

LIVED EXPERIENCE

## How a lived experience of cancer shaped the doctor I am today

*If you can learn a simple trick, Scout, you'll get along a lot better with all kinds of folks. You never really understand a person until you consider things from his point of view, until you climb inside of the skin and walk around it.* Atticus Finch in *To Kill a Mockingbird* by Harper Lee

This article focuses on my lived experiences of episodes of cancer both in my teens and in adult life and how they have impacted my life. Specifically, I'll attempt to summarise how these physically and emotionally traumatic experiences have impacted on me in the way I work as a doctor, my understanding of team dynamics, the way a child or their family might be feeling, and generally the way I live my life and view my life. Everything I write here is based on my own experiences and my personal take. These events and experiences might be interpreted quite differently by somebody else.

Several people have reflected on their own lived experiences, and some felt that they didn't contribute to making them a different or even better doctor. Some discussed the experience that they had of illness at the time they were also a doctor and the different insight this gave them into being a patient. The picture of cancer is of pain and nausea, with hair and weight loss. For me, this was a very accurate depiction, but I hadn't expected the fear, loneliness, and loss of control. You also 'pop the balloon' that cancer is something that happens to other people; you have to be there to fully understand. Whilst I wouldn't choose to live one moment of it again, it has certainly given me insights that, I think, have improved my clinical care.

I was first diagnosed with leukaemia when I was a needle-phobic 14-year-old girl. The diagnosis could have been easily missed by our general physician (GP) who delayed taking a blood test and told my mother that she was overreacting to my episodes of fainting. My parents wanted to make a complaint as they were unhappy with the GP's management of my care. This was probably one of the first times that I reflected on how I would want to be treated as a doctor. I remember saying I hoped that one day when I become a doctor, people would be understanding if I made a mistake, and so, I didn't want a complaint to be made.

The first really major intervention that I experienced was having a bone marrow biopsy. Afraid of the sort of needles used for vaccinations or blood tests, the idea of a needle going through a bone into my bone marrow was virtually incomprehensible and incredibly frightening.

It was a frightening and painful experience. My mother stayed with me. I don't think I could have managed without her. Now I am aware that not everyone is in the fortunate position of having such family support.

This was also my first experience of having no control over what was being done to me and what I could choose to do. I knew that there was no choice but to have this test; nevertheless, I felt as if I was trapped into a corner with no escape. In addition, I was given a benzodiazepine to offer some sedation. It was meant to be helpful, but I quickly realised that if you are just 14 years old and under sedation, your requests are taken less seriously. It was essential for me to know that if at any point, I asked the doctors to stop that they would. To be sure I could do this, I refused any sedation unless it was a general anaesthetic (so that I knew that I would maintain some vestige of future control).

The team chose to manage me under adult services rather than transfer me at the age of 18 years. I think I would have had a very different experience had I been under the paediatric team. Understandably, the adult team were not used to working with children, especially very frightened ones.

I have written about loss of control. I experienced this partly because I knew that this illness had to be treated however traumatic this would be and because I often wasn't given a great deal of information. I didn't know what the treatment would be, what the side effects would be or the prognosis. This was probably partly because of being a child and partly as an attempt to protect me in addition to being the way that medicine functioned differently at the time with respect to giving information to patients and particularly child patients. It is beyond the scope of this piece of writing to explore this in depth, but even as late as 2003, Say and Thompson [1] wrote that patients were still not being included in decisions about their treatment.

There were several days before I was given the diagnosis of leukaemia. I don't think I really understood the implications, and they certainly did not explain to me at the time. My main concern was realising that I wouldn't be returning to school that week! I had no idea that it was likely to be over a term before I returned. I only discovered some of the long-term complications, and even that I would lose my hair, almost by accident. I really valued being included in discussions and having the implications of treatment explained to me.

One incident stands out for me. I had my first visit with the radiotherapy consultant. I was asked to leave the room and wait outside whilst he explained the procedure to my mother. At the time, I felt very angry to be excluded as *I* was the patient, and *I* would experience the side effects. The consequence of this is that I'm always careful to include children in conversations and choices. There is a great deal that one can explain to even quite a small child if you take time and perhaps draw pictures. The impact of excluding a child can be losing their trust.

The limited information I was given had an impact on the doctor–patient relationship we developed, and my ability to ask the most difficult questions. It was not the doctors who I asked about the possibility of dying and what would happen to me if I died. I wanted to tell someone that I didn't want a post-mortem. My friends were concerned that, as an atheist, I would not get into heaven. Fortunately, there was a lovely Chaplain who allowed me to untangle my thoughts without making any attempts to convert me!

Even at 14 years, I intended to become a doctor. I felt that this was genuinely taken on board by many of the doctors who treated me, and because of this, they began to give me more information. The consultant would tell new junior doctors that I planned to study medicine. I felt that I was accepted as an 'embryonic' doctor, one of the club. I think it helped to be seen as a potential doctor. This also meant that, sometimes when I felt very overwhelmed, I was able not only to face the treatment for myself but also to think about the people I would treat in the future. Knowing that I was going to be a doctor one day, I looked out for qualities that made what was, in my eyes, a good doctor, as opposed to qualities that were less good and even harmful.

Practical skills were clearly essential, but what made the greatest difference was the ability to empathise, self-reflect, and see me as more than just a patient. I'm going to give you some examples and describe how they affected me at the time and how they shaped or changed my own practices. It was on the treatment schedule that I first saw the letters 'IT'. When I asked about this, I was told that it meant 'intrathecal'. I discovered that this meant that medication would be injected into, and fluid would be taken out of, my spinal cavity. This was possibly one of the most terrifying things I had to face. It was only later that I was helped with these fears by a junior doctor who realised how frightened I was. This was one of the many experiences that went on to trigger post-traumatic stress disorder (PTSD). Information has the potential to be a double-edged sword. At 17 years, when I relapsed, and as an adult patient with breast cancer, there were times when I didn't want information, I just wanted doctors to treat me.

As a child with needle phobia, I rapidly developed a great fear of any intervention. With a doctor who lacked empathy, it was much more likely that I would struggle to face the intervention ahead of me. A good example of this is a day when I was feeling utterly overwhelmed by the chemotherapy and walked out of the clinic. The consultant asked my mother to bring me back to his room later if I was willing. When I joined him there, we engaged in what was clearly a game. He was playing the role of requesting that I consider resuming treatment. I played the role of graciously accepting. We both knew that really, there was no choice but to continue with chemotherapy, but for a few moments I was given the illusion of being in control and he was willing to take an hour out of his time. It is difficult to convey quite how important this was for me, and I will never forget.

In my own practice, I spend time with my patients trying to give them as much control and information as I possibly can. I find that patients who can give genuine informed consent, who understand how the treatment will work and what the side effects may be are far more likely to continue taking medication or to keep going with a difficult psychological therapy. My own experience of being a patient taught me that I was far more likely to trust those doctors with whom I could communicate well and who took time to really explain things to me.

I experienced that seemingly small things can cause distress, greater than the sum of their parts both at 17 years, when I relapsed, and as an adult and when I suffered from breast cancer. Treating insomnia, understanding how distressing, for example, hair loss or frothy saliva is, is something a good doctor doesn't dismiss, but takes seriously. It can result in a patient being able to better bear the larger trauma (e.g. the chemotherapy).

One of the most powerful experiences I had (one that I relate to medical students to illustrate extraordinary practice) was at the first dressing clinic after my mastectomies. The consultant asked me how I was. As a polite patient, I replied 'fine'. I will never forget his response; 'What is this "fine" business?', he asked, 'I can check your wounds and drains, but that wouldn't be being a good doctor would it? So, tell me. How are you?' and he sat down and listened. Even recalling this, years later, his compassion still moves me to tears.

It is not easy to know without actual experience what may look trivial is actually overwhelming or even 'the last straw'. Take time to listen; to show you want to hear their worries, their interest in ABBA or their interest in the periodic table; and to know that their favourite colour is green. If I take this into my own practice, my patients will more easily be able to tell me how they cannot bear the weight gain the medication causes or that it leaves them feeling 'spaced out' and unable to think.

At 18 years, whilst I had a bone marrow transplant, I experienced superb care. At the root of this was the team dynamics. The consultant and matron had an excellent working relationship. This filtered down to the junior doctors, nurses and nursing students.

Although the consultant was an international expert and one who had commitments both overseas and at home, I only experienced compassion and a feeling that in 'that' moment I was his priority. This approach was mirrored by the whole team. I remember a student nurse who gave up a day of annual leave so that I wouldn't be alone during an intervention, so my mother could return home to spend a day with my year-old brother. I remember another student nurse brought in his computer for me to use so I wasn't bored. I also remember a ward cleaner whose laughing and chatting, and generally lifting of spirits, were just as much her role as disinfecting my room. Basically, I experienced a consultant and matron who led their team using the approach of 'do as I do' not 'do as I say'.

The compassion and professionalism of the entire team really helped me to cope and recover. I take my experience of being a patient in a team with a shared vision, as well as my own training in group dynamics, to my own work. I try to prioritise the whole team. If we all work well as a team, we can help our patients more effectively.

If I have compassion, and I listen, if I have a chance to understand the families I work with, then I can better convey their experiences to my colleagues and thus offer a truly holistic care.

### Short Biography



Deepa Parry-Gupta is a Child and Adolescent Psychiatrist working with a multidisciplinary team in Merseyside, UK. She received her BA degree in Medicine from Cambridge University in 1990, MB BChir and MA from Cambridge University in 1993. She gained her MRCPsych in 2004.

Deepa was first diagnosed with leukaemia in 1983 and went on to have a bone marrow transplant in 1986, before going on to university to study medicine. In 2012, she was diagnosed with breast cancer, ductal carcinoma in situ (DCIS) in one and solid tumours in both breasts. She had double mastectomies.

Deepa is married and enjoys living in rural North Wales where her interests include baking, craft work, and spending time with her nephews and nieces.

### Dedication

I would like to dedicate this piece of writing to Mr Kenneth Graham who found out what 'fine' really was and all the many healthcare professionals who have treated me so well and taught me so much.

### Reference

1. Say RE, Thomson R. The importance of patient preferences in treatment decisions – challenges for doctors. *BMJ* 2003; 327(7414): 542–5. doi: 10.1136/bmj.327.7414.542

### Deepa Parry-Gupta

Email: drdspg@gmail.com