WHAT YOUR PATIENT IS THINKING

Help me find treatments and clinical trials

Lorna Pender shares her experience of discussing treatments for alopecia and how learning about clinical trials would have helped her

Lorna Pender

My alopecia started when I was 8 years old, but in 2019 I noticed my hair falling out much more rapidly than before. I could no longer camouflage the hair loss. I also noticed that my eyebrows were gone, my eyelashes had fallen out, and I had lost all my body hair too. The scalp hair loss accelerated rapidly, and I sank into a deep depression, with suicidal thoughts.

Finding the courage

For three months I could barely function and had to take sick leave. I needed an urgent solution, so I took out a substantial loan and paid for a very expensive bespoke hair system. This fitted to my scalp and did not cause skin irritation, but the hair needed replenishing frequently. I also decided to have eyebrow tattoos. Eventually I mustered some courage to consult my GP by phone.

I was asked to send a photo of the three hairs that remained on my scalp, which was excruciatingly painful to document. I despised looking at myself—without the hair system I am another person. The doctor suggested I have blood tests to rule out any underlying contributing factors. During a follow-up appointment to discuss the test results, the doctor mentioned referring me to a specialist. This is what I wanted, but I also really wanted to talk about my mood and suicidal thoughts.

Feeling dismissed

During my appointment with the specialist, the door of the consultation room was repeatedly opened wide by incoming staff. This left me exposed to the waiting room. I wish they had asked if I wanted to sit behind a curtain while they examined me. When the examination was finished I was given only a few moments to adjust my hair system before the doctor continued the consultation. A small recognition of my dignity—during the examination and afterwards—would have indicated that they understood my distress. It would have shown me empathy and compassion, which would have helped create a more trusting relationship.

We started to talk about treatments. I had researched guidelines and treatments for alopecia, so I was angry when some of these options weren’t mentioned. I desperately wanted to ask about them, but felt I was being ushered out of the consultation room. I tried to inquire about psychological support but was told I would have to source it myself via my GP, and there was nothing more they could do for me. I was devastated, but opted to keep going.

Finding hope in research

I returned to the GP and requested to be referred to a dermatologist with expertise in alopecia. I intended to discuss other treatment options, but I had also researched a clinical trial that was recruiting, for which I suspected I would be eligible. I felt immense relief when, in 2021, I finally saw an alopecia expert with whom I could have a high level scientific discussion about the emerging treatment options and the future direction of research, and we formed a management plan together.

What you need to know

• Hair loss can be very distressing. Ask a patient how they are feeling, how their condition has affected their life, and guide them to support and information
• After examination, allow patients time to adjust any hair system they have before continuing the consultation
• Learning about clinical trials can give patients hope and provide an additional route to access treatments

Education into practice

• How would you advise a patient interested in enrolling on a clinical trial?
• How could you ensure privacy and dignity for a patient in a busy clinic? What steps could you take to improve a patient’s experience during physical examinations?

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