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WHAT YOUR PATIENT IS THINKING

Incontinence is lonely and hard to talk about

Luce Brett shares what it is like to speak with a healthcare professional about incontinence

Luce Brett

I became incontinent at the age of 30, after the birth of my first baby, with urge and stress incontinence. Initially, both conditions responded well to bladder training and physiotherapy, but after the birth of my second child, the stress incontinence became increasingly problematic. Since then I have had many treatments, with varying success.

Incontinence seeps into every area of my life. I am tired from the logistics, the shame, the spare clothes, the laundry, from drowning in drudge, multiple appointments, and health admin.

Facing an appointment

I have faced lots of embarrassing problems, and have had many vaginal examinations. Even now I'm struck by a kind of pity for my GP, that they have to look at my body, get close to it, or touch it.

I try to be confident, but even as an old-timer, sometimes I am scared or really embarrassed. I am afraid of farting or leaking in examinations, and of clinicians finding something new. Doctors ask me to summarise and prioritise my symptoms, which is hard. I don't know what is "normal," what I am allowed to complain about, or whether I am making a fuss.

During consultations, I often feel stupid, even though I've been a continence patient for a long time. I sometimes rush and I can't tell when I am the expert or when my GP knows more than I do. I don't want to waste their time.

The importance of language

Health professionals sometimes say "don't be embarrassed" or "I've seen it all before" to reassure me and destigmatise. Perhaps that works for some patients, but for me it feels indifferent. We are socially conditioned to be embarrassed of our genitals. It is a big deal to show someone else or bring up intimate details. I'm always relieved when professionals acknowledge that it isn't very easy to talk about. It is also reassuring when they say they want to help, and the examination will help us understand what is going on to move forward.

Sometimes I feel like health professionals are afraid of saying they don't know the answers. During one appointment a GP told me he didn't know and needed to find out more. It was scary, but it was also reassuring—nobody knows everything. He listened, and we worked together to figure out what to do next. He said he had learned from me, which was useful. It showed me he was on my side and prepared to learn.

Honesty and loneliness

Something else I have found helpful is being told that I have been really unlucky to get so many issues so young. Hearing that another health professional I saw was frustrated for me and wished she could do more made me feel less like a failure for getting overwhelmed. Especially because I often blamed myself for my health issues.

Incontinence is lonely. Sometimes my GP is the only person who knows the worst bits. Especially the day-to-day and ongoing issues and the way multiple embarrassing problems are hard to untangle. I'm lucky they understand that talking is hard and that sometimes I need help prioritising.

What you need to know

- Discussing incontinence is embarrassing and scary, so avoid using phrases that suggest these feelings are irrational
- Telling a patient you don't have all of the answers, sharing frustration, and learning together can help patients feel supported
- Even experienced patients sometimes need help prioritising and support with difficult conversations

Education into practice

- How could you ensure a patient feels welcome and supported to talk about difficult topics, including incontinence?
- What language and techniques can you use to lessen stigma and provide reassurance when a patient feels embarrassed?
- How can you help a patient prioritise different elements of their health when trying to create a plan together for their care?

Additional information

- www.whenyouarethatwoman.co.uk Luce Brett's memoir, which explores incontinence, birth trauma, postnatal depression, resilience, and survival, is out now. *PMSL: Or How I Literally Pissed Myself Laughing and Survived the Last Taboo to Tell the Tale*, by Luce Brett with a foreword by Elaine Miller. <https://www.bloomsbury.com/uk/pmsl-or-how-i-literally-pissed-myself-laughing-and-survived-the-last-taboo-to-tell-the-tale-9781472977489/>

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