

Language Matters

Language and diabetes



Foreword

“With Great Power....”

Diabetes care continues to evolve at pace with modern technology, insulin and dietary modifications in exciting stages of evolution & development.

However, as healthcare professionals, it is also imperative to remember that we perhaps don't live the lives of those living with diabetes - and thus need to be aware of the impact our words may have on their diabetes care. For the brief moment we see them, our approach needs to be collaborative and inclusive, not judgemental; as words (verbal or non-verbal) can have impact far reaching than one can comprehend, especially in the setting of a long term condition. To be perfectly honest, it is up to the person concerned as to how they would like to be addressed, supported and understood but as healthcare professionals, we need to be aware of the need to give them that choice, not make it for them.

In view of this, NHS England have worked with a range of diverse individuals living with diabetes as well as all relevant stakeholders to develop this piece of work - which hopefully will act as a guide to all healthcare professionals interacting with people living with diabetes.

A word of thanks to Professor Jane Speight & Renza Scibilia for their pioneering work in this arena in Australia and to Jane Dickinson from the USA who have been great inspirations and help in making this idea come true. Importantly, a special thank you to the group that have helped to develop this document; especially Cathy Lloyd and Anthea Wilson for their research; Anne Cooper, Bob Swindells, Rosie Walker, Jen Nash & Sarita Naik for their time and dedication to the project, and to Simon Enright for his support of this work.

Diabetes care is changing – and if we as healthcare professionals want to make a difference, it is the building of relationships and relationships and respect which places the patient at the heart of that change which will take it to the next stage. We need to be trusted guides in the journey of those living day in, day out with diabetes.

As the saying goes...

“With great power, comes great responsibility”. Hopefully this piece of work goes some way towards realising the importance of that ethos.

Dr Partha Kar

Associate Clinical Director, Diabetes
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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; verbal, written and non-verbal (body language) which is more inclusive and values based, can lower anxiety, build confidence, educate and help to improve self-care. Conversely, poor communication can be stigmatising, hurtful and undermining of self-care and 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 stereotypes.

People with diabetes internalise messages from the media, 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 engage and manage that condition proactively.

In this document, the authors and supporting organisations have set out practical examples of language that will encourage positive interactions with people living with living with diabetes and subsequently 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.

Anne Cooper

Living with Type 1 Diabetes

Bob Swindell

Living with Type 2 Diabetes



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.

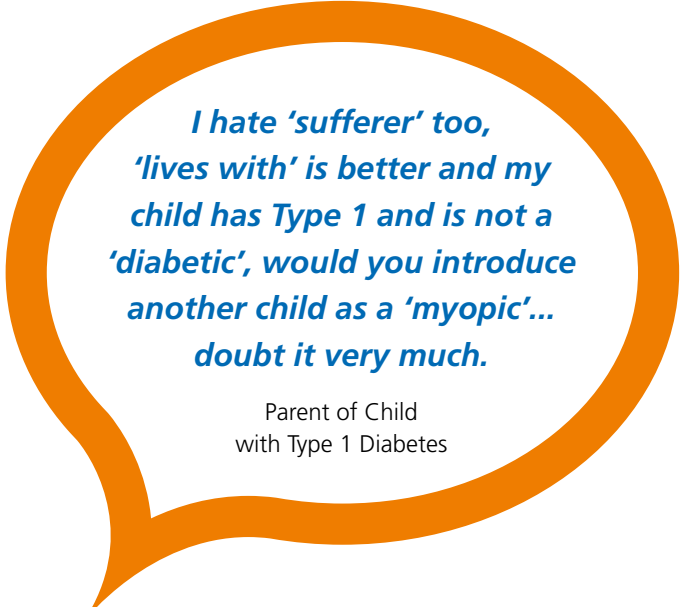
Person with Type 1 Diabetes

Principles and practice

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.
- Recognise 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'); is inclusive and values based language.
 - person-centred, (also known as 'person-first') to avoid labelling a person as their condition.
 - 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 which attributes responsibility (or blame) to a person for the development of their diabetes or its consequences.
- Avoid language that infers generalisations, 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.
- 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 non-verbal communication i.e. body language and recognise if it may be creating a negative effect.
- Consider how to limit any negative effects from language used, both for yourself and with others around you.



I hate 'sufferer' 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

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 addressed and reduced.

*So much language
used implies blame just
for having diabetes*

Person with Diabetes



'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, eat healthily or exercise) compared to 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 judgmental terms, whatever your intentions.

'Should you be eating that?'

- People with diabetes often feel criticised 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 maybe 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 these 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.
- These statements may indicate the presence of diabetes distress, a clinically recognised response to the challenges of living with diabetes. It can reflect the often overwhelming demands of managing diabetes daily and it can be increased if there are negative interactions with health care professionals.
- It is important to address diabetes distress for many reasons, not least because it is directly linked with glucose levels that are above target and negative health outcomes as well as having an adverse effect on quality of life.
- Distress can be recognised and considered when supporting people with diabetes; so being aware of the words used in clinical encounters is important.

Possible Alternatives:

- Recognise 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 told by a variety of uniformed people 'You can't eat that you're diabetic'; 'It's your fault you're diabetic.'

Person with Type 2 Diabetes

'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.



*For me the question
"Why were you high/low here?"
is so cutting. It's a judgement
of me; that always hurts.*

Person with Diabetes

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/passive. 'Person' is a good alternative.
- Avoid 'disease' or suffering with' or 'burden' due to 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

Seek to be more

Empathic (for example, 'it sounds as though your diabetes is really hard to manage at the moment')

Empowering and Inclusive (for example, 'what changes do you feel are needed right now?')

Respectful (for example; 'I appreciate you coming to our appointment today')

Trust building (for example, 'I will definitely discuss your situation with xx and let you know what they say')

Person centred (for example, 'what thoughts have you had yourself about your recent glucose levels?')

Encouraging (for example, 'I can see the effort you're putting in, keep up the great work!')

Clear (for example, 'yes, your HbA1c this time is higher than recommended')

Reassuring (for example, 'diabetes brings lots of ups and downs, but it is manageable and there are lots of ways you can deal with it')

Understanding (for example, 'now doesn't sound the best time to be concentrating on your diabetes')

Exploring (for example, 'what makes you say, 'I feel like a failure?')

Collaborative (for example, 'let me talk you through the different medications and then see what you think would suit you best')

Congruent in words and behaviours (for example, looking at the person when welcoming or asking questions)

Culturally competent (for example, exploring individuals' cultural, religious/faith and spiritual beliefs about diabetes)

Seek to be less

Stigmatising (for example, 'you're in denial')

Shaming or blaming (for example, 'it's being so overweight that is causing you to have all these problems')

Authoritarian (for example, 'you must take your medications properly in future')

Demanding (for example, 'before you come to see me, I want you to take 4 blood tests a day for 3 days, so I can check what's going wrong')

Disapproving (for example, 'you aren't meant to take your insulin like that')

Discriminating (for example, about someone, 'I don't think they'd get much from a diabetes education class')

Stereotyping (for example, 'people from xx background often dislike the idea of injections')

Assumptive (for example, 'I think you'd cope best with once a day insulin, as it's simpler')

Pre-judging (for example, about someone, 'no-one in that family has ever taken much notice of their diabetes, they will be the same')

Judgmental (for example, 'I think you're making the wrong decision')

Threatening (for example, 'If you don't improve your control you will end up on insulin')

*I've been spoken
about - rather than to -
in my presence.*

Person with Type 2 Diabetes

The Language Matters working group members

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- Richard IG Holt, University of Southampton
- Daniel Howarth, Diabetes UK
- Cathy E Lloyd, The Open University
- Partha Kar, NHS England.
- Dinesh Nagi, Association of British Clinical Diabetologists
- Sarita Naik, University College Hospital
- Jen Nash, Positive Diabetes
- Helena Nelson, 'JDRF, the type 1 diabetes charity'
- Katharine Owen, "Oxford Centre for Diabetes, Endocrinology and Metabolism"
- Bob Swindell, Diabetes UK and parkrun Outreach (Diabetes)
- Rosie Walker, Successful Diabetes
- Clare Whicher, Young Diabetes & Endocrinologists Forum representative
- Emma Wilmot, Chair: Diabetes Technology Network UK, Derby Teaching Hospitals NHS Foundation Trust



Ask me how I feel, talk to me about numbers but don't treat me 'as' numbers and use language that doesn't judge me.

Person with Diabetes

Supporting organisations

Thank you to the following organisations for their support in developing this guidance.



This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request.

Please contact england.ndpp@nhs.net.

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Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities