

support

A personal view of moving to adult services . . .

In the last issue of Delivery we included an article called 'Taking Liver Disease into Adulthood', which discussed some of the issues involved in moving from children's to adult services. We understand that everyone's experience of moving to adult services will be different, but here is one young adult's story.

Maribel is 25 years old and has biliary atresia. This is her personal experience of transition:

Moving from the paediatric team to the adult team is a very daunting experience for most young adults, and in my case it happened very quickly when I was 18 years old. I had been admitted to hospital and was still under the care of the paediatric team so I was put on the children's ward. During my three week stay I was told that I needed a liver transplant and because I was too old to stay under the paediatric team it was time they transferred my care over to the adult team. This news made me very anxious as I didn't know what to expect. All I knew was that not being on a children's ward meant that my mum would not be able to stay with me in hospital during admissions and that scared me. The thought of having new doctors who didn't know me was also a worry as I had built up a close relationship with the paediatric staff and doctors.

One of the clinical nurse specialists came to speak to me about the transition and introduced me to some of the doctors on the adult team who would be taking over my care. I also had the opportunity to visit the adult liver ward to see what it was like and to speak to some of the staff. It was very different to the children's ward, it seemed very quiet and everyone was older than me. I was reluctant to move because I couldn't see myself fitting in and thought I would be lonely. In time however I became accustomed to it and I got to know the staff and doctors.

The good thing about moving to adult services was that I was able to get more involved in my care and it made me want to research further about my illness so that whenever I went to clinic I could ask the doctors questions. I then began to come to clinic on my own and it gave me the confidence to take more control over my care as opposed to my mum and the doctor talking about me. The downside was that I had to make some big decisions, like signing the consent form for a transplant.

There are a lot of advantages to being in adult services, especially the involvement and knowledge you gain from taking more responsibility for your own well being. I feel really comfortable and confident now with the adult team and I know I can always talk to someone to discuss any issues I might have.

If you would like to talk about any issues raised in this article or as a parent would like to tell us your personal experience of transition, please do get in touch. You can contact the support team on: 0121 212 6023 or e-mail: info@childliverdisease.org



Maribel

In loving memory

Danny James Smith

16 June 1997 –
5 February 2002

Ellen Grace Housley

14 March 2006 –
12 January 2007

The support team would be grateful if you would note that whilst we may have met you and your child, we are not automatically informed by the hospital that your child has died. Please forgive us if we do not make contact, it probably means that we do not know. We would be most grateful if you would ask a friend or family member to get in touch.

If you would like your child's name to be included in this column or in our Memory Book please contact the support team on: 0121 212 6023