



# family support



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Family Support Officer

## Transplant Issues

The first UK liver transplant on a child took place in 1968 and currently about 100 children receive a liver transplant in the UK every year. This article looks at just a few of the many non-medical issues that families may face before and after a liver transplant and is based on some of the concerns that families have spoken to us about. The issues, however, will vary from family to family. We have overview leaflets available on liver transplant and intestinal transplant.

Please contact the support team if you would like to discuss any issues or if you would like some information. In addition, CLDF provides a pack called "Stepping Stones in Liver Transplant" to transplant units to accompany the assessment programme. This pack is only available through the children's transplant units. CLDF is also currently working on a stepping stones pack to accompany the intestinal transplant programme.

### Before:

- **Mental preparation** — Many families have found that the best way to prepare mentally is by talking about the transplant with family and friends, asking your child's medical team all the questions that you have going through your mind and getting information. It is also important to talk about your feelings and to recognise that no one can be fully prepared for what will happen and not to be too hard on yourself when you find it tough going.

It could be the case that your child outwardly appeared to be well

before transplant and so it is difficult to accept that they need one. On the other hand, for some families the transplant is needed as a matter of urgency, so there is no time to think about it. Families tell us that it can be some time after the transplant that it all sinks in and it may be at this point that support is most needed.

- **Waiting** — Families often tell us that once their child has been placed on the transplant list it is the waiting that causes the most stress. Whether the waiting is at home or in hospital, all describe their lives as being "on hold". Sometimes you may get called in and the transplant doesn't take place as the donor organ wasn't suitable and then you have to go back to waiting. You may feel constantly anxious or you might feel calm, you might be pleased that your child is going to have a transplant or you might feel upset or angry. Some parents have said that they also felt guilty for wishing for a donor organ as it usually involves the death of another person.
- **Practical issues** — Before the transplant takes place you will also have lots of practical issues to consider, for example, arranging the care of your other children during your hospital stay, arranging accommodation, making travel and work arrangements. All of these things can have a major financial impact, adding to your stress. It is important to seek support from family, friends, the hospital team, possibly including the social worker, and financial support too in the form of benefits such as Disability Living Allowance. If your child is having a

living related transplant, there may be additional issues to think about, particularly concerning the donor and their stay in hospital and recuperation.

### After:

- **Immediately after surgery** — You will have been anxiously waiting for your child to come out of theatre and immediately after the transplant your child will be in intensive care which can be very daunting and stressful. Intensive care is very different to being on the ward and the strange environment combined with the fact that your child has just had major surgery makes this an incredibly emotional time. You may experience a wide range of feelings which could include: fear, anxiety, exhaustion — mental and physical, numbness and hope.
- **Going home** — When your child gets home there will be a period of readjustment for all the family. After having a medical team on hand it can be very daunting to 'go it alone'. If the donor was living related then there may be two people at home who need some care which can add extra pressure and anxiety. Other people's expectations that the child is now 'fixed', 'well' and 'normal' can be difficult to deal with. You can get support with these issues from your hospital team including the social worker and from the support team at CLDF.
- **Psychological and emotional issues** — having a transplant can be traumatic for both the child and their family. Some children and families react positively to the transplant and the changes it

brings to their lives, but others struggle with coming to terms with what having a transplant means. Some young people are troubled by the knowledge that they are being kept alive by having a dead person's liver inside them and some experience guilt that their life depended on the death of another. It can also be difficult to cope psychologically with the changes the transplant has made to their body in terms of the scar and their general physical appearance. Your child might ask lots of questions and you will need to decide how much information you want to give them. It might be helpful to involve the hospital play specialist with this.

Families may also find it difficult to cope with the changes in their child, although many say that changes in personality and behaviour are positive ones. You may be considering whether or not to contact the donor's family and this can raise a lot of emotions and questions which you should speak to your medical team about. It may be helpful to know that donor families say that a letter from the recipient family can be very comforting and acknowledging of the very generous gift that has been given. It is very important that you all have someone to talk to about these issues and you

might find it helpful for your child to see the hospital psychologist or for you to seek external support such as a counsellor or the CLDF support team.

To end on a positive note here is a quote from a family whose child recently had a transplant:

*"I'm quite amazed how much the transplant has changed his life, not only with his health, but also with his development, confidence and general state of mind."*

Don't forget; the support team is here if you or your child needs us. If your child has had a liver transplant and you have any suggestions or advice for other parents and patients, then please get in touch:

Ellen Cooper: 0121 212 6014  
fso2@childliverdisease.org

  
**Did you know?**

**During the past five years over 1,200 healthcare professionals have attended a CLDF study day - 98% of those attending the study days viewed the day as an effective learning experience**

# In loving memory

**Arwen Eve Waters-Goff**

21 February 2005  
– 30 May 2006

**Alexis-Faith Chandon Hudson**

15 July 2002  
– 15 March 2005

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.

