

We knew that our son Jenson was seriously ill when my wife Angela went for her 20 week scan. We were told that part of his oesophagus was missing and that he also had a problem with his heart; the blood was unable to flow from the right ventricle into the pulmonary artery and onto the lungs.

Jenson was born at 33 weeks after an emergency caesarean at The Royal Victoria Infirmary in Newcastle, 25 miles away from our home. Doctors operated just 2 days later to fit a tube into Jenson's stomach so that he could feed, it was then that we were told that he would be in hospital for the next four months as he needed to grow before further surgery would be possible.

Obviously we couldn't bear to leave our new born baby's side, but having just given birth Angela needed rest herself. We were so grateful when we were offered a room at Crawford House, The Sick Children's Trust's Home from Home at The RVI for the 18 weeks that Jenson was receiving treatment, because going home was just not an option.

The 'Home from Home' was amazing and we were astounded that such a place existed so close to the hospital wards. Our room was clean and comfortable and we had all the facilities we could possibly have asked for. Our bedroom had a telephone linked directly to Jenson's ward, so we knew we could be contacted day or night and be by his side within minutes – this meant we could really relax when we spent time in the Home from Home, both emotionally and physically.

Being able to make home cooked meals and relax in the comfortable living areas was invaluable and we found that having other families to talk to who were going through similar experiences was extremely supportive. It is very easy to feel alone when you have a seriously ill child in hospital, so being able to chat to other families who are experiencing some of the same emotions and concerns can be extremely helpful.

When you have a seriously ill child, it's easy to forget about yourself. But it's important at a time like this to keep your strength up and the Home from Home enables you to gather your emotions in privacy. I really don't know how we would have coped without The SCT; having the opportunity to stay so close to our baby and to support one another during such a traumatic time helped us all to cope so much better.

Jenson has now had all the surgery he needs to his oesophagus. He has also had heart surgery whereby a donor conduit was used to repair his heart. Further surgery will be required as Jenson will outgrow the conduit in approx 5 – 10 years but this surgery will not be as severe as the last operation. A tracheostomy tube has also been inserted into his windpipe to help him breathe, this is a temporary measure for approximately 1 year. Again Crawford House was invaluable while we received training to learn how to care for Jenson while he has a tracheostomy.

Crawford House really is an amazing place – a warm and welcoming environment away from the wards. It's hard to put into words just how much staying in the Home

from Home helps when you have a seriously ill child in hospital and how grateful we are to everyone at The Sick Children's Trust. In fact, Crawford House has become somewhat of a refuge to feed Jenson when attending the many out patient's appointments we have!

Steve, Jenson's dad