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Language matters. Addressing the use of language in the care of people with diabetes: position statement of the English Advisory Group

Journal Item

How to cite:

Cooper, A.; Kanumilli, N.; Hill, J.; Holt, R. I. G.; Howarth, D.; Lloyd, C. E.; Kar, P.; Nagi, D.; Naik, S.; Nash, J.; Nelson, H.; Owen, K.; Swindell, B.; Walker, R.; Whicher, C. and Wilmot, E. (2018). Language matters. Addressing the use of language in the care of people with diabetes: position statement of the English Advisory Group. *Diabetic Medicine*, 35(12) pp. 1630–1634.

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Version: Accepted Manuscript

Link(s) to article on publisher's website:
<http://dx.doi.org/doi:10.1111/dme.13705>

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MRS ANNE COOPER (Orcid ID : 0000-0003-0776-7768)

DR CATHY E LLOYD (Orcid ID : 0000-0002-8863-3069)

DR KATHARINE R OWEN (Orcid ID : 0000-0003-3982-1407)

Article type : Diabetes UK Position Statements

Title: Diabetic Medicine

Created by: Maria Davie

Accepted: 07.06.2018

Email proofs to: anniecoops101@gmail.com

Article no.: DME-2018-00261

Article type: Diabetes UK Position Statements

Short title/*Authors running head*: Language and diabetes: addressing the use of language in the care of people with diabetes • A. Cooper *et al.*

Diabetes UK Position Statements

Language matters. Addressing the use of language in the care of people with diabetes: position statement of the English Advisory Group

A. Cooper¹, N. Kanumilli², J. Hill³, R. I. G. Holt⁴, D. Howarth⁵, C. E. Lloyd⁶, P. Kar⁷, D. Nagi⁸, S. Naik⁹, J. Nash¹⁰, H. Nelson¹¹, K. Owen¹², B. Swindell¹³, R. Walker¹⁴, C. Whicher¹⁵ and E. Wilmot¹⁶

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/dme.13705

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¹Person with Type 1 diabetes, ²Greater Manchester Strategic Clinical Network, ³TREND-UK, ⁴University of Southampton, ⁵Diabetes UK, ⁶Open University, ⁷NHS England, ⁸Association of British Clinical Diabetologists, ⁹University College Hospital, ¹⁰Positive Diabetes, ¹¹JDRF, the Type 1 diabetes Charity, ¹²Oxford Centre for Diabetes, Endocrinology and Metabolism, ¹³Diabetes UK and Parkrun Outreach (Diabetes), ¹⁴Successful Diabetes, ¹⁵Young Diabetes and Endocrinologists Forum representative and ¹⁶Diabetes Technology Network UK, Derby Teaching Hospitals NHS Foundation Trust, UK

Correspondence to: Anne Cooper. E-mail: anniecoops101@gmail.com

What's new?

- The use of language by healthcare professionals can have a profound impact on people living with diabetes.
- Our working group, which represents people with diabetes and key stakeholders, has developed a set of principles to guide healthcare professionals, with the goal of improving interactions with those living with diabetes.

Abstract

The language used by healthcare professionals can have a profound impact on how people living with diabetes, and those who care for them, experience their condition and feel about living with it day-to-day. At its best, good use of language, both verbal and written, can lower anxiety, build confidence, educate and help to improve self-care. Conversely, poor

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communication can be stigmatizing, hurtful and undermining of self-care and can have a detrimental effect on clinical outcomes. The language used in the care of those with diabetes has the power to reinforce negative stereotypes, but it also has the power to promote positive ones. The use of language is controversial and has many perspectives. The development of this position statement aimed to take account of these as well as the current evidence base. A working group, representing people with diabetes and key organizations with an interest in the care of people with diabetes, was established to review the use of language. The work of this group has culminated in this position statement for England. It follows the contribution of Australia and the USA to this important international debate. The group has set out practical examples of language that will encourage positive interactions with those living with diabetes and subsequently promote positive outcomes. These examples are based on a review of the evidence and are supported by a simple set of principles.

Introduction

The language used by healthcare professionals can have a profound impact on how people living with diabetes, and those who care for them, experience their condition and feel about living with it day-to-day. At its best, good use of language, both verbal and written, can lower anxiety, build confidence, educate and help to improve self-care. Conversely, poor communication can be stigmatizing, hurtful and undermining of self-care and can have a detrimental effect on clinical outcomes [1]. The language used in the care of those with diabetes has the power to reinforce negative stereotypes, but also has the power to promote positive ones.

People with diabetes internalize messages from the media and from those around them, but most of all from their healthcare providers. When these messages are perceived negatively, whether it is intended or not, this can lead to feelings of shame, guilt and resentment. People who are ashamed of a condition will find it much harder to manage that condition proactively.

In the present document, the authors and supporting organizations have set out practical examples of language that will encourage positive interactions with those living with diabetes and subsequently promote positive outcomes. These examples are based on research and supported by a simple set of principles.

The preferences of those living with diabetes as to how they wish to self-identify or be addressed should always be respected, but it is important to remember that the relationship between healthcare providers and those with whom they interact is often not an equal one. It is recommended therefore that all professionals working with the diabetes community, including healthcare professionals, commissioners, educators and those in the media who report on the condition, adopt the principles and practice set out in this document.

Being described as 'non-compliant' is awful and does not reflect the fact that everyone is doing their best, maybe not the same best as someone else, or even their best 'best' but just the best they can at that moment. Life is way more than Type 1 diabetes and it isn't always given top priority. Life gets in the way.

Person with Type 1 diabetes.

'It wasn't necessarily the language used, but rather the tone of voice and attitude of the medical professional in question. I've been shouted at, I've been spoken about – rather than to – in my presence, I've been ignored...but the same doctors and nurses have been extremely helpful at times too. I am yet to experience the ideal: an adult and constructive conversation in an atmosphere of mutual trust and respect. Language is certainly part of that, but so is attitude.'

Person with Type 2 diabetes.

Principles

The following section sets out the principles for good practice for interactions between healthcare professionals and people living with diabetes, drawn up with reference to the experience of people who have diabetes, healthcare professionals and published research.

- Be aware that language, both verbal and non-verbal, has enormous power, which can have positive or negative effects.
- Recognize that some words, phrases and descriptions are potentially problematic, whatever the intention of the user.
- Use language (including tone and non-verbal gestures) that is:
 - free from judgment or negative connotations, particularly trying to avoid the threat of long-term consequences or scolding ('telling off');
 - person-centred, (also known as 'person-first') to avoid labelling a person as their condition;

- Accepted Article
- collaborative and engaging, rather than authoritarian or controlling.
 - Review the use of common expressions and what underlying attitude they may convey, regardless of intention.
 - Avoid language that attributes responsibility (or blame) to a person for the development of their diabetes or its consequences.
 - Avoid language that implies generalizations, stereotypes or prejudice, or links one individual with previous experience of others of a similar background or in a similar situation.
 - Use or develop an empathic language style which seeks to ascertain a person's point of view of their condition, rather than assume it.
 - Listen out for a person's own words or phrases about their diabetes and explore or acknowledge the meanings behind them.
 - Become alert to the use of language and recognize if it may be creating a negative effect.
 - Consider how to limit any negative effects from language used, both for yourself and others around you.

'I've been told by a variety of uninformed people 'You can't eat that you're diabetic'; 'It's your fault you're diabetic'. And by docs and nurses, 'You're on insulin because you're a bad diabetic'. This is on our first meeting and before they have seen the results of my HbA1c or know anything about me!

Person with Type 2 diabetes

Hate 'suffer' too, 'lives with' is better and my child has Type 1 and is not a 'diabetic', would you introduce another child as a 'myopic' ...doubt it very much. -- Parent of child with Type 1 diabetes

Practice

So much language used implies blame just for having diabetes.

Person with diabetes

In the following section of this document, we set out some common examples of language use and suggest alternative responses or ways to deal with them. These are by no means comprehensive, but are intended to highlight major themes and demonstrate the negative impact of language in everyday diabetes practice and how this could be reduced.

'What's your diabetes control like?'

- For someone with diabetes, this question seems to focus solely on their diabetes rather than on their whole life, how diabetes fits in to it and what challenges or successes they have experienced.
- It may also assume that diabetes can, in fact, be 'controlled', ignoring the many variables that contribute to clinical outcomes, and the daily efforts people make to incorporate the demands of diabetes into their lives.

Possible alternatives

- Avoid the idea of 'control' and discuss how diabetes is affecting the person's life in general.

- Be more specific about your intention: ‘Can we talk for a few minutes about your blood glucose levels, so I have a better idea of how things are going for you?’
- Ask the person about their perspective and relate your following conversation to that, using similar language to them.
- Be aware of your tone and non-verbal signs when asking any questions and aim for these to be empathic.

‘It’s probably one of those non-compliant Type 2 diabetics who couldn’t care less about looking after himself’

- Judging, blaming or shaming a person who is experiencing the consequences of diabetes is common.
- People with diabetes may also be held up as ‘threats’ or ‘bad examples’ to others with diabetes in an attempt to improve someone’s perceived lack of self-management.
- There is no linear relationship between ‘compliance’ and good health.
- Remember that having diabetes does not make a person more likely to be ‘compliant’ with health messages (for example, to eat healthily or exercise) compared with someone without diabetes.
- Healthcare professionals can tend to see successful outcomes as reflecting on themselves and negative outcomes to reflect on the person with diabetes.

Possible alternatives

- Become aware of use of terminology, such as ‘compliant/non-compliant’, in relation to a person with diabetes and try to find out about their current situation and how it might be affecting their diabetes.
- Try to find ways of describing a person’s current situation rather than providing an opinion, or judging their past behaviour: for example, rather than ‘He/she has not had

good diabetes control and now has a complication as a result' try: 'he/she is experiencing xx condition and he/she also has diabetes'.

- Try using 'person first' language, e.g. 'a person with diabetes', rather than 'a diabetic'. Some people feel the use of 'diabetic' is acceptable and if you are unsure, ask the individual rather than assume.
- Be aware of talking about someone to others, especially other people with diabetes, in negative or judgemental terms, whatever your intentions.

BG test: Tests are either passed or failed. Prefer 'check' as this just lets you know where you are so can see if you need to do anything.

Person with diabetes

'Should you be eating that?'

- People with diabetes often feel criticized or judged by others, including health professionals, about their food choices and eating habits.
- Food serves many psychological functions, including emotional regulation and reward.
- Healthy eating education is important. However, putting this advice into practice can be a struggle.
- For people who are using food for emotional or 'non-hunger' reasons, extra support may be needed.

Possible alternatives

- Shifting the focus from the 'what' and 'how much' of eating to exploring the reasons why someone eats the way they do is more likely to lead to a helpful discussion.

- Try an invitation such as, 'There are many reasons why we eat, would you like to talk about them?'

'I hate diabetes' / 'It's so hard for me to control what I eat and do everything, it is a big effort'

- Phrases such as the above, said in a clinical encounter, may be traditionally considered by health professionals as ones that show 'denial', 'lack of motivation' or 'non-compliance'. They are sometimes met with the reaction that the people with diabetes should just 'get on with it', or at best, a sign that someone is 'not ready' to engage with their diabetes.
- Such statements may indicate the presence of diabetes distress, a clinically recognized response to the challenges of living with diabetes. Diabetes distress can reflect the often-overwhelming demands of managing diabetes daily and it can be increased if there are negative interactions with healthcare professionals.
- It is important to address diabetes distress for many reasons, not least because it is directly linked to glucose levels that are above target and negative health outcomes as well as having an adverse effect on quality of life.
- Distress can be recognized and considered when supporting people with diabetes; so being aware of the words used in clinical encounters is important.

Possible alternatives

- Recognize and acknowledge diabetes distress and its impact on well-being and diabetes management.
- Address comments made by the person with diabetes and explore the ways that diabetes has an emotional impact.

- Say something like: ‘Thank you for sharing how you feel with me, it’s common to feel this way’
- Try: ‘Diabetes isn’t just medical – your feelings about it are important’.

‘I’ve been a bad diabetic, I know you’re going to tell me off’

- This is a common statement used by an individual attending a clinic and may stem from previous experiences with healthcare professionals, but its use is linked to stigma and negative stereotypes.
- If a person who has diabetes refers to themselves as a ‘bad diabetic’, or other similar phrases, this may suggest that someone has been made to feel ashamed of their condition (for example, during an episode of hypoglycaemia) or their self-management.
- The language of consultations between healthcare professionals and the person with diabetes can be detrimental if we continue to focus on the ‘good’ or ‘bad’, or ‘failing to’ carry out certain self-management activities.
- It can imply that following instructions will result in perfect glucose levels, even though it is known that the tools to manage diabetes are far from perfect.
- Advising people with diabetes to ‘follow the rules’ of self-management can lead to feeling helpless and inadequate when unachievable.
- Shame may prevent the person living with diabetes confiding in their healthcare professional or accessing care for fear of judgment or a negative response.

Possible alternatives

- Explore what someone means when they say such things as ‘I’m a bad diabetic’ rather than dismiss, agree or admonish.

- Try to avoid words such as ‘should’ or ‘can’t’ or ‘must’ or ‘must not’. This suggests that instructions must be followed or otherwise the individual may not achieve ‘perfect’ self-management. Instead, think about using words like ‘could’ or ‘consider’ or ‘you could choose’.
- Do not use the word ‘failed’ as it may precipitate shame or imply disappointment. Using ‘was not able to’ or ‘on this occasion didn’t’ is more neutral.
- Avoid ‘patient’ with diabetes – it can imply that the person is not actively participating/is passive. ‘Person’ is a good alternative.
- Avoid ‘disease’ or suffering with’ or ‘burden’ because of the negative implications. ‘Has diabetes’ or ‘is living with diabetes’ is more accurate.
- Be sure to respond to words or behaviours that imply shame or embarrassment. For example: ‘There is no such thing as ‘good’ or ‘bad’ diabetes’. Or, ‘You’re not the sum of your diabetes numbers, it’s your efforts that matter most’.

Conclusion

The way language is used can profoundly affect the interactions between people with diabetes and their healthcare professionals. Table 1 provides guidance for healthcare professionals.

Funding sources

None.

Competing interests

None declared.

Acknowledgements

We thank the following supporting organizations and the many parents of children with diabetes and people with diabetes who graciously gave us their views during the development of this work: the Association of British Clinical Diabetologists; Diabetes UK; the Diabetes Technology Network UK; 'JDRF, the Type 1 Diabetes Charity'; NHS England; TREND-UK; and the Young Diabetes and Endocrinologists Forum.

Reference

1. Lloyd CE, Wilson A, Whicher C, Holt RIG, Kar P, on behalf of the Language Matters Group. Language matters; a UK perspective. *Diabet Med* 2018;

Table 1 Guidance for healthcare professionals on use of language in the care of people with diabetes

Seek to be more	Seek to be less
Empathic (e.g. ‘It sounds as though your diabetes is really hard to manage at the moment’)	Stigmatizing (e.g. ‘You’re in denial’)
Empowering (e.g. ‘What changes do you feel are needed right now?’)	Shaming or blaming (e.g. ‘It’s being so overweight that is causing you to have all these problems’)
Respectful (e.g. ‘I appreciate your coming to our appointment today’)	Authoritarian (e.g. ‘You must take your medications properly in future’)
Trust building (e.g. ‘I will definitely discuss your situation with xx and let you know what they say’)	Demanding (e.g. ‘Before you come to see me, I want you to take four blood tests a day for 3 days, so I can check what’s going wrong’)
Person-centred (e.g. ‘What thoughts have you had yourself about your recent glucose levels?’)	Disapproving (e.g. ‘You aren’t meant to take your insulin like that’)
Encouraging (e.g. ‘I can see the effort you’re putting in, keep up the great work!’)	Discriminating (e.g. about someone, ‘I don’t think they’d get much from a diabetes education class’)
Clear (e.g. ‘Yes, your HbA _{1c} this time is higher than recommended’)	Stereotyping (e.g. ‘People from xx background often dislike the idea of injections’)
Reassuring (e.g. ‘Diabetes brings lots of ups and	Assumptive (e.g. ‘I think you’d cope best with

downs, but it is manageable and there are lots of ways you can deal with it')	once a day insulin, as it's simpler')
Understanding (e.g. 'Now doesn't sound the best time to be concentrating on your diabetes')	Pre-judging (e.g. about someone, 'No-one in that family has ever taken much notice of their diabetes, they will be the same')
Exploring (e.g. 'What makes you say, "I feel like a failure?"')	Judgemental (e.g. 'I think you're making the wrong decision')
Collaborative (e.g. 'Let me talk you through the different medications and then see what you think would suit you best')	Threatening (e.g. 'If you don't improve your control you will end up on insulin')
Congruent in words and behaviours (e.g. looking at the person when welcoming or asking questions)	
Culturally competent (e.g. exploring individuals' cultural beliefs about diabetes)	