



family support



Parent Annette Orton and patient Sarah Worth told conference delegates of their transition experiences

Taking Liver Disease into Adulthood

Moving from children's to adult services is a big change for many families and like any change it can be stressful. However you feel about this change, it is important, and that's why it was on the agenda at our annual conference and why we now have a new leaflet series for parents which aims to help you through the process. We're delighted to announce that this project is being funded by a grant from the Department of Health.

We would like to share with you some of the thoughts, feelings and suggestions families and professionals have shared with us about moving from children's to adult services.

Acknowledge your feelings; it can be a difficult time

The transition from child to adult involves many different changes, all of which can seem to happen within

a very short space of time. Moving on to adult hospital services brings with it many challenges for both parents and young people. It is normal to find this daunting. For many families the medical care team at their children's hospital will have become very familiar and comfortable. Parents will have been used to being an important part of the partnership looking after their young person's medical needs. The medical team supporting them has been a safe and trusted place. Is it any wonder that many parents report feelings of loss as they leave this known situation and anxiety at the thought of getting to know a new team?

Whilst you'll never change from being a parent and wanting to be involved in discussions regarding your child's health, increasingly your child will be encouraged to take part in these discussions and will have time to talk to the medical team on their own. This is an important part of the growing up process for everyone (including the medical teams) and also helps many young people to

start to take responsibility for their liver condition. This can lead to some parents feeling left out, particularly if they've given a significant part of their life to caring for their sick child. Letting go can be very hard and it is important that you can acknowledge and express the range of emotions you may experience at this time, even if you feel positively about the changes.

Your child's feelings; everyone is different

Some young people will be ready to discuss and think about moving to adult services sooner than others, for some it won't even be an issue. From our experience boys generally find this change easier than girls. It will also differ depending on how long they have been a part of children's services and the attachments and trust they have built with that team. It is important that your child understands the process of moving to adult services and that they have the opportunity to ask questions and discuss how they feel about it. They may be worried and upset or they may be looking forward to it and see it as a positive change. Everyone is different.

Role of the medic

Consultants, nurses, play specialists, in fact everyone involved in the care of your child all tell us that they find 'handing your child over' difficult too, and you might want to take some time to speak to them and say goodbye.

Differences in adult services

Parents tell us that they are concerned that the standard of care won't be the same. It is true to say that the amount of money available to spend per patient is less in an adult hospital compared to a children's unit. It is also helpful to



Did you know?

Support sends information packs to approximately 20 families each week



CLDF Family Support Services

CLDF is constantly aiming to improve and enhance its range of services and here's an update on new range of family support services.

If you have any comments or questions about these services, please contact Ellen Cooper on: **0121 212 6014**.

- **CLDF Literature Service** — a wide range of literature including new leaflets:
 - Taking liver disease into adulthood
 - Jaundice in the new born baby
 - Routine investigations for liver disease
- **CLDF On-Call** — contact the support team via e-mail: fso2@childliverdisease.org or by phone: **0121 212 6014**. The phone service is available between 9 and 5 weekdays and most Wednesdays until 7pm. In an emergency someone can be reached on: **07831 846 760**.
- **CLDF Face2Face** — hospitals are not always the easiest place to talk confidentially, so if you would like to arrange a visit to see us in our office in Birmingham, please do get in touch.
- **CLDF Website** — www.childliverdisease.org
- **CLDF e-talk** — our new forum to exchange views and experiences — www.childliverdisease.org/forum/
- **CLDF e-news** — CLDF news to your e-mail address every six weeks. Please contact us if you would like to receive this new service.



Did you know?

CLDF has five dedicated office volunteers who help the charity on a weekly basis

The Support Team is currently developing a new support leaflet on living without a diagnosis. If you have been or are in this situation and feel you could contribute to this leaflet we would really value your comments and suggestions. We particularly want to know how not having a diagnosis made or makes you feel, and if you have any tips for other families on how to live without a diagnosis.

For more information please contact Ellen Cooper on: **0121 212 6014** or fso2@childliverdisease.org



know that the approach is very much centred on the patient in an adult hospital rather than on the family.

Many families find it hard to adapt initially; the clinics may seem less friendly, full of people and just altogether different from the clinic visits and ward stays that you are used to. If you have concerns it is important that you discuss these. You should find that over time you settle and adapt just as you did when you first started attending the children's services.

Start early

The best piece of advice we can give is to start thinking, talking and preparing early for moving to adult services. Ask questions of the team so you are comfortable with how they will be handling the transition. Units are recognising the need to have a properly managed transition programme and this will be tailored to the individual units and the adult services with which they

are linked. It may be that your child is seen at a children's hospital presently, in which case the hospital team may start discussing it with you at a particularly early age as you will be changing to a different hospital as well as a different team. It's wise to start early as transition should be phased, not rushed, and should be done at a pace suitable for your child. Find out from your medical team when and how transition will happen for you and your child.

Support for you and your young person

The CLDF support service is here for you, please do contact us if we can help in any way. Remember also that we have a young persons support officer who can help your young person through this time.

The positive

Many families find transition to be timely and smooth, some young people

are keen to move 'up' to an adult hospital where they feel they will be treated more like the adult they have become. They also tell us that they enjoy the fact that both the clinic and the ward can be quieter and calmer.

As always, please let us know what you think about this article. If any parents or young people would like to tell CLDF about their own experiences of transition we could follow up this article with your own stories in the next edition of Delivery.

CLDF now has a leaflet called 'Moving to Adult Services', part of the 'Taking Liver Disease Into Adulthood' parent series of leaflets, which you can order from us.

We look forward to hearing from you. For more information and support, please call Ellen Cooper: **0121 212 6014** or e-mail fso2@childliverdisease.org