PRACTICE

WHAT YOUR PATIENT IS THINKING

Be brave

Sophie Lyons describes what it's like to be a frightened child patient, and explains why being called "brave" doesn't help

Sophie Lyons

I was born with several heart conditions. By the age of 10, I'd had around 18 cardiac procedures: three with my chest opened, others by keyhole, others simply diagnostic. All came with general anaesthetics. Throughout my childhood I was called brave and told there was nothing to be scared of. Doctors, nurses, family members—they all said these words to try and comfort me, especially when I told them I was sad or frightened. But the words didn't stop me from feeling scared. They just made me feel it was wrong to cry, to have these feelings, or even to talk about them.

I just needed a break

The most terrifying experience was going under anaesthetic. It was such an alien feeling—so different from sleeping—that I linked it to death. Every time I was put to sleep, I thought I'd never wake up again. My distrust of anaesthetists started around age 6. I was crying so much from the fear of what was about to happen that they allowed me to sit on my mum's lap in the anaesthetic room. I just needed a break; I needed her to carry me out for a few minutes, make me feel safe, and tell me it was all going to be okay, that I'd wake up again. However, the anaesthetists wafted the gas mask over my mum's shoulder instead, increasing my anxiety during future procedures.

I felt that nowhere was safe

People who I thought I could trust still insisted on taking my blood. Strangers in radiology and echocardiography gave me stickers and bravery certificates after medical tests. I felt like there were no safe spaces inside the hospital, that nobody understood me. I tried to understand what brave meant. Keeping quiet for the happiness of others? Not crying for too long to help them get on with their jobs?

The power of empathy

Years later, when I worked in a children's nursery, I often saw children in pain and distress being told they were brave, or that they shouldn't be sad or cry. It reminded me of my experience, so I tried a different tactic. One day, a child fell, grazed her knee, and was shocked by her unexpected stumble. I told her

she'd be okay, and instead of calling her brave, I told her about a friend who likes to scare me by making me jump. It made her laugh, and instead of feeling silly for falling over, she understood grown-ups can feel scared too.

I thought about how differently I might have felt about certain situations if doctors and nurses empathised more instead of calling me a word I didn't feel; if they'd explained what a test was for and why I needed it, and apologised if they could see I was upset.

Two of the best things health practitioners did for me was that one made me a chicken balloon out of a glove for doing well during a blood test (way better than a sticker) and another stuck heart monitoring stickers onto his arms for me to rip off, to balance out my pain after a day of intrusive tests. I appreciated the latter's willingness to share some of the rough ride with me, when it wasn't his heart function that was being tested. The thing I most respected with clinicians at one children's hospital, was their "three strike" policy. If they couldn't get a vein within three attempts, they wouldn't try again that day—on the one occasion this happened, they took off their gloves and aprons and told me I could go home. I felt like I finally had a bit of control in the situation.

Having worked with children, I know how frustrating it can get when you're under pressure and they're not cooperating. But just take a moment to reflect, and ask yourself: if I was this upset, what would I want someone to say, if they couldn't make it stop?

What you need to know

- Consider the impact of the word "brave" on a child patient when it is used during a time of distress
- Children's trust in their clinician can be eroded if their pain and fear aren't treated as real or important
- Designated safe spaces, allowing time for comfort and calming, or rules such as "three strikes" can help an anxious child feel respected and in control in a hospital environment

Education into practice

- Can you think of a time when you asked someone to be brave or described them in this way in a medical context? What was his or her reaction?
- What might be the benefit or harms of asking someone to be brave?
- How do you manage situations where children who are upset or worried during a medical consultation or procedure?
- Can you think of better ways in which you, or your team, could support children through difficult experiences such as procedures?
- Is there anything else you might do differently as a result of reading this article?

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SL blogs about her experiences growing up with congenital heart disease at <http://achdandme.blogspot.co.uk/>.

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