LIVER UK

The new name for the British Liver Trust and Children's Liver Disease Foundation

# Support through your child's liver journey



Help, support and guidance for children and families

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# Welcome

Welcome to this guide, which has been created to help you navigate your child's liver journey. It offers information, practical advice and guidance on the support available to you and your family.

**This information has been written for:**

Parents and carers of children and young people with a liver condition.

**Others who may also find this information useful:**

- young people with a liver condition
- healthcare professionals

**You may also find it helpful to read the following resources:**

- An introduction to liver disease in children
- Supporting young people – a guide for parents and guardians
- Education pack
- Siblings pack

Use this QR code to view our resources or visit **www.liveruk.org**

# Introduction

You may feel shocked and worried as you come to terms with your child's diagnosis. It's normal to feel anger, fear or helplessness and you may worry about how this will affect the rest of your family.

It can feel as though you are on your own, but you are not. **Liver UK is here every step of the way** to provide information, help and support. There are other families who have been in your shoes and you can reach out to them when the time is right for you.

Every family will have a different experience. Liver diseases can vary widely in severity and some children are affected more seriously than others. Families all cope in their own different ways.

This booklet is designed an an overview of the help and support available to you. It provides advice for parents and guardians whose child has recently been diagnosed with a liver condition. If you would like a clinical overview of liver disease in children, see our booklet "An introduction to liver disease in children."

This leaflet contains a lot of information.

Don't feel you need to read it all at once.

The Liver UK Children and Families Team are also here to provide support, advice and information.



# Medical care

There are three specialist liver centres for children in the UK:

- Birmingham Children's Hospital
- King's College Hospital, London
- Leeds General Infirmary

Most children who have a liver condition will be referred to one of these centres and will be seen by a consultant hepatologist (a specialist liver doctor).

Your child may also be seen at one of the "shared care" clinics across the UK. This is when appointments are shared between specialist liver centres and hospitals closer to where you live.

Medical professionals at each hospital will work closely together to ensure your child receives the best care. This also helps your local hospital get to know your child and their needs, should they ever need to be admitted.

There are many sources of help and support on offer within your child's hospital team. The people available will vary in each hospital, but possible team members you can speak to are:

- clinical nurse specialist/liaison nurses
- transplant co-ordinators
- play specialists
- psychologists
- consultant paediatric hepatologists
- specialist social workers
- family support workers

It can also be useful to be aware of your local community facilities such as GPs, health visitors, community nurses, school nurses and teachers.

# Looking after yourself

## The most important thing to know is that you need to look after yourself in order to be there for your child.

This means remembering to eat, exercise, sleep and give yourself time to relax. This will help you to be refreshed and more able to cope.

It may help to talk to people in similar situations. If you'd like to do this, speak to the Liver UK Families Team who can help to arrange contact.

Make sure you accept help when it's offered. You may want to deal with everything on your own, but family and friends often want to help however they can.

Useful tips:



Do something just for **you** - such as a long soak in the bath, time out with friends, going for a walk or reading a book.

Try relaxation techniques such as listening to podcasts and music.





Eat well but also treat yourself when you need it.

Get some sleep. If your child is in hospital, sitting by the side of the bed for 24 hours with no break will only make you tired, hungry and weak, meaning you are less able to support them.





Speak to other family members or friends and see if you can help each other.

Try not to feel guilty about having time for you, laughing, forgetting for a minute or giving in to your emotions.

Speak to family, friends or someone you trust about how you are feeling.

Remember that you are not just a parent or carer – your individual well-being matters too.



# Finding information

## You may want to know as much as you possibly can about your child's condition when you first receive a diagnosis.

You should be given information by the healthcare professionals looking after your child. This information may be produced by the hospital or it may be from Liver UK.

It is tempting to search online for more information. However, there is a lot of inaccurate information online, so it is hard to know what to trust.

Liver UK information has been produced with medical professionals to ensure it is accurate, up-to-date and easy to understand. Only use information from trusted sources such as Liver UK or your child's specialist centre.

Remember that information you find online may not be accurate. So if you read something which raises questions, write these down and take them to your child's next hospital appointment, call your child's clinical nurse specialist or get in touch with Liver UK.

### Social Media

Many parents join social media sites to talk with others in a similar situation. This can be reassuring for some people, but remember that you shouldn't follow medical advice from other parents because all children are unique. Two children with the same diagnosis may have different symptoms, complications and experiences.

Online forums can be a great source of support, helping you connect with others who understand what you're going through. However, it's worth remembering that people are often more likely to share their worries or difficulties than the times when things are going well.

# Advice after diagnosis

## We asked parents and guardians of children with a liver condition what advice they would give to others. Here are their top pieces of advice:

### Remember that every child is unique

Two children with the same condition can have very different journeys. It can be hard to find any positives when you receive a diagnosis, but sometimes we hear bad news and fear the worst. Childhood liver diseases can be serious and children can be very ill, but many children live full and happy lives.

### Asking questions is vital

At every step of the way make sure you ask questions of the doctors, nurses, dietitians and anyone else involved in your child's care. You can write these down before appointments and take them in with you. Or get the email address/phone number of the clinical nurse specialists at your child's specialist centre so you can contact them if you are ever unsure of anything.

You can also phone Liver UK and speak to the Families Team to ask them any questions you may have.

### Take each day as it comes

It can be difficult not knowing what the future holds, but taking each day as it comes is an important part of accepting your child's condition and still living life. You don't know what will happen in the coming months or years, so focus on the present without worrying too much about the future.

### Don't blame yourself

Your child's condition is not your fault. Some liver conditions have a genetic cause and for many more the cause is unknown, but you are not to blame.

### Normalise life. Don't let your child's condition define them

It is difficult to find out that your child has a liver condition, but they are still the same child they were before their diagnosis. It can be easy for life to revolve around their condition, but the key is to manage it while still enjoying life to the full.

**Be kind to yourself and make sure you take at least 20 minutes off ward each day to breathe some fresh air or to have a quiet coffee.**

Parent

**It is OK to deal with it differently than your partner. There is no right or wrong way to cope or respond.**

Parent

**Remember to laugh.**

Parent

**Don't let the disease limit his/her possibilities.... yes, there will be struggles but push through and you'll be stronger for it. Kids are more resilient than we give them credit for!**

Parent

# Top tips for clinic visits and hospital stays

## Clinic visits and hospital stays can be tiring, stressful and sometimes overwhelming. Here are some helpful tips to make things more comfortable.

- Be honest with children. Instead of saying, "It's fine, ...it won't hurt," you can say, "I know this is horrible but it will be over soon and then we can do something nice."
- Take breaks.
- Home comforts, such as taking your own mug, your child's own pillow, blanket and a few favourite toys, help the environment feel more familiar.
- A dressing gown, pyjamas, eye mask and ear plugs are essential for a good night's sleep.
- Pack a range of comfy clothes that you can layer, as the temperature on the ward can vary.
- As your hands can get dry with all the washing and hand sanitiser – carry a nice moisturiser to help with dry skin.
- Take all your child's medication with you so that it is all to hand if you need it or there are any questions about it.
- Carry plenty of cereal bars, fruit and other snacks as well as a variety of coins for vending machines.
- Days can feel very long, so a good book and a laptop to keep in touch with family and friends or to watch programmes on are essential.
- Keeping a diary of medical events is really useful at the time of illness (when sleep deprived) but also for emotional reflection afterwards.

**Remember: If your child is distressed during a procedure, it is ok to ask the healthcare team for a break or to try again later.**

# Blood tests and procedural distress

## Procedural distress is a combination of fear, anxiety and pain. Medical procedures can be distressing for children, their parents and healthcare staff.

There are many things that can cause a child to feel distressed or anxious, such as having a blood test or needing an injection.

A qualified play therapist within the hospital team may support your child through procedural distress. They will also work with the medical team to see if an element of choice can be brought into the procedure, e.g. asking your child which arm they would prefer to have blood taken from or which plaster they would like. This allows your child some control over the situation.

As a parent or carer, you can play an important part in supporting your child:

- Honesty is the best policy. Don't try and surprise your child with a procedure. Make sure they are aware of it and understand why it is being done before they get to the hospital or GP surgery.
- Don't tell them that it won't hurt if it will.
- Letting your healthcare team know what your child is worried about can help them find ways to make things easier. For example, they may be able to offer a local anaesthetic to reduce pain.
- There may be opportunities to distract your child with play or with a tool such as an electronic game or photo album. But be aware that some children may find attempts to distract them distressing. Consider what would work best for your child.

# Accessing support

## Being the parent or guardian of a child with a rare condition can feel isolating, but you are not alone. There is a large amount of support available for you and your family.

### Liver UK support

The Families Team is available for you to call if you have any queries.

**Call our helpline to talk to one of our team: 0800 652 7330**
**Email: families@liveruk.org**

Find out how we can help you: **www.liveruk.org/support**

Young people can access our Young People's Service (11–24). This includes access to HIVE/HIVE+, our social media platform for 13–24 year olds. Find out more at: **www.liveruk.org/young-people**.

You can contact the Young People's Team in the following ways:
**Call our helpline to talk to one of our team: 0800 652 7330**
**Text: 07928 131955**
**Email: youngpeople@liveruk.org**

Use this QR code to find out how we can help you: **www.liveruk.org/support**

# Financial Support

## Travel costs

If you receive benefits or have a low income, you may be eligible to apply for funding for travel costs for getting to hospital. In most cases, you are expected to pay for your travel and claim back the costs. For more information visit:

**www.nhs.uk/nhs-services/help-with-health-costs/healthcare-travel-costs-scheme-htcs**

## Disability Living Allowance

Disability Living Allowance (DLA) is available to help with the extra costs of looking after a child under 16 who has difficulty walking or needs more care than a child of the same age who does not qualify. They must have had these difficulties for at least three months and expect to have them for at least six months. Most children with a liver condition won't be eligible, but your child may qualify if they are very unwell.

For more information visit:
**www.gov.uk/disability-living-allowance-children**

You can call the Families Team for help and advice with your application.

Please be aware that once your child turns 16, they will need to transfer to the Personal Independence Payment (PIP).



# Education support

## Nurseries, schools, colleges and universities should put measures in place to ensure your child is safe and is supported to achieve their best potential.

An individual healthcare plan is a document that sets out your child's medical needs and how they should be handled, e.g. medicines they can administer and what to do in a medical emergency. This can help to make it easier for everyone involved in your child's care and education.

Individual healthcare plans are not the same as education, health and care (EHC) plans. EHC plans outline the support needed by children with special educational needs. Some children may have both types of plan if their needs are significant.

Liver UK has an Education Pack that explains the needs of children and young people living with a liver condition. It also includes useful templates to help support your child. You can share the pack with your child's school, nursery or other educational setting to help them better understand your child's needs.



# Siblings

## When your child is ill, it can be difficult for their brothers and sisters to understand what is happening and you may worry about how they will cope.

There are lots of things you can do to help your other children to understand and adjust:

- Make sure that siblings have an age-appropriate understanding of the illness and why their brother or sister is in hospital. It's natural to want to protect your children from worry, but not explaining what is happening may lead them to make their own assumptions, which may not be correct.
- Ensure there are times for siblings to ask questions and talk about their worries or fears.
- If appropriate, offer an opportunity for siblings to come to appointments before an admission to hospital (e.g. at pre-transplant assessment) so they can see the hospital, understand where their sibling will be, and meet some of the team.
- Provide siblings with a helping role. Make them feel involved and part of the team working to make their brother or sister better. Possible roles might be helping to pack a bag for hospital, collecting 'get well soon' messages from school, or organising decorations for the hospital room.
- Ensure siblings can communicate regularly, such as through social media, video calling or a diary.
- Consider agreeing a plan for emergency hospital admissions, e.g. they can call first thing each morning, they will be allowed to visit if the admission lasts longer than 24 hours. This may help them to feel more in control.

**Contact the Liver UK Children and Families Team to order a copy of our education pack.**

- If the child who has a liver condition is being encouraged to make a memory box or scrapbook about their illness journey, encourage their siblings to contribute to this, or even make their own.
- Where possible, support the siblings to have time together, whether that's cuddle time, talking time or simply time to have fun.
- Make sure you find space to have time with siblings not in hospital.
- If appropriate, inform siblings of Young Carers support: **www.childrenssociety.org.uk/youngcarer/help-for-young-people**

Liver UK has a Siblings Pack to help siblings understand and express their feelings during their brother or sister's liver journey. To order a copy, please contact the Liver UK Children and Families Team.

# Family and friends

## Friends and family can often feel powerless when a child is ill. It can be doubly hard for grandparents who see the effects on both their child and grandchild.

It can be helpful to keep them updated about your child's care to make them feel included. Friends and family can also provide invaluable help and support, so don't be afraid to ask. As well as offering emotional support, they may be able to help with practical tasks. For example, they could look after your pets while you're in hospital with your child, spend time with your child in hospital to give you a break, or help with the school run for your other children.

You can order a Liver UK Friends and Relatives pack, which contains information about the liver, your child's liver condition and practical information on how friends and family can help.

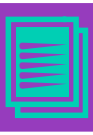
# Going on holiday

Holidays are important. They are a chance to get away, relax and spend some time with family and friends. Further along your family's journey, having a liver condition or transplant and going on holiday should be part of normal family life.

Before you book anything, talk to your nurse, specialist, consultant and/or GP and ask whether it is advisable for your child to go on holiday. It is important for them to know the details of where you are planning to travel and any planned activities. It may be that flying or travelling abroad may not be advised but a break within the UK would be OK.



Once you have had the all-clear, you can begin to plan your holiday. Wherever you are going, there are a number of things you can do to ensure a stress-free time:



Carry an up-to-date letter from your consultant or GP for insurance and security purposes, including details of your child's medical conditions/transplant, medicines and dosage.

Allow plenty of time for medicines to be ordered and collected before you travel and make sure that you have enough to cover your trip.





Some medicines to treat liver conditions or transplants can cause increased sun sensitivity. Buy sun lotion with a protection factor of at least 25+ and follow the directions for application. It is strongly advised that all transplant patients wear hats and cover up as much as possible with cool clothing.

Check whether immunisations are required and the type needed. Find out more from the NHS website **www.nhs.uk/vaccinations/travel-vaccinations** Check with your local hospital whether the type of vaccine required is suitable for your child. Live vaccines should not be given to people who have had a transplant. Your clinical nurse, specialist or consultant will be able to advise you.






If you are unsure about the healthcare available in the country you are visiting, contact the Embassy or High Commission of that country and ask for the relevant information.

All prescription medicines should be carried with you.
Check the current rules for carrying medicines in your hand luggage before you fly.



## Travel insurance

Having a liver condition or transplant may mean it can be difficult to buy adequate travel insurance. Premiums can be high if you are travelling with an existing medical condition and it is important to ensure you have the right level of cover. We advise you to shop around when looking for travel insurance to get the best quote. Be completely honest when purchasing travel insurance and be clear about the needs of your family.

If you have not fully disclosed any pre-existing illness and any medicines used, in addition to any change in condition or medication before departure, your cover may not be valid.

## School trips

All of the above information is relevant, but it is also important that the trip organisers are made aware of any medical needs and have all relevant information to hand. You may want to consider purchasing a medical alert disc, as medical professionals across the globe can access your child's medical conditions and medication from the details engraved on the disc. If your child has a mobile phone you may be able to input medical information in the medical ID section of the phone. This can be accessed without passwords in an emergency situation.



**You can find more information about going on holiday and a selection of travel insurers recommended by other parents on the Liver UK website.**

# Advice and tips from other parents

The doctors know what they are doing, trust them!

Don't Google! Ask the doctor or Liver UK.

Enjoy your baby! They are so much more than a liver disease.

It's scary as hell, take a breath and enjoy life. Go places, make memories on good days – they will get you through bad days. Smile lots.

Don't expect people who don't have a child with a liver condition to always understand. People may struggle to know what to say. Find your tribe through Liver UK – they will totally get it!

Allow yourself as a parent to feel and grieve the diagnosis, talk about it, get help and support. Then you can move forward and deal with it. You have unbelievable strength and positives will come.

Ask lots of questions but remember each journey is different. Don't hesitate to contact your care team any time, day or night. You know your child best, trust yourself.

Keep positive and try as best you can to keep some sense of normality in your family life. Liver UK has such a great support network with so many positive and inspirational stories. Lastly, fill your life with love and cuddles.



**Every child's journey is unique – what works for one doesn't for another. Never give up hope – Liver UK is always there when you need someone.**

**Always trust your instincts and be strong.**

**Get in the liver community; it's amazing what you find out.**

**Two of the most important things to remember are – don't blame yourself and there is never a stupid question.**

**Parents end up co-ordinating a lot of their child's care. As the parent your main role is to be your child's advocate, loving, comforting and nourishing their personalities.**

**Take each day as it comes**

Don't think too far ahead. Always ask questions and talk to people. Meet up with other families with liver kids and talk about your worries – it's great therapy. Liver UK staff are always there to answer any questions, and, yes, don't Google.

# Useful resources



## Useful websites

**Liver UK**
**www.liveruk.org**
Information and support for everyone living with a liver condition.

**Medicines for children: advice and guides**
**www.medicinesforchildren.org.uk/advice-guides**
A website with general advice on medicines in children.

## How Liver UK can help

A diagnosis of liver disease can be worrying, and you may have a lot of questions.

The Liver UK Children's and Families Team are here for you and for your family and friends.

Whether you have questions or just need someone to listen, we can help.

Find out how we can help you:
**www.liveruk.org/support**

Call our helpline to talk to one of our team: **0800 652 7330**

# How we produce information

## Feedback and information services

Your feedback is important to us and will help us improve our information. To provide feedback, email **patient-info@liveruk.org**

For more information on how our information was developed, visit our website: **www.liveruk.org**

## Thanks

All our information resources are reviewed by medical experts and families.

We would like to thank all our clinical experts and parent and family reviewers.



**Disclaimer**

This resource provides general information but does not replace personal medical advice. It is important to contact your medical team if you have any worries or concerns.

LIVER UK

# Donate to Liver UK

We are entirely funded by donations.

To make a gift in support of our work today, please scan the QR code or visit

**www.liveruk.org/donate**

Liver UK is the UK's leading charity dedicated to supporting adults, children and young people affected by liver disease or liver cancer. Our mission is to transform liver health by raising awareness, promoting prevention, and improving care and support for everyone affected.

**www.liveruk.org**
**info@liveruk.org**
**0300 1311 292**

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