



The Open  
University

**'Language Matters: Supporting Emotional Health  
in People with Diabetes'**

**Questions, Answers, Comments and Responses from  
Webinar Presented on 30 September 2020**

**Introduction:**

The Webinar was presented live on 30<sup>th</sup> September 2020 and recorded. The recording can be viewed via this link:

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

and the resources accompanying it can be accessed here:

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

Questions and comments were welcomed during the webinar and some, but not all, were able to be answered live by the various speakers. In this booklet, we have put together a complete collection of the points raised along with responses. These are presented in order of the programme speakers, with additional comment and editing in places by Rosie Walker, the Co-Host.

We are still welcoming survey responses to the Webinar. If you have watched it, please record your thoughts via this link <https://www.surveymonkey.co.uk/r/Z8RG7QH>, or email either of us with any questions or comments.

Best wishes

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Rosie Walker: rosie@successfuldiabetes.com

## **Speaker and Co-Host Professor Cathy Lloyd**

Q: How do you (gently) challenge colleagues who inadvertently use stigmatising/derogatory language? I hear it regularly as I'm very aware of the issue.

A: This is a difficult one and it can be tricky to challenge someone who, as you say, isn't really aware of the use of this type of language. Attempting to discuss this issue during a coffee break or making sure that the language matters document is clearly in sight may help. These are gentle ways to get the message across. The link below is also useful as it gives practical ways to optimise clinical encounters with people with diabetes.

<https://behavioraldiabetes.org/xwp/wp-content/uploads/2015/12/BDIAdultEtiquetteCard.pdf>

Q: Will the guidance be rolled out to all professionals who consult with people with diabetes, including GPs?

A: We are hoping to reach as many as possible! The guidance was initially distributed through all the CCGs and we know many GPs downloaded the guidance. It was also launched at a Diabetes UK professional meeting, and is on the NHS England and Diabetes UK websites, both of which are regularly used by health professionals of all types.

A new website - [www.languagemattersdiabetes.com](http://www.languagemattersdiabetes.com) - has also just been launched. Maybe you could offer this information and/or the 'Language Matters' document to your diabetes team or GP. If you don't feel able to do this directly (and we understand that many people don't), another route could be via your local CCG patient forum or diabetes support group.

## **Speaker Dr Pete Jennings:**

Q: What are the time in range parameters based on? Is it normal, non-diabetes ranges?

A: Reference for HCPs

<https://care.diabetesjournals.org/content/42/8/1593>

Reference for People with Diabetes

<https://www.mysugr.com/en/blog/5-things-know-about-time-range/>

Q: Do you think when inviting people with diabetes to their clinical appointment for their first encounter, it might be useful to provide this background information about how you work?

A: I think this is an excellent idea! The one risk is doing this, is that while I can share my philosophy with the people with diabetes I meet in clinic, I can't guarantee all the people they'll encounter in the clinic will share this approach. But it will be worth starting the discussion.

Q: The NHS often sets targets and markers for eligibility for certain things like pumps and Libre. How do you explain to a person they may no longer be eligible if they don't meet these targets?

A: Thanks for asking this question. Yes, there are eligibility criteria that guide the use of technologies in diabetes. Some people who don't meet the criteria may not qualify for funding for some technologies. Sometimes, there are things people can do, such as attend a structured education programme like DAFNE, to qualify for an insulin pump. I would also revisit the most up-to-date criteria to ensure that the decision is being made using the most recent guidance. Hope this helps.

Q: I think it is interesting that Pete said he asks what percent above/below they would like to be, rather than what would be acceptable. Do people normally say 0%?

A: sometimes people do say that and are pleasantly surprised when they realise that they have some wiggle room and high and low glucose can be expected.

Q: We notice that over 60-70% of patients do not know their HbA1c and what is the recommended. Do you have any thoughts about what can be done about this? What sort of encouraging language can be used in this relation?

A: One idea you could try would be to ask them if they know why we, as healthcare professionals, are interested in measuring their HbA1c? When I've done this in clinic, it has led to interesting discussions about how for people with type 1 diabetes, a lower HbA1c is associated with a lower risk of longer-term complications or side-effects of diabetes. It sounds like you may have an opportunity for health promotion for people with diabetes to learn about HbA1c. Here's a link to a resource from Diabetes UK that might help to update people's knowledge about HbA1c: <https://www.diabetes.org.uk/guide-to-diabetes/managing-your-diabetes/hba1c>

Q: With my daughter who has type 1 diabetes, at times I must inform people (in school) of her condition. She dislikes it when I do and feels no-one needs to know

A: Thanks for sharing this. I can see how this puts you in a challenging position. One thing that might help is if you might be able to read through this information from Diabetes UK with your daughter, to help her understand why you are informing people at her school about her diabetes: <https://www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools>

Q: How do you motivate someone who is struggling?

A: Thanks for asking. One thing I like to explore is what's happening in someone's life at the moment. So if they are facing lots of challenges at home, work, school, finances, etc..., I sometimes try to take the pressure off from the diabetes and may spend some time listening to a person talk about the challenges they're facing. Interestingly, sometimes people find this is as helpful as discussing their diabetes

Q: My diabetes team doesn't discuss (time in) range

A: Feel free to ask them about it and hopefully they will be open to discussing it with you. Time in Range is relatively recent and may also be new to them! It may be worth bearing in mind that it mainly applies to people with type 1 diabetes using continuous glucose monitoring or flash glucose monitoring.

## **Speaker Professor Arie Nouwen:**

Q: What are methods that can help diabetes distress in parents of children with type 1 diabetes, is it assessed?

A: As a parent it is not easy to see their children diagnosed with a life-long condition such as diabetes. It is therefore not surprising that parents who have children with diabetes often report distress. This may arise from worries about hypos, the possibility of diabetes complications and, when they reach adolescence, having to 'let go' and hand over the responsibility of the diabetes self-management to their youngsters. Most parents start gradually sharing this responsibility early on and guide their children through this process. This, of course, requires openness and trust between parent and child.

Diabetes distress and parent distress can be formally assessed through the child and parent version of the Problem Areas of Diabetes scales, which are available on the internet. However, I would certainly discuss your worries with your child's diabetes team. They will be able to help you and your child to cope with living with diabetes. Other sources of information and support are Diabetes UK ([www.diabetes.org.uk](http://www.diabetes.org.uk)), Juvenile Diabetes Research Foundation (JDRF, [www.jdrf.org.uk](http://www.jdrf.org.uk)) and the various diabetes community information and discussion forums such as [www.t1resources.uk](http://www.t1resources.uk), another new website [www.nhstype1.mydiabetes.com](http://www.nhstype1.mydiabetes.com), and using #gbdoc on Twitter

Q: How do you motivate someone who is struggling?

A: I have never seen anyone with diabetes who is unmotivated to take care of diabetes. What I have seen is that many people find it hard to juggle taking care of the illness with the other requirements of life including work, family and children, taking care of the house, friends etc. In addition, diabetes is a very difficult condition to take care of. Often, despite efforts, the results in terms of blood glucose control is not optimal, frustrating further efforts. Often, just the fact of recognising this will reduce worry and feelings of being overwhelmed by diabetes and its care.

Perhaps the best way to answer this question is by rewording it: What is the best way to support someone who is struggling with diabetes? The obvious answer then is: have you asked the person with diabetes how you could support them? You could also explore with the person what makes taking care of diabetes so hard and whether there is anything that could be done to make taking care of diabetes easier. Most frequently, problems with diabetes care concern the so-called 'lifestyle' aspects such as diet and exercise. Realising that a healthy diet is not an 'all-or-nothing'

requirement and that they are already doing many of the dietary self-care activities well is important. People can then build on their successes rather than their shortcomings.

For further information (especially for health care professionals) see [https://diabetes.medicinematters.com/psychosocial-care/diabetes-distress/william-polonsky/17989734?utm\\_source=CanChange&utm\\_medium=referral&utm\\_campaign=WhyPsychosocialCareMatters&utm\\_content=Hub&utm\\_term](https://diabetes.medicinematters.com/psychosocial-care/diabetes-distress/william-polonsky/17989734?utm_source=CanChange&utm_medium=referral&utm_campaign=WhyPsychosocialCareMatters&utm_content=Hub&utm_term)

Q: I was diagnosed as depressed and it turned out it had a physical cause – wrong diagnosis and a waste of HCP time trying to help me mentally. I discussed how I felt for years and my diabetes was blamed and my bad control of it. You can imagine a low blood sugar and low haemoglobin

A As there are no known biological markers of depression, and a diagnosis is solely based on symptoms, it is often difficult to draw conclusions about the underlying factors contributing to the depressive symptoms. It is therefore useful if both the depressive symptoms AND the diabetes symptoms are addressed simultaneously in treatment.

Q: Do you feel these issues should be touched on at diagnosis, so people can know it is likely to affect them emotionally as well as physically? Also, do you think this will help people raise issues sooner?

A: Diagnosis of diabetes is often a stressful and difficult time for people with diabetes. It involves receiving a lot of information and, depending on the nature and circumstances at diagnosis, may include training and further tests. It is normal to feel overwhelmed and stressed at that time. A discussion about feelings, beliefs and images about diabetes can certainly be helpful, addressing underlying anxieties and worries. A discussion about potential mental health issues can be included in more detail when the dust of the diagnosis has settled.

Q: First-hand experience: We experience diabetes inside outwards. No doubt this does sometimes strike a chord. Clearly our numbers can't always add up. Life's stresses times send us haywire so much. We live with an awkward dysfunction.

A: (Rosie Walker) You put this so well, thank you. I think it reflects the importance of looking after the mind as well as the body, as Arie's presentation also shows. Diabetes can certainly be awkward and hopefully through work like this, support is available when life's stresses get in the way.

Q: I have been asked to help in training potential doctors, by my GP

A: Sounds like a good plan. Experiences of people with diabetes will certainly help to inform doctors in training what it is to live with diabetes and to sit at the other end of the table.

**Speaker Dr Keith Meadows:**

Q: Can you complete a DHP online to take into an appointment with you?

A: Yes, I'm very pleased to say that our associates at Oxford University Innovation have developed such an online tool reproducing the DHP. The system does allow for respondents to either print their completed DHP (for example to take with them to their clinic appointment) or email them to an email address of the respondents choosing (for example, the GP surgery).

The system is deliberately designed not to capture personalised information and responses are deleted after the online session is closed, so there are no issues with data regulation compliance. The online DHP completion is available free of charge for publicly funded healthcare and non-commercial use purposes, under licence from the Clinical Outcomes team at Oxford University Innovation. Please contact them directly for further information and guidance – healthoutcomes@innovation.ox.ac.uk. Clinical Outcomes would like to recognise the kind support of NHS England in the development of the online PRO system.

Q: The cause of depression may not always be due to diabetes

A: Absolutely and probably this occurs frequently. However, depression may still adversely affect diabetes and therefore addressing negative mood remains important in its management.

Q: Do you think the DHP should be used more in clinics? I thought it may help to open appropriate dialogue with those who may not take an approach around emotional health, to take the DHP

A: The answer to that is a very much a yes. Just asking the person to complete the DHP and then to look at their responses with them, will be a good start to opening up a dialogue. But, do some initial prep with the person, so you are not taken back about their response. Also, plan some referral routes, should a problem be revealed that needs more immediate attention or is outside your practice area.

Q: Can you use DHP in young adults 16-23 years?

A: Yes, the DHP is appropriate for people age 11 years and older.

Q: Fantastic tool – is there one for parents of children with Type 1?

A: Thank you for your positive comments but I'm sorry to say there is currently not a proxy, parent / care-giver version of the DHP. However, if you or colleagues or your team are interested in such a tool we would be open to discussion about how we could achieve that.

Q: I am curious to know how Language Matters fits with the DHP and what consideration was given to language used in the DHP (including the term DHP itself)

A: This is a good question. Language is critical in getting people to respond to the DHP. When developing the DHP we spoke to over thirty people with diabetes, so we could use their actual wording where possible to frame the actual questions. I remember one instance when someone said to me after completing the DHP "you've been speaking to people with diabetes."

Q: Do you have experience of using DHP – 1 with adults recently diagnosed with Type 1?

A: Not recently but, the feedback we've had in the past has been very positive.

Q: What are the differences between DHP and PAID?

A: The PAID provides an overall score. The DHP is more sensitive than this as it gives you a score on three important areas of living with diabetes. These are psychological distress, barriers to social activity etc. and finally, eating problems as a result of diabetes. Scores on each of these scales have shown relationships with high sugar levels, not checking sugar levels and existing psychological problems.

Q: Challenging for patients to complete if they have limited English – often BAME groups who are vulnerable, but also depression may be seen as a stigma or culturally not known?

A: This is a very important point. An additional problem is for example, a woman completing the DHP in the presence of her husband. These are very important cultural issues and really can only be addressed with support from someone with an understanding of the community.

## **Speaker Mr Bob Swindell:**

Q: The patient's scenario is so important I feel, and even acknowledging this makes you feel more valid as a person and your struggles are appreciated

A. Absolutely! There are so many things that can challenge our ability and capacity to self-manage, but even a little validation and understanding can be powerfully supportive.

Q: 'Language matters' - early and for everyone. I have introduced our pre-reg nursing students to the document and they have found it a very useful resource

A. Thank you! It's so much easier to get your approach to language right from the start, rather than trying to change habits later on. Great motto - 'LM early and for everyone' (that includes diabetes and beyond :)

Q: On a similar theme, is this helpful document specifically aimed at tackling stigma around obesity?

A: Yes there is a version dedicated to obesity language, link below. It was produced by and included input from those living with T2D as well. It was led by Obesity UK, a charity with a great commitment to listening to those with lived experience;

<https://cdn.easo.org/wp-content/uploads/2020/07/31073423/Obesity-Language-Matters- FINAL.pdf>

Q: As a person with diabetes, I have in the past said politely how an HCP's language has made me feel, as I don't think it's always intentional and gives something to reflect on

A: Absolutely, some of the toughest comment to receive come from people with good intentions. It is not always possible to or easy to challenge these in conversation, but here is a link to the 1 page "Etiquette Guide" mentioned in the Q&A after my (Bob's) presentation which can be helpful;

<https://behavioraldiabetes.org/xwp/wp-content/uploads/2015/12/BDIAdultEtiquetteCard.pdf>

## **Speaker Dr Emma Wilmot:**

Q: How do you deal with the guilt when you are told to try harder to control?

A: Hopefully the approaches discussed so far in the webinar, and the approach in consultations I describe below, will help people to express and discuss these feelings. Also, you will get useful answers from people with diabetes themselves! Many such questions are discussed and peer support offered on discussion forums, eg via Diabetes UK, or on social media, for example Facebook groups and Twitter using #gbdoc

Q: How do HCPs 'do' this in their time constraints?

A: Communication is the bedrock of good diabetes care. Above all else we must get this right, otherwise we fail the people we are trying to support. Letting the person with diabetes talk freely for the first few minutes of the consultation gives them space and provides insight into their agenda and sets the scene. It is possibly the most important part of the consultation. If we fail to engage people living with diabetes and they no longer come to clinic, we have failed. We need to avoid this outcome at all costs.

Q: As a person with diabetes, this is the first time I have engaged with the language matters document. I think a form of it could be useful for people with diabetes to steer and manage conversations they have with HCPs. Do you have any comments on this?

A: Great idea! thank you for this suggestion.

Q: Playing devil's advocate, the HCP may feel frustration at not being able to just point things out which may help both people and more efficiency. I'd be interested in what the panel think about this.

A: There are ways of 'pointing things out' which facilitates a plan from the person living with diabetes. For instance: 'How do you feel your glucose levels are these days?' 'What thoughts do you have on this?', leading to them suggesting things they may want to change with gentle nudges from us, compared to 'your glucose levels are too high, you need to do XXX there'. If the person with diabetes leaves the room feeling empowered to action their plan, we have succeeded. Imposing our plan on them does not always have the same success, in my experience.

Q: Sometimes HCPs use good language with negative tone or body language, or the wrong emphasis. Do you think it's as important also to be sincere in the use of language?

A: Yes definitely, point well made. Communication is verbal and non-verbal.

In workshops, training etc, we always encourage 'authenticity' as, as Pete mentioned, our internal thoughts and feelings can come over in our interactions, albeit unconsciously. Raising awareness of tone and non-verbal signals, as well as actual words is important (additional comment by Rosie Walker)

Q: Motivational interviewing is a helpful approach to consultations

A: (from Rosie Walker). Agreed! Any person-centred approach that prioritises the thoughts, feelings and plans of the person themselves, and encourages them is likely to result in a positive experience, for health professional and person with diabetes alike.

### **General Comments and feedback received during the Webinar – thank you everyone!**

- Wow what a great presentation! Plenty to think about as well
- Thank you Bob, that was very powerful and thought provoking
- Thanks Emma...wish I had had this type of approach over the years
- Fantastic presentation (as always). Thank you
- Yes treat the person not initially the diabetes
- Thanks guys! Brilliant presentations & lots to reflect on
- I would like to send huge thanks to all of you speakers today and Rosie. The information is invaluable and I believe people with diabetes can play an important role also in shaping better consultations and conversations. Thank you
- Thanks very much to all speakers, it has been a really good webinar to highlight the importance of appropriate language and empathic, person centred approach!
- Thank you so much

### **Additional Contribution, entitled 'Get the Point':**

"Day begins with her first fix units of 6 insulin and another to balance. She takes a blood test before meals and from time to time subsequently to assess. Recommended by her specialist nurse. Lunchtime, more insulin essential from her wallet of tricks. Jabs her stomach when out. Feels awkward in middle of café. All doubtless eating, but do not know what she is doing. They look on in amazement. Is she on drugs? Teatime comes round, she does another sugar test. Not bad considering her exercise through the day. Cycling good for levelling those occasional rises and falls. And so another fix. Most say goodnight when they go to bed but she must inject middle region again. Long acting insulin takes her through to morning when her day begins with her first fix"

Rosie Walker: This is a heartfelt testimony from 'anonymous', reflecting the daily burden of diabetes. Very much reflects the 'tough gig' that Emma Wilmot talked about. Thank you to the person who wrote it, it gives us all much to remember always.

