

## Tara's Story

Even though I felt deep down that something was wrong, having my worst fears confirmed shattered my world. The 12 week scan started off normally but then my husband and I were given the terrible news that our baby had anencephaly, a rare condition where the bones in his head had not correctly formed. I felt numb, unable to cry or absorb any information apart from the fact that it was fatal.

We were referred to the specialist medical team, seeing consultant Martin Cameron who confirmed the diagnosis and lead midwife Alison Evans who talked us through our choices about what happened next. I believe the minute you discover you are pregnant, you become a parent. You tailor your life to making sure your baby is healthy and when, on medical advice, we made the heart-breaking decision to terminate, it was as parents making the choice we felt was best for him and us.

While the internet can be a blessing, in my case I found it made the situation worse – general searches came up with horrific images as well as confusing and often incorrect facts which only muddled what I was already feeling. I wish I had stuck to the literature given to me at the time and made use of the team who are available to answer questions and give the correct medical advice. The chaplaincy team at the NNUH were a comfort, even though I do not have religion in my life.

After the procedure, it was difficult to know how to act. Very few people, outside of our immediate family, knew about the baby and we did not know whether to say anything. I was struggling to come to terms with what had happened and unsure whether I was allowed to grieve or how to do it. In the early days I felt like I needed to pretend I was strong when really I was crumbling inside.

I think the key is to take the time you need, this could be two weeks or two months. Even after I had returned to work, I had good and bad days. The smallest things would set me off – such as a colleague announcing her pregnancy or even friends and family telling me that “things happened for a reason” or it was “just bad luck” in an effort to make me feel better.

I first found comfort in a private online forum for women who had to make similar heart-breaking choices and who knew what I was going through, but what really helped me was the private counselling I received a year later through my work as part of their occupational health programme. The chance to talk about it with someone not directly connected to me, to say without fear of being judged or of upsetting someone, how I really felt was very freeing. It also helped me to reconnect with my husband, who was keeping his grief locked up because he believed he had to remain strong for me.

We will never forget our baby boy and although we are still sad that he is not here with us we can now think about him and talk about him with love – knowing that we made the right decision.