

Health concerns: **Childhood Liver Disease**

Charity CLDF offers advice on supporting young children with childhood liver disease, and their parents...

More than two children a day are diagnosed with a liver disease in the UK. Most are lifelong, life-threatening conditions caused through no fault of the child or of their parents. The causes are varied, differing greatly from those occurring in adulthood. The treatments are equally varied.

Children of all ages may be diagnosed: 50 per cent receive their diagnosis in infancy, 20 per cent during childhood and 30 per cent during adolescence. This article will focus on those diagnoses in children aged six and below.

Childhood liver diseases

Many diseases in infancy are diagnosed shortly after birth. Examples of liver diseases in this age group are biliary atresia (where the bile ducts of the liver and biliary tract become progressively inflamed and thus bile cannot flow out of the liver), affecting some 60 babies in England every year, alpha 1 anti-trypsin deficiency and Alagille syndrome. Slightly older children may be diagnosed with autoimmune liver disease, which is treated with steroids. In the case of this group, parents may have had to be assertive to obtain a diagnosis, as the signs of liver disease are often non-specific.

Treatments are varied. Some require surgery and others will be treated by medication. In babies with biliary atresia, the treatment is major surgery, preferably before the baby is eight weeks-old. The aim of the operation is to try to establish bile drainage from the liver. If this procedure fails then the only treatment option is liver transplantation. Early identification is critical, and more information can be found at yellowalert.org

Up to a third of the babies born with

biliary atresia will need a transplant before the age of one. Liver transplantation is a treatment and not a cure. It involves swapping one set of problems for another set of problems, hopefully better than the original: a lifetime of medication to prevent rejection; and medical monitoring to ensure the child stays well. There are up to one hundred liver transplants on children under the age of 18 in the UK each year. Transplant has revolutionised the outlook for children with liver disease and for many it is highly successful with children growing up and taking their liver disease into adulthood.

warning signs

Typical indicators of liver disease include the following:

- **Jaundice - yellowing of the whites of the eyes and the skin.**
- **Pale stools.**
- **Yellow urine in a baby (it should be colourless).**
- **Very yellow urine in an older child.**
- **Tiredness.**
- **Itching.**



findoutmore

Children's Liver Disease Foundation (CLDF) is a UK charity which takes action against the effects of childhood liver disease by providing support to young people affected and their families; information to families and to healthcare professionals; funds for vital research; and a voice for all those affected.

For more information on childhood liver disease, to find out how you can support the work of CLDF or to order a nursery pack, call 0121 212 3839 or visit childliverdisease.org

The effect on parents

Many parents find the time taken to obtain a diagnosis highly stressful. Some children will never receive a diagnosis. Most parents are shocked and exhibit the signs of grief; they have lost the healthy child of which they had dreamed. Medical interventions come to the fore and interfere with all the unspoken, yet accepted, things a parent does for their child. This includes feeding, as many children with a liver disease do not absorb the nutrients from their food because of the poor bile flow. They need special milk formulae and a nasal gastric tube to ensure that they remain well nourished.

There are three specialist centres treating childhood liver disease: Birmingham Children's Hospital, King's College Hospital, and London and Leeds General Infirmary. Many link with affected children's local hospitals to provide shared care once treatment has started, and the local unit will assist with monitoring the child. This helps to reduce the amount of travel but, for many parents and children, there remain frequent, stressful hospital trips and long distances to be travelled. Complicating matters, many GP practices are unfamiliar with childhood liver disease, so affected families must become experts in their child's condition and may feel they need to keep on top of things constantly in order to ensure their child remains well.

How can you help?

Accept a baby/child with a liver condition into the setting: Like any child, it is vital that babies and children with liver disease mix with their peers and develop their social skills. Parents/carers seek normality as much as possible. Children's Liver Disease Foundation has a 'schools & nurseries' pack which provides information on a range of liver diseases and has a special schools and nurseries leaflet to support early years settings.

Liaise with parents/carers: It is helpful to inform parents/carers of children with a liver disease if there are illnesses going around the nursery, in particular diarrhoea and vomiting and other childhood infections. It may mean that a child is better remaining at



home. For those babies and children who have had a liver transplant, it is vital that parents know if there is a risk of chicken pox as action may need to be taken to protect a child if they become exposed to this infection and have not had it prior to transplant.

Understand the effects of childhood liver disease:

- Some of the children may tire easily.
- Others may have an enlarged tummy because of a large spleen or liver; this may affect attainment of developmental milestones such as sitting up, or impede play.
- Watch out for signs of bullying. A jaundiced child may look different to others.
- Help families keep their child in touch with nursery friends if they have been out of nursery due to illness.

Signpost families to CLDF: Families and children may feel isolated and alone. CLDF is a national charity providing information and support, and funds pioneering research. It has projects so families can meet, share and have fun. There are under-fives' days held around the country. It has an online community (cldf.healthunlocked.com) and a programme of Skype calls so parents can talk to one another easily. There is also a families officer available to speak to families or contact them via email and Facebook.

Join in Big Yellow Friday: CLDF has a national fundraising day based on the theme of yellow on the first Friday of March every year. To find out how your nursery could join in, visit bigyellowfriday.org

IT'S GOOD TO TALK

WHEN MARIA'S SON, JAMES, STARTED AT RGS SPRINGFIELD NURSERY IN WORCESTER, GOOD TWO-WAY COMMUNICATION WAS A VERY IMPORTANT ISSUE FOR HER...

"James was born with biliary atresia and had a liver transplant when he was just 11 months-old," says Maria. "By the time he started nursery he wasn't sick but a lot of compliance was - and still is - needed to ensure he remains well, and the nursery staff were only too happy to play their part."

"Good hygiene practices, such as regular hand-washing, are vital to minimise the risk of infection for James due to his compromised immunity, and the nursery made sure this was observed. Likewise, if there was a suspected case of chicken pox, they would ring me immediately to ensure I could get the right medication to him as soon as possible. Although they communicated brilliantly with me, James was made to feel just like



any other child, which was exactly what we wanted.

"When a small child has been through a traumatic time and has been so dependent on you, letting them go off to nursery is hard, yet you know it's the right thing for them. The excellent communication I've enjoyed with RGS, where nothing is too much trouble, enabled me to do this by building up trust. James loved his time at nursery and is now enjoying school. It was the nursery staff who helped me to let go, and that is just priceless."