback
### Responsibilities

<table>
<thead>
<tr>
<th>Carers Australia</th>
<th>Association</th>
<th>Deakin University</th>
</tr>
</thead>
</table>
| Oversight project| Change NCCP intake  
- Recruit carers to survey  
- Record carers details | Receives and analyses data |
| Funding | Mail outs x 3 | Co-publish outcomes with Carers Australia |
| Supply project training to Association | Create and maintain data lists of carers x unique identifier | Supply data analyses to Carers Australia |
| Supply project coordinator  
- Liaises with Association on project issues  
- Liaises with Deakin University on project issues  
- Liaises with funder DoHA | Recommend changes to collection processes if needed | Provide expertise on and recommend changes to collection processes if needed |
| Develop, print and supply survey forms | | Constructs the first draft of the report |
| Return data analyses to Association | Have contact person for project | |
| Supply data analyses to DoHA | Use new carer feedback form instead of Form D | |
| Co-publish data outcomes with Deakin University | Decide and test best local use of data, eg care and counsellor feedback | |
Appendix A5. Ethics and Letters of Contact with Carers

A5.1 Ethics approval

Human Ethics Advisory Group – Faculty of Health, Medicine, Nursing and Behavioural Sciences
221 Burwood Highway,
Burwood Victoria 3125 Australia
Telephone +61 3 2517174
Facsimile +61 3 9251 7425
hmnbs-research@deakin.edu.au

Memorandum

To Prof Robert Cummins
Date 3 December, 2010
School of Psychology

From Secretary – HEAG-H
Faculty of Health, Medicine, Nursing, and Behavioral Sciences

HEAG-H 135/10: Carers subjective wellbeing longitudinal evaluation - effect of counselling
Approval has been given for Prof Robert Cummins, School of Psychology, to undertake this project for a period of 1 year from 3rd December 2010.

The approval given by the Deakin University HEAG-H is given only for the project and for the period as stated in the approval. It is your responsibility to contact the Secretary 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 that have been requested by other Human Research Ethics Committees

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.

HEAG-H 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). An Annual Project Report Form can be found at http://www.deakin.edu.au/research/admin/ethics/human/forms/ which you will be required to complete in relation to this research. This should be completed and returned to the Administrative Officer to the HEAG-H, Dean’s office, Health, Medicine, Nursing & Behavioural Sciences, Burwood campus when the project is completed.

Good luck with the project!

Steven Sawyer
Secretary
HEAG-H
Cc Mr Peter Campbell
A5.2  SCRIPT for asking carers to participate

Would you like to take part in a survey to improve the Counselling Program? The survey is completely voluntary. Whether you say yes or no won't affect the service you get from the Program.

The survey is about your wellbeing. It will take about 10 minutes. You will be asked to do it three times over the next few months and it is filled in at home. You do it once before you come to counselling, once three weeks after you finish, and again three months after you finish. It is confidential and you don't put your name on it.

The information you provide helps us make sure the Program is meeting yours and other carers' needs.

If you agree to take part in this survey a questionnaire will be sent to your home address in a stamped, addressed envelope each time. When you've filled it in, you forward it to Deakin University who condense it into research data with other carers' responses and analyse the results to see if counselling helps carers. If you decide to withdraw, just stop sending the forms. Withdrawing will not affect the service you get.

We will also ask you for feedback about the service you got here on a separate form after you have used the Counselling Program. Please send that feedback back to us at Carers Victoria, not to the university.
Dear Friend

Carers Australia and Deakin University are recording the experience of carers who use the National Carer Counselling Program. We are seeking to document the wellbeing of carers just like you. We want to know how you feel about your health, the help you can get, how you cope and related matters. The results will tell us how well the National Carer Counselling Program is working.

We invite you to contribute your experience to this study.

How to complete this survey

- We have sent you this letter and the first questionnaire. There is also a reply-paid envelope to post the completed questionnaire to Deakin University.
- The questionnaire should take you about 10 minutes to complete. You will be asked to answer some questions such as how satisfied you are with your health, your life as a whole and your standard of living.
- There are no right or wrong answers, just fill it in as best you can.
- We will send you two more questionnaires after your counselling sessions:
  - one three weeks after completing counselling
  - another three months after completing counselling.

If for any reason you feel distressed by anything asked in the survey, please call the Carers Victoria Advisory Line on 1800 242 636 from 8.30am to 4.30pm, Monday to Friday. After hours, please call Lifeline on 13 1114.

Some important points about participating

- You are free to participate or not as you wish. You may withdraw at any time.
  - if you withdraw after posting, any responses you have posted will be used in the overall analysis.
- When you return the questionnaire we assume you are doing so willingly
  Your returned questionnaire is entirely anonymous so please do not include any identifying information. Your answers will be entered into a database and only the combined data will be examined. The database is securely stored electronically at Deakin University and will only ever be used for this Carers Project and academic research.

The chief researcher on this project is Professor Bob Cummins from the Centre on Quality of Life at Deakin. His team, in partnership with Australian Unity, measures the wellbeing of the Australian population on a regular basis. You can read their reports at: http://www.deakin.edu.au/research/acqol/index_wellbeing/index.htm. For further details of the study, please contact Professor Cummins on 03 92446845

Should you have any concerns about the conduct of this research project, please contact the Secretary, Ethics Committee, Research Services, Deakin University, 221 Burwood Highway, BURWOOD VIC 3125. Tel (03) 9251 7123 (International +61 3 9251 7123).
A5.4 Initial letter following referral

Dear

This letter confirms your referral to the following counsellor through Carers Victoria's Carer Counselling Program:

Counsellor details:

The Carer Counselling Program provides you with up to six counselling sessions, over the next six months, relating to the experience and impact of your caring role. Counselling aims to provide a supportive, safe and neutral space in which to express and reflect on your feelings and issues, with a view to managing your specific situation more comfortably. Your counsellor will talk to you about what you hope to achieve from counselling when you first meet, and answer any other questions you might have.

If you initially agreed to participate in the Carers Australia and Deakin University survey, the first part of that is enclosed for you to complete and return directly to Deakin in the reply paid envelope. You will receive the second and third components of this survey after your counselling sessions are completed.

Also enclosed are the Carer Counselling Program and Rights and Responsibility brochures for your information. When your case is closed at the end of six sessions, we will send you a questionnaire so you can also provide some direct feedback to Carers Victoria about your counselling.

We hope that your experience of using the Carer Counselling Program will support and assist you in your caring journey. If at any stage you wish to discuss your counselling directly, or have any concerns or queries, please call Carers Victoria on 1800 242 636 between 8.30 and 4.30 Monday to Friday.

Warm regards

Ruth Rechner
Program Manager
Carer Counselling & Advisory Service

If you have any other information or support needs, you can call the Carer Advisory Service on 1800 242 636 between 8.30 and 4.30 Monday to Friday
A5.5 Second letter following completion of counselling

Dear (hand write name)

We are writing to you about your recent experience of counselling through Carers Victoria’s Carer Counselling Program.

Your case has now been closed and we have received a brief summary from your counsellor about what you worked on through the counselling sessions, your current situation, and any ongoing supports recommended. If you were originally referred by another service provider we will advise them that your counselling sessions have now been completed, but we do not pass on any other details to them.

If you have agreed to participate in the Carers Australia and Deakin University survey:

• The second part of the survey is enclosed for you to complete and return directly to Deakin in the reply paid envelope.

Whether or not you are a part of that survey:

• Your feedback about the program and the service you received from Carers Victoria is equally important to us. It helps us review and improve the quality of services to carers, ensuring that the Carer Counselling Program is meeting your needs.

For this purpose a specific questionnaire is enclosed for you to provide some direct feedback to Carers Victoria about your counselling experience. You have the choice of providing this information anonymously, or you can add the details of yourself and/or your specific counsellor. Please feel free to indicate both positive and negative aspects of your experience. If you would prefer to complete the form online, please use this link.


We hope that your experience of using the Carer Counselling Program has supported and assisted you in your caring journey. We look forward to hearing back from you.

Warm regards

Ruth Rechner
Program Manager
Carer Counselling & Advisory Service

If you have any other information or support needs, you can call the Carer Advisory Service on 1800 242 636 between 8.30 and 4.30 Monday to Friday
A5.6 Program feedback form

National Carer Counselling Program
An Australian Government Initiative

Program Feedback form

This form allows you to tell us what you thought of how we run the Carer Counselling Program. It is confidential and your identity will be hidden.

1. How long have you been in contact with the counselling program?

- Less than 6 months
- 6 - 12 months
- More than 12 months

2. Overall, how satisfied were you with the counselling program?

<table>
<thead>
<tr>
<th></th>
<th>Very dissatisfied</th>
<th>neutral</th>
<th>completely satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>The waiting time for your first appointment</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How easy it was to contact or get to the service</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Affordability</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

3. Do you feel that...

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Tick your choice)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your counsellor understood your needs?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>You had an opportunity to participate in decisions about the counselling?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The counselling you received helped your situation?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. What type of counselling did you receive?
Appendix A5: Ethics and Letters of Contact with Carers continued

(Tick your choice)

Face to face  

Telephone  

Web-based  

Group  

Tele-group  

5. Did this type of counselling meet your need?

Yes  

No  

If No, what would you prefer?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

6. How can we improve our program?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
7. Would you recommend this program to others?
   - Yes □
   - No □

Please tell us why

8. Would you use this program again?
   - Yes □
   - No □

Please tell us why

9. Do you have any other general comments about the counselling program?

Name of counsellor (optional)

Thank you for your participation
Please return your form in the envelope provided
A5.7 Final letter 3 months following counselling

Dear Carer

I am writing to you because you agreed to participate in the Carers Victoria and Deakin University evaluation of the Carer Counselling Program.

The third and final part of the survey is enclosed for you to complete and return directly to Deakin in the reply paid envelope.

Thank you for participating in the survey, and we hope your experience of using the Carer Counselling Program has supported and assisted you in your caring journey.

Warm regards

[Signature]

Ruth Rechner
Program Manager
Carer Counselling & Advisory Service

If you have any other information or support needs, you can call the Carer Advisory Service on 1800 242 636 between 8.30 and 4.30 Monday to Friday