



PRACTICE

WHAT YOUR PATIENT IS THINKING

Are you well controlled?

Why the way you talk to me about my condition is important

Judith Hendley

I have type 1 diabetes. I'm also a mum, a northerner who has made my home in south east London, a health policy geek, and an avid Radio 4 listener. So it troubles me to be referred to as a "diabetic" or for people with diabetes in general to be called "diabetics." Although this does not bother everyone, I feel this reduces me to being someone with diabetes and nothing more.

Being identified by my condition

Since developing type 1 diabetes as an adult I have realised that once you have a long term condition there are certain things you can come to expect. One is always to be referred to as a patient, regardless of what role you are in at the time. Another is that you are no longer allowed to belong in the category of people described as healthy, however well you feel in yourself and however active you are. It's as though at the point of diagnosis you pass over an invisible line and are never allowed to cross back.

I would like to be identified as a person first and not as a "diabetic patient." This means not having assumptions made about me or about what might be important to me because of my condition and not making one of the first questions I'm asked my most recent HbA_{1c} result.

The power of language

I've always been interested in the meaning and interpretation of words and language. Language can convey meaning, and shape understanding. It can stigmatise and label or it can empower and affirm. The language used by healthcare professionals, the media, and others can make a big difference to how I feel about having a long term condition.

It's important to me to think that I can determine how I integrate diabetes into my life. Living with type 1 diabetes requires mental agility combined with resilience, stamina, perspective, and a healthy sense of humour, so state of mind is everything and language plays a big part in that.

I am supported by fantastic NHS diabetes specialists who are committed to helping me to achieve my goals and who also understand that diabetes isn't the only thing going on in my life. But I have also found that some healthcare professionals with less experience in diabetes can sometimes struggle to find the

right language to talk to me about it. For example, I can be asked, "Do you suffer from diabetes?" This makes me feel as though the person asking the question perhaps perceives me as the passive victim of my condition. It is hard to be passive with diabetes, and I "suffer" far more when I have a cold. (It might be better just to ask—"Do you have diabetes?")

Being "well controlled"

I'm also sometimes asked if I am "well controlled?" I find this question difficult because it feels like a question about my behaviour and how "good" I have been. Whenever I'm asked the "control" question, a part of me wants to reply, "No, in fact you just can't take me anywhere." It can also make me question if the person asking has an understanding of the difficulties in achieving a consistent equilibrium with type 1 diabetes and what the trade-offs can be. I'd prefer to be asked questions like, "How are things going with your diabetes?", "Are you having any difficulties with your blood sugar at the moment?", or "Is there anything that you're finding particularly challenging?"

Open questions

In general, any kind of open question that allows me to feel understood and supported and not judged for the choices I make about how I manage my condition is more helpful. For example, "How are you feeling about your diabetes at the moment?", "What is most important to you right now?", or "What ideas have you thought about for how you could handle that?"

It may seem overly precious to be so concerned about language in the overall scheme of things. However, as a healthcare professional, reflecting on and reframing the language you use while still making sure you get the information you need could make a big difference to how the people in front of you see themselves and their condition—and how they see you.

What you need to know

- Listen to the language patients use and try to reflect it back to them in your observations or questions
- Take the time to find out what matters to your patients—the things that they are worrying about might not be obvious to you
- Think about the language you use when you are referring to or writing about people with diabetes or other long term conditions—would they find the language you have used empowering or disempowering?

Education into practice

- What other examples of conditions or situations might this topic of language also be important to?
- When quantifiable biomarkers are part of condition management, how else could you talk about them?
- How might you get feedback from patients on the language you use?
- How could you change the language you use to empower and support patients with long term conditions to achieve their goals?

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