

PRACTICE



WHAT YOUR PATIENT IS THINKING

The heart of medicine: growing up with pioneering treatment

Liza Morton

In our patient authored series, Liza Morton describes what it feels like to be a child with a serious condition, and what clinicians can do to make that experience easier. For more information about the series, contact Rosamund Snow, patient editor, rsnow@bmj.com.

At a few days old, I was transferred to hospital, where, already in congestive heart failure, I was attached to an external cardiac pacemaker. When this restored life—in a world first for an 11 day old baby—I was diagnosed as having complete heart block and fitted with an implantable pacemaker.

Now an adult and mother of one, I am tremendously grateful to the NHS, advances in medicine, and those pioneers for my life. Congenital heart disease is a success story of modern medicine—90% of babies born with this condition now survive into adulthood, compared with just 20% in the 1940s.¹ Yet, medical advances raise questions about the psychological and emotional impact of being dependent on lifelong medical care.

Growing up with a heart condition has not been easy. Early pacemakers were unreliable and often needed reprogramming. I remember lying still, surrounded by a team of men in white coats armed with a magnet, leads, cold gel, stethoscopes, and electrodes. They would make my heart beat faster, then slower, as they interrogated the pacemaker. I was a medical curiosity. I was also a little girl who just wanted to do things that other little girls took for granted. We were told I should be able to function normally, yet those early pacemakers were single chamber ones that propelled my heart to beat at a fixed rate whatever I did, limiting me physically. I turned blue when cold, vomited on overexertion, and often felt dizzy. I wasn't allowed to attend dance or horse riding lessons, jump on a trampoline, take part in gym lessons, or join in with skipping games. Sometimes, I felt that these limitations were dismissed perhaps because nothing could be done about them or through fear that I would give up. Yet, instead of being told I should be able to lead a normal life, it would have helped me to have these obstacles validated so I was better supported to find my own way.

Often these early pacemakers and leads failed completely, my heart rate slowed, I became dizzy, and started vomiting—prompting an emergency trip to hospital. I was lucky that my mum was able to stay with me in hospital to provide continuity of care and communicate my needs. Children need their parents, never more so than when they are poorly. My most traumatic memories are of being wheeled away from my mum to theatre, where she wasn't allowed, and coming round in her

absence. Thankfully, she was present to support my mountainous recovery from cardiac surgery back on the ward. I squeezed her hands during the painful freedom from each piece of medical equipment I'd been attached to and the excruciating removal of the row of thick, black butterfly stitches, one by one. Looking back, as a mum myself, I have no idea how she coped. By the age of 7, I had been fitted with five pacemakers, each by thorocotomy.

I was a quiet child and was often told how brave and courageous I was. However, I was never sure if this was an observation, expectation, or demand. Often I didn't feel very brave. I just developed a fine ability to keep very still and quiet. If you wriggle when having a catheter inserted or an injection it hurts more and takes longer. Being a "good patient" was rewarded with a smiley sticker. Although it helped to have treats to look forward to during difficult experiences, it is important that they are not used as a "reward" for suppressing emotion. I knew that I didn't really have any other choice—being sensible made the experience easier for everyone—and besides, my life depended on it. But my stoicism didn't mean that it didn't hurt, that I wasn't afraid, or that somehow I was "used to it." Looking back, it would have helped if I had been told it was okay to cry, scream, or feel angry, even if after the event, because these are normal responses to pain or threat.

During my early teens I was fitted with my first variable rate pacemaker, which was physiologically more responsive and enabled me to be more active. Soon after I had open heart surgery to repair an atrial septal defect and I have since had four further pacemakers, totalling 10, and a risky lead extraction. I was fortunate that my care throughout my childhood was delivered by the same team, enabling me to build a close bond with them. However, this has not been the case since reaching adulthood. My experiences have led me to trust medical professionals who listen to me and acknowledge my life long experience of living with this condition and those who involve me in my care, are honest about the limitations of their knowledge, seek guidance, and remember I am not just a medical condition. The misguided care I have experienced (difficulties in the emergency department, accessing specialist care, and during pregnancy) has occurred when this has not been the case. When I have been cared for by a nurturing, mutually supportive team it is apparent in the sense of camaraderie, warmth, and compassion. By contrast, my experience of stressed out staff has been that of being snapped at, forgotten, and consequently feeling unsafe. I often wonder if medical professionals would

be better able to accommodate the emotional needs of their patients if they had space to explore their own feelings about the difficult work they are required to do.

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- 1 Warnes CA, Liberthson R, Danielson GK, et al. Task force 1: the changing profile of congenital heart disease in adult life. *J Am Coll Cardiol* 2001;37:1170-5.

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The bottom line

- Please consider the emotional and psychological impact of living with a serious medical condition. Acknowledge that being in and out of hospital can't be easy; let patients know that it is normal to feel frightened, angry, or upset; and encourage the presence of a caregiver to provide comfort
- If your patient has lived with a condition from birth he or she will know better than anyone when something is not right: we can help, so please listen to what we have to say. If our case is complex, you won't know everything about it; we prefer you to admit that and seek advice
- You also need to look after yourself to be able to perform at your best and to engender a supportive work culture. Value the important work that you and your team do. Support each other in taking breaks, and prioritise self care. Don't risk becoming so "burnt out" that you can no longer see the person behind the condition

Further reading

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