

Language Matters

Language and Diabetes



2nd Edition: April 2023

Foreword

“With Great Power...”

Diabetes care continues to evolve at pace with modern day technology, insulin and dietary modifications in exciting stages of evolution and 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 moments 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 had worked with a range of diverse individuals living with diabetes as well as all relevant stakeholders to develop this original piece of work in 2018 and refine it for the 2nd edition – which hopefully will act as a guide to all healthcare professionals interacting with people living with diabetes.

A word of thanks to Renza Scibilia for her 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 Swindell, Rosie Walker, Jen Nash and Sarita Naik for their time and dedication to the project

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. The concept of “Language Matters” is no longer an adjunct of optimal diabetes service delivery- but very much at the core of good, empathetic care.

Professor Partha Kar
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Foreword

As healthcare professionals, it is essential for us to recognise the impact our language has on people living with diabetes. There has been much progress in diabetes treatments and care over recent years. Yet a key and unchanging component is the importance of the way in which we communicate.

The language we use has the power to encourage positive interactions, build confidence and empower effective self-management. Whilst the use of negative language can reinforce harmful stereotypes, increase stigma and add to the psychological burden of living with diabetes. This principle becomes even more important when interacting with children and young people, who are particularly vulnerable to negative messages, at a time when they are still developing their self-identity.

As we support young people to gain independence in their diabetes management and navigate the challenges of adolescence, it is essential that our interactions are supportive and non-judgemental, with the overall aim of building confidence and positive relationships with health care professionals. Keeping young people engaged in services during the transition between paediatric and young adult care is particularly important and this document provides really helpful and practical advice to achieve this.

I would like to add a particular word of thanks to the children, young people and families living with diabetes, for their invaluable contribution to the development of the second edition of this document.

Dr Fulya Mehta

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Introduction to the 2nd edition

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 stigmatising, hurtful and undermining of self-care and 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 it also has the power to promote positive stereotypes. This document aims to raise awareness of the importance of positive, supportive language during clinical encounters with all those with diabetes across the life course.

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, which may never be reversed. For example, for those diagnosed as children or as a young person, these reactions can set the scene for a whole lifetime of added burden of living with diabetes.

In this document, the authors, people with diabetes and supporting organisations have set out practical examples of language that will encourage positive interactions with those living with diabetes and subsequently positive outcomes. These examples are based on research, our work with young people with Type 1 diabetes, as well as adults with diabetes, and is supported by a simple set of principles.

The preferences of those living with diabetes of all ages as to how they wish to self-identify or be addressed should always be respected but it is important to remember that the relationship with 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. Our recommendations are pertinent for both 'in person' clinical encounters as well as those where remote technology (e.g. online conversations, facetime, telephone and email) is utilised.

Cathy Lloyd, The Open University

Rosie Walker, Successful Diabetes

Based on the introduction to the 1st edition, by Anne Cooper, living with Type 1 diabetes and Bob Swindell, living with Type 2 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 experiences of people who have diabetes of all ages, healthcare professionals and published research.

- Be aware that language, both verbal and non-verbal, has enormous power, which can have positive or negative effects and these can be long-lasting: 'labels last', as Rose Stewart, diabetes psychologist, puts it)
- Recognise that some words, phrases and descriptions are potentially problematic, whatever the intention of the user for example 'diabetic', 'disease', 'compliance'
- Use language (including tone and non-verbal gestures) that is
 - Free from judgement 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
 - Collaborative and engaging, rather than authoritarian and controlling
- Notice and review the use of common expressions and what underlying attitude to them may convey, regardless of your 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 it
- Listen out for a person's own words or phrases about their diabetes and explore or acknowledge the meanings or experiences behind them
- Become alert to the use of language and consider 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

Principles

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‘What’s your diabetes control like?’

- For someone with diabetes, this question seems to focus solely on their diabetes and their blood glucose levels rather than their whole life, how diabetes fits into it
- 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. For example, trying not to sit behind a desk, which can indicate a position of authority and control. This may be a particularly important consideration in relation to children and young people

‘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’ or ‘adherence’ and good health. Indeed, these words imply an unequal relationship between the healthcare professional and the person with diabetes, whereby the latter must do as they are told and if not, then they are ‘naughty’ or need ‘telling off’ (see below)
- Remember that having diabetes does not make a person more likely to follow health messages (for example, eating 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 using terminology such as ‘compliant’, ‘non-compliant’ or ‘adherence’ and focus on supporting the person with diabetes and try and find out about their current situation and how it might be affecting their diabetes or vice versa
- Aim 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/they has / have not had good diabetes control and now has a complication as a result’, try ‘they are experiencing xx condition and they also have diabetes’
- Try using ‘person-first’ language, e.g. ‘a person with diabetes’ rather than ‘a diabetic’. Some people but not all, feel the use of ‘diabetic’ is acceptable, so if you are unsure, ask the individual, rather than assume
- Beware of talking about someone to others, especially other people with diabetes, in negative or judgemental terms, whatever your intentions



Should you be eating that?

- People with diabetes often feel criticised or judged by others, including healthcare professionals, about their food choices and eating habits, especially in the context of their weight. Children and young people can be particularly prone to disordered eating as a result of this emphasis, including eating disorders. These add to the distress and burden of living with diabetes
- 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

'The scariest time in my life was changing over to the adult clinic...they spoke to me so differently'

- Transition from children's to adult services can be a very tense and sometimes confusing time for young people that needs careful explanation and management of expectations
- The language and tone used can sound very different and be a stark contrast which, without preparation, might make or break a young person's desire to attend in future
- Young people report that they feel less supported in adult services if transition is not managed well, for example seeing a different healthcare professional on each visit, or being alone in a consultation

Possible alternatives:

- Remember to treat discussions or questions about eating or weight with great sensitivity
- 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?'



Possible alternatives:

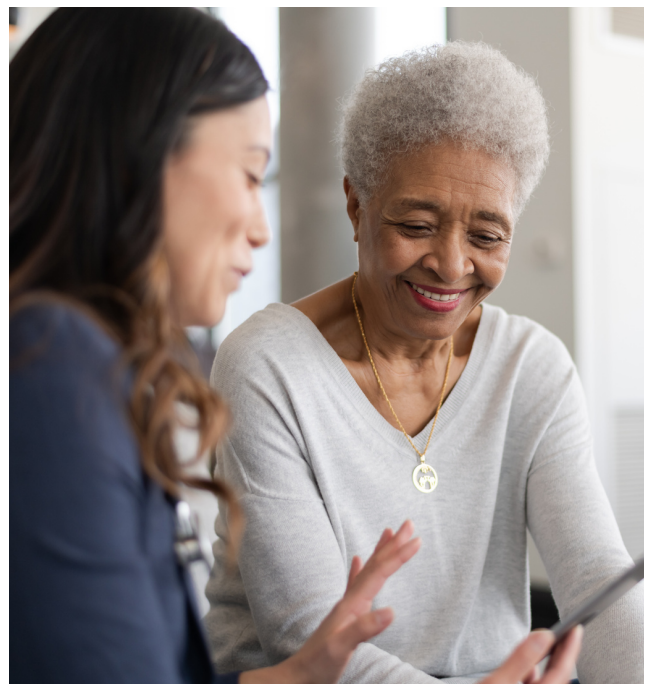
- Make arrangements for healthcare professionals from children's and adult services to jointly consult in clinics with young people, to plan and provide transition introductions, or hold meetings or focus groups to explain and discuss potential differences
- Hold meetings with your specialist young people /adult colleagues to better understand each other's services, so as to be able to relay this to young people
- At any consultation with a young person with diabetes at or approaching transition age, ask what their concerns are about transition or being in a new clinic and what their questions are. If you are not a specialist healthcare professional, you can still help to explain, reassure or signpost
- Consider if you need to find out more about best practice on transition services

'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 healthcare professionals as ones that show 'denial' or 'lack of motivation'. They are sometimes met with the reaction that people with diabetes should just 'get on with it', or at best, a sign that someone is 'not ready' to engage with their diabetes
- Instead, 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, for example if there are negative interactions with healthcare professionals. It may also indicate challenges within the home/family/friends environment where the needs of the person with diabetes are different from others in the same household/peer group
- It is important to address diabetes distress for many reasons, not least because it is directly linked with blood 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 of any age; 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 self-care
- Address comments made by the person with diabetes that might indicate diabetes distress and explore the ways that diabetes has an emotional impact
- Acknowledge the expression of these strong feelings: for example, 'thank you for sharing how you feel with me' or 'diabetes isn't just medical – your feelings about it are important too'
- Avoid the temptation to dismiss or minimise such statements, or put them down to, for example 'being a teenager' or 'hormones', or falsely reassure, e.g. 'you'll feel better in time' or 'things will stabilise soon'



'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. Its use is linked to stigma and negative stereotypes
- If a person refers to themselves as 'a bad diabetic', or other similar phrases, this may suggest they have been made to feel ashamed of their condition, for example during an episode of hypoglycaemia or their self-management approach
- 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 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 to 'follow the rules' of self-management can lead to feeling helpless and inadequate when unachievable
- Shame may prevent the person with diabetes confiding in their healthcare professional or accessing care/attending appointments for fear of judgement 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...'
- Avoid 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 – people are only 'patients' for a tiny amount of their time
- 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 really 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 1

Seek to be more	Seek to be less
Empathic (for example, 'it sounds as though your diabetes is really hard to manage at the moment')	Stigmatising (for example, 'you're in denial')
Empowering (for example, 'what changes do you feel are needed right now?')	Shaming or blaming (for example, 'it's being so overweight that is causing you to have all these problems')
Respectful (for example; 'I appreciate you coming to our appointment today')	Authoritarian (for example, 'you must take your medications properly in future')
Trust building (for example, 'I will definitely discuss your situation with xx and let you know what they say')	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')
Person centred (for example, 'what thoughts have you had yourself about your recent glucose levels?')	Disapproving (for example, 'you aren't meant to take your insulin like that')
Culturally competent (for example, exploring individuals' cultural beliefs about diabetes)	Assuming about a person's cultural background (for example, you look like you are from a xx background so your religion must be xx and might well impact on your diabetes at certain times of the year)
Encouraging (for example, 'I can see the effort you're putting in, keep up the great work!')	Discriminating (for example, making assumptions about someone, 'I don't think they'd get much from a diabetes education class')
Clear (for example, 'yes, your HbA1c this time is higher than the recommended range')	Stereotyping (for example, 'people from xx background often dislike the idea of injections')

Seek to be more	Seek to be less
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’)	Assumptive (for example, ‘I think you’d cope best with once a day insulin, as it’s simpler’)
Understanding (for example, ‘now doesn’t sound the best time to be concentrating on your diabetes’)	Pre-judging (for example, about someone, ‘no-one in that family has ever taken much notice of their diabetes, they will be the same’)
Exploring (for example, ‘what makes you say, ‘I feel like a failure?’’)	Judgmental (for example, ‘I think you’re making the wrong decision’)
Collaborative (for example, ‘let me talk you through the different medications and then see what you think would suit you best’)	Threatening (for example, ‘If you don’t improve your control you will end up on insulin’)
Congruent in words and behaviours (for example, looking at the person when welcoming or asking questions)	



Conclusion 2

Practical examples and models have been developed which show how language matters in a service.

The following have originated in Children and Young People's services, but are relevant for any service supporting people living with diabetes who wish to make explicit their focus on language matters.

Example 1

Clinic Posters - Leeds Children's Hospital

Leeds Children's Hospital have developed posters to explain their philosophy of language used in their clinics, and shared these throughout the clinical areas

Example 2

The Ormskirk Model of HbA1c / time in range

The Ormskirk team have developed a new HbA1c and time-in-range scale, aimed at creating a non-judgemental discussion based on the principles in this document, and solution-focussed practice

For Reference and contact details see the reference section:



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1st Edition

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Supporting Organisations: 1st Edition

- Association of British Clinical Diabetologists
- Diabetes UK
- Juvenile Diabetes Research Foundation
- NHS England
- TREND-UK
- Young Diabetes & Endocrinologists Forum

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- Rose Stewart, Betsi Cadwaladr University Health Board, UK Diabetes Psychology Network
- Reza Zaidi, Royal Liverpool and Broadgreen University Hospitals NHS Trust

References and Resources

Diabetes UK Emotional Health Guide

<https://www.diabetes.org.uk/professionals/resources/shared-practice/psychological-care/emotional-health-professionals-guide>

Guyers, M., Bray, D., Ng, SM (2020). Language Matters: image matters too. The Ormskirk Model: a new HbA1c-time-in-range solution focussed model. Diabetes Care for Children and Young People, 9, 2, P1
Language Matters Diabetes. Website containing all published documents worldwide relating to language matters

www.languagemattersdiabetes.com

Ng, SM., Hulikere, S. (2022). Diabetes Transition: A time to act. Diabetes care for children and young people. 11 (early view publication)

<https://diabetesonthenet.com/diabetes-care-children-young-people/diabetes-transition/>

NICE guidance for diabetes (Type 1, Type 2, children and young people) – single link but including CYP

<https://www.nice.org.uk/guidance/conditions-and-diseases/diabetes-and-other-endocrinal--nutritional-and-metabolic-conditions/diabetes/products?GuidanceProgramme=guidelines>

Webinars and associated materials relating to Language Matters

Language Matters: Supporting Emotional Health in Diabetes Care here:

<http://stadium.open.ac.uk/stadia/preview.php?whichevent=3545&s=31>

Language Matters: The Impact on People Living with Diabetes here:

<https://abcd.care/resource/demand-webinar-language-matters-impact-people-living-diabetes>

Language Matters: Supporting Resources here:

<http://www.successfuldiabetes.com/living-with-diabetes/sd-news/item/231-language-matters-webinar-recording>