

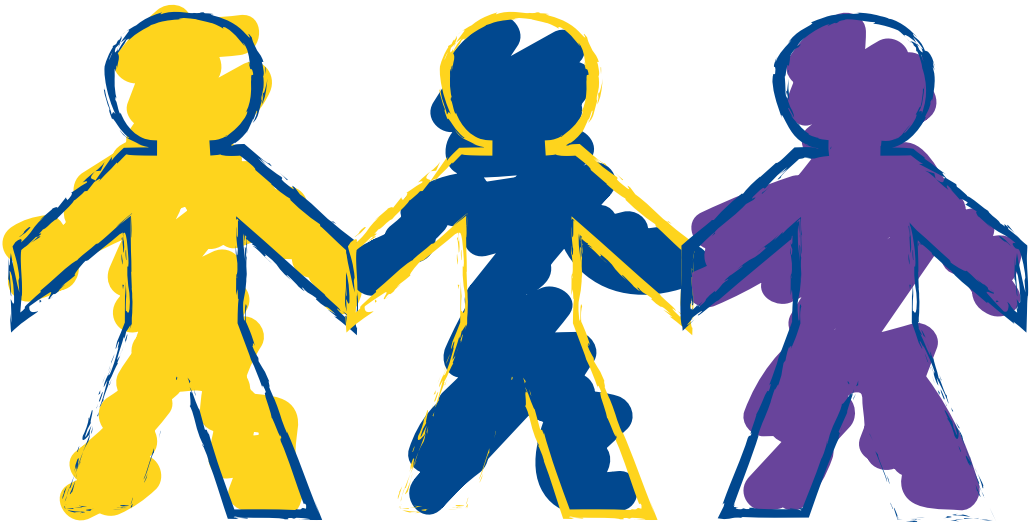


Children's Liver
Disease Foundation

fighting childhood
liver disease

Support through your child's liver journey

A guide for parents and guardians



An introduction to support through your
child's liver journey and helpful tips

This leaflet has primary been written for:

- Parents/carers of children and young people with a liver condition

Others may also find this information useful:

- Young people with a liver condition
- Healthcare professionals who would like to find out more about the practical, social and psychological impact of childhood liver conditions

It provides information on:

- What medical care to expect and the medical team
- Looking after yourself
- Information sources
- Blood tests and procedural distress
- Accessing support services and resources
- Going on holiday and school trips
- Advice and tips from parents/carers

You may find it helpful to also read the following CLDF leaflets:

- Education pack
- Siblings Pack
- Introduction to Liver Disease
- Supporting Young People – a guide for parents and guardians

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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 the implications for the rest of your family. It can feel as though you are on your own but you are not. **CLDF 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 as an overview of the help and support available to you and provides advice for parents/guardians whose child has recently been diagnosed with a liver condition. If you would like a clinical overview of liver disease in children see CLDF's leaflet "An Introduction to Liver Disease."

Medical Care

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

- 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 ensures that your local hospital becomes familiar with your child in case of admissions.

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 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.

Support through your child's liver journey

It may help to talk to people in similar situations. If you'd like to do this, speak to CLDF's 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, 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.



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

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

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 about your child's condition from the healthcare professionals looking after your child. This information may be produced by the hospital or it may be from CLDF.

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.

CLDF 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 CLDF or your child's specialist centre. Remember 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 CLDF. Also, information can quickly become outdated so make sure you check when it was last updated.

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 and that all children are unique. Two children with the same diagnosis may have different symptoms, complications and experiences.

Always talk to a medical professional if you have any worries or concerns about your child.

Online forums can be emotionally supportive and it can help to talk to others who have been in your situation but remember people may often post about difficulties rather than when things are going well.

Advice after diagnosis

We asked parents/guardians of children with a liver condition what advice they would give to others. Here are their top pieces of advice for those with children newly diagnosed with a liver condition.

- **Remember 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 phone them if you are ever unsure of anything.

You can also phone CLDF 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

**"Remember to laugh."
- Parent**

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

- Being honest with children is vital. Instead of saying, “It’s fine, daddy/mummy is here...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 when you’re in hospital, 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.

Blood tests and procedural distress

Procedural distress is a combination of fear, anxiety and pain. Medical procedures can be unpleasant for children and sometimes it can be very distressing for them, their parents/carers and even the staff looking after them.

There can be many triggers for a child to become distressed e.g. needles for blood tests.

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 sticker/plaster they would like. This allows your child some control over the situation, which may help them to overcome the pain, discomfort and fear they experience.

As a parent/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. It may be best to 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.
- By making sure the healthcare team know about your child's fears they may provide options such as offering local anaesthesia or a play specialist to support your child.
- There may also be opportunities to distract your child with play or with a tool such as an electronic game or photo album. Be aware that some children may find attempts to distract them distressing. Therefore, consider what would work best for your child.

Accessing support

Being the parent/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.

Children's Liver Foundation (CLDF) support

The Families Team is available for you to call if you have any queries. There are also events you can attend with other families to share your stories and build relationships with others in similar situations.

You can contact the Families Team in the following ways:

Call: 0121 212 6023 (Monday to Friday, 9am – 5pm)

Email: families@childliverdisease.org

**Complete the online contact form:
childliverdisease.org/cldf-support-service-form**

Young people can access CLDF's Young People's Service (11–24). This includes events where they can meet other young people and access to HIVE/HIVE+, CLDF's social media platform for 13–24 year olds. childliverdisease.org/young-people/hive.

You can contact the Young People's Team in the following ways:

Call: 0121 212 6024 (Monday to Friday, 9am – 5pm)

Text: 07928 131955

Email: youngpeople@childliverdisease.org

**Complete the online contact form:
childliverdisease.org/cldf-support-service-form**

CLDF runs events and activities around the UK with the aim of bringing families affected by childhood liver disease together. Different events are held around the country and there is something for everyone and all ages from one day events to weekends and longer residential trips. To find out more see CLDF's events calendar online.

You may also find it helpful to contact other organisations or peer support groups such as PSC Support, PFIC Network and hospital support teams.

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:

nhs.uk/NHSEngland/Healthcosts/Pages/Travelcosts.aspx

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, however your child may qualify if they are very unwell.

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

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 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.

CLDF has an Education Pack available with information about the needs of children and young people with a liver condition and includes useful templates. You can give this to your child's educational establishment.

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, such as:

- Make sure that siblings have an age-appropriate understanding of the illness and why their brother or sister is in hospital. You can try to protect the well sibling but this may lead to them developing their own (often incorrect) interpretations of the situation.
- 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 who will be looking after their brother or sister while they are in hospital.
- 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 Skype, 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.

- 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: childrenssociety.org.uk/youngcarer/help-for-young-people

CLDF has a Siblings Pack to help start conversations about their feelings and to provide helpful tips. You can contact the CLDF Families Team to order a copy.

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 and make them feel included. Friends and family can also provide invaluable help and support so don't be afraid to ask. As well as providing emotional support they are often keen to offer practical support, such as looking after pets if you are in hospital with your child, sitting with your child in hospital to give you a break or picking your other children up from school.

You can order a CLDF 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. If you would like to order a pack you can call the Families Team or order one from the CLDF website.

Going on holiday

Holidays are important. They are a chance to get away, relax and spend some time with family and/or 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 activities. It may be that flying or travelling abroad may not be advised but a break within the UK would be OK.

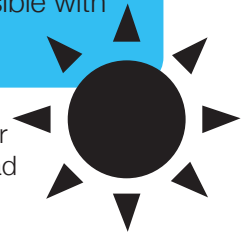
Once you have had the all-clear, you can begin to plan your holiday. Wherever you are going there, are a number of things you can do to ensure a stress-free time:

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 ([nhs.uk/conditions/travel-vaccinations](https://www.nhs.uk/conditions/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/guardians on the CLDF website.

Advice and tips from other parents

The doctors know what they are doing, trust them!

Keep positive and try as best you can to keep some sense of normality in your family life.

CLDF has such a great support network with so many positive and inspirational stories. Lastly fill your life with love and cuddles.

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

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 CLDF – 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.

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

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

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.

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.

Always trust your instincts and be strong.

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

Don't Google! Ask the doctor or CLDF.

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. CLDF staff are always there to answer any questions, and, yes, don't Google.

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.

Notes

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Notes

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CLDF produces a wide variety of information resources for children and young people up to the age of 25 with liver disease, their families and the healthcare professionals who look after them. This information can be downloaded or ordered from CLDF's website childliverdisease.org. For further enquiries regarding CLDF's information please contact the Information & Research Hub Manager by email at irhm@childliverdisease.org or call **0121 212 6029**.

Thanks

The booklet has been written, edited and reviewed with the help of staff at each of the specialist paediatric liver centres: Birmingham Children's Hospital, King's College Hospital and Leeds Children's Hospital as well as parents/guardians and young people. Thank you to everyone involved who have made the production of this leaflet possible.

Disclaimer

This leaflet provides general information but does not replace medical advice. It is important to contact your/your child's medical team if you have any worries or concerns.

Feedback and Information Sources

Information within this leaflet has been produced with input from the three specialist paediatric liver centres in the UK. To provide feedback on this leaflet, for more information on the content of this leaflet including references and how it was developed contact Children's Liver Disease Foundation: info@childliverdisease.org

This leaflet has been reviewed in February 2020. It is due to be reviewed by February 2023.

What is Children's Liver Disease Foundation (CLDF)?

CLDF is the UK's leading organisation dedicated to fighting all childhood liver diseases. CLDF provides information and support services to young people up to the age of 25 with liver conditions and their families, funds vital research into childhood liver disease and is a voice for everyone affected.

Are you a young person up to the age of 25 with a liver condition or a family member? CLDF's Families and Young People's teams are here for you, whether you want to talk about issues affecting you, meet and share with others, or just belong to a group which cares, knows what it's like and is fighting to make a difference. You are not alone.

If you are a parent/carer or family member then get in touch with CLDF's Families Team:

Phone: 0121 212 6023 **Email:** families@childliverdisease.org

If you are a young person and want to find out more about CLDF's services you can contact CLDF's Young People's Team:

Phone: 0121 212 6024 **Email:** youngpeople@childliverdisease.org

CLDF have a dedicated Facebook page called HIVE/HIVE+ for 13–24 year olds with a liver disease/transplant to make new friends, connect and share stories childliverdisease.org/young-people/hive

Would you like to help us support the fight against childhood liver disease?

CLDF's work relies on voluntary donations. Please help us to continue to support children, young people and families now and in the future. To find out more about fundraising and how you can join the fight against childhood liver disease you can visit childliverdisease.org/support-us. Alternatively you can email the Fundraising Team at fundraising@childliverdisease.org or call them on **0121 212 6022**.

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Main site: childliverdisease.org

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Children's Liver
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fighting childhood
liver disease