

## Ben's Story



I've been volunteering now for about 8 years and help by sharing my own experience with other expectant mums and dads at antenatal classes. I'm glad to be able to share our story as I remember how helpful that was for us at the beginning.

My son Patrick was diagnosed at the 20-week scan with coarctation of the aorta (a narrowing of the main artery leading to the heart) and AVSD, which stands for 'atrioventricular septal defects' affecting the valves in the heart.

I remember at the diagnosis we both felt completely lost - we had no context within which to understand what was happening and we didn't know anyone with any experience that we could talk to. We felt very alone.

A few weeks later we attended the antenatal class and it was the first time we got to speak to people in a similar situation and talk informally to professionals about what we should expect. It was really reassuring.

One of the highlights was hearing from a parent who was further on in the journey. Whilst her

experiences were (and continue to be, we're still in touch) different because of the health issues of her child, we got a really clear idea of what to expect, how to prepare for it, and what questions to ask.

We both came away feeling a lot more positive about what was to come and a lot more confident about the way our heart baby (and we) would be treated. **It certainly wasn't the last time we'd worry about things, but it laid quite a few of our fears to rest. That's why I thought I'd like to get involved, to tell our story as well.**

It's great when people ask lots of questions and you can see them beginning to engage - it's hard when you're feeling so overwhelmed, but coming together to talk and share is really important. It's great meeting new people and getting to know them as a volunteer and fellow heart-parent.