

Eliza's story



Eliza is now a healthy 6 year-old – thanks to her pacemaker. When Eliza was a baby, she would 'go off' – looking grey, slightly stiff and yelping for breath. As a tiny baby she had also slept for long periods (without waking to feed) although this was never linked directly to her later diagnosis.

The GP reassured me she was healthy but I knew there was something wrong when, in the middle of a children's birthday party, Eliza became upset and suddenly blacked out, going completely still and stiff and a ghastly shade of grey. She remained like this for almost a minute and only came round when I frantically stuffed a dummy in her mouth - I have to admit I was almost hysterical and thought she was dead. However, by the time the ambulance had taken her to hospital, Eliza was behaving and presenting as a healthy toddler.

We went to see a paediatrician privately and ECGs showed a regular healthy heart. Eliza had more frequent episodes of 'going off'. It often occurred when she was upset or tired. It was only because her father has an irregular heartbeat that the paediatrician referred Eliza to a cardiologist, sure that the prognosis would be healthy.

Eliza wore a 24-hour heart monitor, which I returned to the hospital for analysis. Meanwhile, she suffered another attack. The next morning I rang the cardiologist in tears, saying I was sure there was something wrong – and he began talking about 'pacemaker, heartblock, urgent'.

The heart monitor had shown that Eliza's heart was stopping for up to 11 seconds at a time, even when she didn't appear to be having episodes.

From then things moved very quickly. Within hours Eliza was in hospital and within days she had a pacemaker fitted for intermittent complete heart block and neurocardiogenic syncope.

Within a couple of months Eliza was back in hospital with a swollen red pacemaker site but a hefty dose of antibiotics brought this down.

I can still see when Eliza 'goes off' but I don't worry about it now, knowing that when her heartbeat drops to a certain level, her pacemaker takes over. We have to be watchful if Eliza is unwell without obvious cause, as this could indicate an infection around the pacemaker.

Within a year the pacemaker will need a new battery and in a few years it will need new leads. The consultant fitted the pacemaker with lengthy loops to ensure they would accommodate growth from toddler to young girl.

Eliza needs to drink plenty and eat salty food (within reason). This helps keep her blood pressure up. This advice was also given to us for Eliza's brother, Jack, who is two years older. He has been having dizzy episodes where he just falls over. A week-long heart-recording device has shown nothing out of the ordinary, so we have to trust that he is healthy.

However, Eliza's condition is always at the back of my mind. If Jack's dizziness worsens or if I see worrying similarities with the symptoms Eliza presented, I would quickly return to specialists. I'm not yet convinced that there is no connection.

Note: Since writing this case study, Jack had a nasty fall on his bike. He was badly winded and lost consciousness for several minutes, going very yellow and grey. His eyes were sinking vacantly back into his head and he could not hear, see or feel anything.

I was panicked but Jack came round on his own, though he was sick and rather wobbly. However, when he was checked at the hospital all his traces were normal and they later said it was concussion, even though he did not hit his head. Luckily Jack is already under a cardiologist and thanks to STARS he is now being monitored for RAS.