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WHAT YOUR PATIENT IS THINKING

Don't shift the burden on to me

Anna Tylor describes the assumptions she faces as someone who is visually impaired, and how healthcare professionals can make information accessible for blind and partially sighted people

Anna Tylor

As I sat down at my appointment I was in for a surprise. The doctor explained that they had received a nice letter from my GP, which said I was suffering with my eyes. It was unexpected because this wasn't an ophthalmology clinic. I had found a lump in my breast that was cancerous, and I was at my first hospital appointment.

The word suffering transported me back to another consulting room and a discussion about hormone replacement therapy and risks of breast cancer. It was suggested that I might have a high tolerance of risk because, with my eyes, it may be better to live a shorter life. What I struggled with most was the assumption that being visually impaired meant I was suffering. I often find people project their fears of sight loss onto me. They immediately think that my life is hard and that I must miss out on so much, rather than trying to understand. I love life, and I worry that these kinds of attitudes will materially impact treatment and outcomes.

Getting on the same page

In both conversations I offered immediate challenge. In one instance an unreserved apology was forthcoming. In the other they wouldn't acknowledge the problem and instead, they asked if I could see their face. Most visually impaired people I know find this approach repugnant. I could feel my hackles rise.

Simply asking what they could do to meet my needs, and how they could best communicate with me, was all that was necessary. It would have taken the sting out of the conversation. Acknowledging that I may not know what I needed at that moment, but being willing to find ways to support me from the start, would have helped.

Accessible Information Standard

The ensuing slew of written communication was a challenge. I know the system is set to a narrow parameter, but the range of what it is to be human is wide. It's hopeless writing to tell me that an appointment has been made for me if I can't read the letter. Offering an additional copy, sent in a format that can be read, should be the minimum. For me that's font size 16. Only once during my treatment did I receive a letter that met these criteria. Similarly, the pharmacy supplying drugs for my chemotherapy said it couldn't provide large print labelling, and it was suggested that I get my friends to read the labels. I was shocked that they were treating me like a child.

Not only is it reasonable to ask for accessible labelling of drugs, but it must be done as a matter of patient

safety, especially as the Accessible Information Standard has been law since 2016. I had to firmly resist efforts to shift the burden of responsibility on to me. Given the critical nature of what was at stake, I found this resistance incredible. I've received my cancer treatment in two health trusts and can see that there is no embedded culture to ensure information access for visually impaired patients.

What you need to know

- Don't make assumptions about what a sight impairment means, but exercise curiosity and ask what the patient needs
- Be practical about what your patient needs to get the most from appointments and in written and electronic communication. Large print or braille might be helpful.
- The Accessible Information Standard ensures patient safety by requiring that medicine labelling is accessible

Education into practice

- How can you ensure you are providing information in an accessible way for patients who are visually impaired?
- How can providing access to information help promote trust and affect health outcomes?

Additional information

- <https://theblindtruth.co.uk/page/7/>
- For more information about RNIB's #MyInfoMyWay campaign to make healthcare information accessible for blind and partially sighted people in health in social care settings, see the [RNIB website](#).

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