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Position Statement

A new language for diabetes

Improving communications with and about people with diabetes

Summary

- Diabetes is the fastest growing chronic condition in Australia, affecting 1.7 million Australians. It is a progressive condition, which can reduce both quantity and quality of life, and requires daily self-care. On average, people with diabetes have higher levels of emotional distress than those without diabetes. Distress can continue throughout life with diabetes.
- The way language is used – both verbal and written – reflects and shapes our thoughts, beliefs and behaviours. Language has the power to persuade, change or reinforce beliefs, discourse and stereotypes – for better or for worse. Words do more than reflect people’s reality: they create reality.
- Language needs to engage people with diabetes and support their daily self-care efforts. Importantly, language that de-motivates or induces fear, guilt or distress needs to be avoided and countered.
- Diabetes Australia believes optimal communication increases the motivation, health and well-being of people with diabetes; furthermore, that careless or negative language can be de-motivating, is often inaccurate, and can be harmful.
- The aim of this position statement is to encourage greater awareness of the language surrounding diabetes, and identify potential improvements.

“Words are, of course, the most powerful drug used by mankind”

Rudyard Kipling

The power of language

People are sensitive to the implications of the words and phrases used to describe, categorise and label aspects of their identity; language can define them and their health. Language, and the attitudes it reflects, can affect self-confidence and motivation, and influence health and well-being directly or indirectly. Certain words and phrases can be de-motivating, inaccurate or even harmful. So, when communicating with and about people with diabetes, it is important to consider how your choice of language could affect their thoughts, feelings and behaviours.

Diabetes Australia recommends using language that encourages positive interactions, and positive outcomes when the person with diabetes leaves the interaction. Careful use of language applies equally to the conduct of health services, health professionals, family, friends and colleagues of people with diabetes, and the media. Furthermore, people with diabetes may do themselves a disservice if they also use negative language.

Language can be inaccurate and harmful

Health professionals and family members, in particular, are in a position to influence people with diabetes positively or negatively. Sometimes, the language used can be inappropriate. Talking about 'good', 'bad', and 'poor control', people 'failing' to adopt certain self-care activities and/or being 'non-compliant' implies that:

- 'following orders' will result in perfect blood glucose levels all the time;
- the person with diabetes is acting irresponsibly or being 'difficult'.

Use of the terms '(non-)compliant', '(non-)adherent' is particularly problematic. Such terms characterise the individual as cooperative or uncooperative, especially when used as adjectives to describe the person rather than the behaviour. Using these labels can mean opportunities are lost to ask relevant questions, develop collaborative goals, tailor treatment regimens and make referrals that actively support the person to manage his or her diabetes. Attempts to increase 'compliance' and 'adherence' generally involve persuading the person with diabetes to change his or her behaviour to fit the health professional's agenda.

Such attempts at persuasion can disregard the beliefs, priorities, preferences, skills and constraints of the individual or their life situation. Focusing on these issues is often the key to improving management plans and outcomes. For example, individuals labelled as 'non-compliant' may simply be exercising their right to make alternative rational decisions that are consistent with their explanatory models, experience, health capability, outcome goals or lifestyle. For example, people with higher blood glucose levels may be making active (but perhaps, silent) decisions to avoid hypoglycaemia. Conversely, those who experience recurrent severe hypoglycaemia may do so because they believe it will prevent them developing long-term complications. Such actions may well be consistent with the advice they received at diagnosis or over many years.

Language can reveal negative attitudes

The language used when discussing 'compliance' can reveal attitudes that:

- ▶ regard the person with diabetes as a passive and submissive recipient of care, who should follow the prescriptions of health professionals or services;
- ▶ define the person as 'weak-willed' or 'difficult';
- ▶ dismiss the challenges the person with diabetes

faces as he or she tries to reconcile conflicting and contradictory information – received from different health professionals, often within the same team or health service;

- ▶ disregard valid choices the person may have made or the complexities of emotions that they may be experiencing, such as anxiety about their diabetes or about the health consultation.

Language can reflect unrealistic ideas about diabetes

Much of the language surrounding diabetes is inaccurate when one reflects on the realities of diabetes:

- ▶ despite people's best efforts, diabetes can be unpredictable and very difficult to manage;
- ▶ all people with diabetes go through stages when their own health is not their highest priority or their efforts seem less effective in managing their diabetes;
- ▶ diabetes is a progressive condition. In type 2 diabetes, health professionals sometimes use the threat of insulin therapy to try to improve self-care. This threat can create fear and avoidance (psychological insulin resistance) and contribute to a sense of failure when insulin becomes necessary to achieve glycaemic control.

Can language influence outcomes?

Persistent references to 'failing to control' blood glucose levels leaves people with diabetes feeling that those around them do not recognise their efforts or that their diabetes can control them.

For people with diabetes, feelings of failure, frustration and self-blame are common consequences of unrealistic expectations. Many individuals stop confiding in their health professionals or family members to avoid judgmental or negative responses.

An important aspect of diagnosis and continuing care is using language that individuals can relate to, understand and feel comfortable with. Language must not demotivate. Referring to health outcomes and medical results without using concrete terms such as 'control', 'good', 'bad' encourages individuals to think of blood glucose and HbA1c as indicators that continually change in response to many controllable and uncontrollable factors, e.g. hormonal changes, medications, emotions, physical health, food, activity.

Language can also create a power imbalance between the health system and the person with diabetes. Over-use of medical jargon can result in distrust of or over-reliance on health professionals who are assumed to 'know best'.

What kind of language is needed?

Many health professionals and services acknowledge that people with diabetes need to participate actively in their self-care yet continue to use disengaging words and phrases (see Table 1) that can disrespect the individual's autonomy. In many instances, such language is used naively, without full appreciation of its unintended meaning or impact. Rather, we need more careful use of language that:

1. Promotes active engagement. Discussing 'diabetes management options' or 'self-management choices' encourages people with diabetes to be actively involved in making decisions about their own health;
2. Supports the self-care efforts people make. Health outcomes depend largely on activities and choices people make outside of health consultations. Using respectful and comprehensible language can help individuals realise they are capable of and encouraged to make informed choices about their diabetes, and that their choices are respected;
3. Acknowledges the frustrations, anxieties, guilt and distress that many people with diabetes experience.

Recommendations

In your verbal and written interactions with or about people with diabetes, Diabetes Australia recommends:

1. **Be aware of the language you use** with each person with diabetes and when referring to people with diabetes.
2. **Take your language seriously.** Language is personal and so is diabetes. Think carefully about what your words might mean to a person with diabetes and be aware your words may not be interpreted the way you intend.
3. **Remember language reflects attitude.** Do not use different language just because you are talking or writing about people with diabetes rather than with them.
4. **Remember everyone is different.** Some people will object to or be irritated by certain language; others may not. Regardless of an individual's immediate reaction (or lack of reaction), your language influences how they think, feel and act. Use language most people would find helpful and encouraging.
5. **Inform but don't judge.** Avoid blame and any language that implies moral judgment about behaviours. Accept and respect that (a) the individual has the right to make choices, (b) he or she has responsibility for his or her own condition and (c) diabetes may not always take priority in his or her life. Your language needs to reflect such understanding.
6. **Be understood.** Try not to use jargon. Listen to the words the person with diabetes uses and reflect that language. Wherever possible, check assumptions, understanding and the effect your language has on individuals.
7. **Take an holistic approach.** Diabetes is frustrating, challenging and distressing for many people. Focusing on their 'non-adherent' behaviour dismisses the very real efforts they may well be making.
8. **Focus on the achievable.** Wellness and health involve more than just gaining 'control'; encourage optimal self-management and behaviour change using appropriate and encouraging language.
9. **Appreciate that the meaning and acceptability of words and phrases changes over time.** Continually reflect on your language and check your assumptions.
10. **Remember language creates reality.** People with diabetes need to know that their continual efforts to improve their health and self-care activities are worthwhile and valued. Focusing on the positive changes that people make and can continue to make in the future is more effective than focusing on past behaviours and outcomes.

Table 1: Examples of language to be avoided, rationale and examples of preferred language

Avoid	Use	Rationale
Diabetic, sufferer, patient	Person with diabetes, person living with diabetes	<p>The term 'diabetic' defines the individual as their health condition. It is better to emphasise the person's ability to live with diabetes. Labelling someone as 'diabetic' positions diabetes as the defining factor of their life.</p> <p>The term 'sufferer' is too negative to be used to refer to all people with diabetes. If you refer to someone as 'suffering from diabetes', is that really true? Does it have to be true? While some people may find diabetes management and its complications challenging and distressing, not everyone 'suffers' with diabetes. Referring to people with diabetes as "diabetic sufferers" positions them as helpless victims, powerless to lead a normal life with diabetes.</p> <p>The term 'patient' implies the person is a passive recipient of care, rather than an active agent in his or her own self-care. Patients are people, and people are individuals, with their own preferences, priorities and lives beyond diabetes.</p>
Disease	Condition	Disease has negative connotations of something that may be contagious and nasty. People with diseases are often avoided or feared. Diabetes is a chronic condition that the person will live with for the rest of their life.
Normal, healthy (person, blood glucose levels etc.)	People without diabetes; target, optimal blood glucose	Referring to people who do not have diabetes as 'normal' implies that people with diabetes are 'abnormal'. This is not the case and not the point. Similarly, referring to 'normal blood glucose levels' implies that levels outside this range are 'abnormal'.
Obese, normal weight	Unhealthy, healthy weight	The term 'obese' is frequently used to label a person, e.g. 'he or she is obese', in a way that frames excess weight as a trait rather than a state. A trait is something we have to live with (like personality), a state is something that can change. Furthermore, with excess weight fast becoming the norm in society, the term 'obese' does not convey the message that excess weight puts health at risk. Nor does it suggest to the person that he or she has the power and the means to change this risk factor.
Describing the person (e.g. 'he or she is ... poorly controlled, cooperative, uncooperative')	Words that describe outcomes or behaviours ('his or her blood glucose is high')	Describing the person rather than the behaviour implies the behaviour will not and cannot change. It has a fatalistic connotation. People with diabetes need to think of HbA1c and blood glucose levels as changing indicators that respond to a variety of factors. When health professionals use such labels, it suggests that they may have given up. Furthermore, it is futile to try to 'make' people change their behaviour or self-care activities. Diabetes care requires a collaborative approach, not persuasion or coercion.
Poor control, good control, well controlled (referring to HbA1c or blood glucose levels)	Stable / optimal blood glucose levels, within the optimal range, or within the target range; suboptimal, high/low	Referring to 'poor' or 'good' control infers a moral judgment about the outcome, i.e. the person with diabetes has been good or bad. No-one needs criticism when things are not going well. Taking the judgment out of the language acknowledges that a variety of factors affect optimal diabetes management, many of which are beyond the person's control. Furthermore, the individual's efforts need to be acknowledged regardless of the outcome.
Control (e.g. diabetes control, blood glucose control, controlling diabetes)	Manage, influence	The idea of controlling blood glucose levels is great in theory, as few people would want to be 'out of control'. However, assuming that true 'control' can be achieved dismisses the fact that blood glucose levels are influenced by many factors outside of the person's direct control (e.g. hormones, illness, stress, prolonged / delayed effects of physical activity, other medications). Continually striving to 'achieve control' or 'maintain control' is ultimately a recipe for feelings of guilt, despair and frustration when it cannot be achieved. Instead, we need to acknowledge that blood glucose levels can be influenced by the person with diabetes but not expect that they can ever be truly 'controlled'.
Should, should not, have to, can't, must, must not	You could consider..., you could try..., consider the following options..., you could choose to...	The individual is an expert in his or her own diabetes. Giving instructions about what he or she should (or should not) do implies that: (a) you know better, and (b) not following the instruction renders the person morally deficient or uncooperative. Suggesting treatment options emphasises the individual's choices, acknowledges his or her autonomy and that he or she has ultimate responsibility for his or her own health.
Failed, failing to...	Did not, has not, does not...	'Failure' implies that one has aimed and missed the target. It implies lack of achievement, ineffective efforts or lack of effort. It also implies disappointment on the part of the person using the term. It is better in most circumstances to rely on facts and avoid judgments about the facts.
Compliance, compliant; non-compliance, non-compliant; adherence, adherent, non-adherent	Words that describe collaborative goal-setting	The terms 'compliance' and 'adherence' refer to the extent to which behaviour matches the prescriber's recommendations. They imply a lack of involvement in decision-making by the person with diabetes. They assume the health professional's guidance was clear, does not conflict with advice of others, and that the person with diabetes recalls the instruction clearly. They also imply that people who do not comply or adhere are irresponsible or uncooperative. There is no single, convenient alternative term. Diabetes management requires active, collaborative decision-making, taking into account the individual's preferences and priorities.
Chances (of complications etc.)	Health risks; risk of complications	Complications are not destiny nor are they entirely due to bad luck. Talking about the individual's 'chances' of developing complications suggests the person has no control over his or her future. It dismisses the very real efforts needed to delay or prevent their onset. Focusing on the individual's actual risk and what he or she can do to minimise it is more pro-active.
Blood tests, testing	Checking, monitoring, self-monitoring	'Tests' imply success or failure and an end result. Rather, people with diabetes need to monitor their changing blood glucose levels throughout their lives.
'Treating this patient'	Managing diabetes	Referring to 'treating this patient' implies something done to the person rather than the diabetes and ignores the active role of the person with diabetes. 'Managing diabetes' enables the person with diabetes to actively engage in decision-making and management of their own condition.

Conclusions

Diabetes Australia believes communications with and about people with diabetes need to be:

- effective in helping people with diabetes manage an unrelenting and challenging condition
- sensitive to people's health capacity, situation, physical and emotional well-being, which all affect their everyday ability and motivation to manage diabetes effectively

Diabetes Australia recognises communication as a skill that can be improved through conscious efforts. Making subtle but significant changes to the words and phrases we use everyday makes a difference to how people with diabetes think, feel and act.

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Further reading

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