BackChat

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Living with primary ciliary dyskinesia (PCD)

So, I'm 19 and well; primary ciliary dyskinesia (PCD), that's just the way it goes sometimes. Not the easiest of things to have to deal with, especially when trying to figure out who you are and cope with all the new bodily and social changes that everybody goes through.

While I may insist that PCD is hardly something to get wound up about, I cannot avoid admitting the intense effect it has had on my life—indeed for many years I unwittingly displayed a subconscious behavioural reaction to certain circumstances.

Although I can remember a time when physio was new, and I had to learn a new breathing pattern, life before seems hardly different. It was just the way things were.

Prior to diagnosis at the age of 5 years, I was certainly one persistent medical mystery. Born 12 weeks premature, numerous infections, and a hearing problem. Successions of grommets, and ear infections followed. Simultaneously I endured prominent tubes sticking out of my nose (''elephant tusks'') as holes were made in my sinuses, plus the removal of my tonsils and adenoids.

I was never under any illusion over why I was going to each appointment, or hospital; my parents made me aware, questions always answered. Yet, I was still not wholly comfortable as I see more clearly now.

Leaving the house for an appointment I would change dramatically, becoming aggressive, deliberately provoking, and awkward towards my mother who usually took me. I would try arguing all the way to the hospital until I succeeded. Once out of my system, I would be fine.

Only when my mum pointed this out a few years ago did I realise the destructive pattern. I still find myself asking obvious questions, continually, in order to release the tension and scared feelings I subconsciously harbour.

Growing up and moving, from a children's to an adults' clinic has been equally frustrating.

At various children's clinics, I was seen by Dr M1 or Dr M2, both of whom I felt extremely comfortable with, and had known for many years. Transferring from Dr M1 to Dr F1 I was expected to adjust and treat the appointments in the same manner as those with Dr M1. Although welcoming, and relaxed towards me, I found I could not bond with her, feeling intimidated and second guessed. Despite trying to connect, regarding my hearing, and hearing aids stigmas, I felt angry that someone who, it seemed, barely knew me could be so personal so quickly. I suspect that as well as my being at an age where adjusting at such a late point medically felt despairing, I was also dealing with the fact that Dr F1 was my first constant permanent female doctor, instantly aware of the difference in male and female approaches.

> A colleague once told me it was unnecessary to confirm a diagnosis of PCD as all you needed to do was treat the bronchiectasis.
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> This month's correspondent tells us there is a lot more to it. As the late, great Michael Balint taught: the doctor is the most powerful drug of all.
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> The PCD Family Support Group is at www.p-c-d.org.uk.

From Dr F1 I ''graduated'' to the adult clinic into the care of Dr F2; in quite a short space of time another new approach to get used to, and my second ever female doctor.

When I was younger, I would sit in the swivel chair, spinning, or play with the manual credit card machine while doctors talked to my mum. It's funny how much is said when people assume you are not listening. Often we'd come out of an appointment and I would ask my mum something, usually surprising her—''I didn't think you were listening''. Sometimes I would pretend extra hard to not be listening so I could hear. It's important that your child with PCD knows everything that's going on—tell them to pretend not to be listening!

The research side of PCD has not left me unclaimed. I've been part of the zoo, in which you are ''invited'' to attend special clinics on a set date, in which all day unknown people (medical students usually) examine you, probing while arguing over where your heart is situated.

I am also phobic of what I call ''jelly things'', otherwise known as ECG leads. I last had them when I was 10, conditionally: that they were placed and removed during my operation while I was unconscious. The same conditions I would insist on today.

PCD is not all bad. Medically it is manageable, only life threatening when untreated—through physio or other means. I'm reluctant to take any antibiotics or even paracetamol unless absolutely necessary. Also, being premature I'm lucky to not have green teeth! PCD aside, I'm pretty average.

Patient/doctor trust issues needs some addressing.

For certain appointments someone always comes with me, more for my moral support rather than their needing to be there.

At one of my last appointments with Dr M2 he asked me how often I did my physio. ''Twice a day''. He asked again, ''Really, how many times''. Shocked, I repeated my original answer, confused. Then, amazingly, he asked my mum who confirmed, ''twice a day''.

What happened? I've known Dr M2 forever, he's pretty cool, yet, somewhere he stopped trusting me. Yes, I was a teenager, but why lie about something so trivial? If I haven't done my physio, I'll readily admit it. Anyway, a good doctor will recognise lying by looking at the state of health. Less infections, or none (wow), and few crackles would indicate good cilia management. Anything digressing indicates otherwise.

It's been interesting growing up with so many links to the medical industry, a sort of double education, running alongside my schooling. I know so much more than the average, yet will never understand why ''tonsil removal, or grommet insertion'' is considered a major operation. My children may have PCD; hopefully not, but if they do, I'll have the contacts and will understand the system. Hopefully their experiences will be more rewarding/positive, with non-existent side.

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