



Children's Liver
Disease Foundation

fighting childhood
liver disease

Living without a diagnosis

A guide for parents and guardians



Information and helpful tips on living
without a diagnosis

This leaflet has been written for:

- Parents/guardians of a child/young person living without a diagnosis

Others may also find this information useful:

- Young people living without a diagnosis

It provides information on:

- Why some liver conditions are difficult to diagnose
- Tips and advice on coping and living without a diagnosis
- Sources of support when living without a diagnosis

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

- Introduction to Liver Disease
- CLDF Pack – introduction and starter kit of vital information
- Education Pack - a pack supporting children and young people under 18 in an educational setting
- Support through your child's liver journey
- Supporting young people - a guide for parents and guardians

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Introduction

Research and developments in science and medicine are continually advancing. For this reason, many believe that doctors can always diagnose a child's condition. This isn't always the case and it can be a distressing time. Living without a diagnosis can be a lonely and frightening experience.

Parents may worry that it may be their fault their child has a liver condition without a formal diagnosis. It is important not to blame yourself.

Parents have said:

"To begin with I blamed myself, then we spent a lot of time trawling the internet for answers. Now we have come to terms with things." - Parent

"We feel in limbo and as though we are playing a waiting game." - Parent

"At first it is extremely worrying and frustrating. You can't help but think you must have done something wrong at some stage and you keep asking yourself what it was and what the future holds for you." - Parent

"Despite feeling isolated and unique we now know there are a number of families in our situation. This doesn't make day to day living easier but does let you know you're not alone in your feelings." - Parent

"The hardest thing about no diagnosis is not knowing what the future holds and not being able to research a specific condition. Only time will tell which way things will go and some days that is really tough. It's also hard to find other people in the same situation so it can feel a bit lonely at times." - Parent

Why are some liver diseases hard to diagnose?

Very rare conditions are sometimes difficult to identify. Finding a medical professional who specialises in particular conditions may take time, leading to a delay in diagnosis. It may also be the case that some conditions have similar features and symptoms which make it difficult to be accurate about a diagnosis. Furthermore, certain features may not appear until your child is older, resulting in a delay or change of diagnosis at a later stage. A further reason may be that your child has signs and symptoms which do not fit into one specific condition.

Why do I need a diagnosis?

It is natural to want to have a diagnosis. Without a diagnosis, parents have said they feel everyone's lives are on hold. Trying to understand what is happening and facing uncertainty about the future can be very tiring, emotionally and physically.

Parents said they feel a diagnosis may:

- help them to find out more about the disease, which empowers them when talking to doctors and other professionals
- enable them to speak to other parents whose children have the same disease
- help as their child grows up as they often want to know why this happened and what the cause is.

It's important to remember:

- care or treatment should be tailored to your child's needs, not to the name of their condition. However, a diagnosis may enable a more focused care or treatment plan.
- you are entitled to have a social services assessment of your child's needs and your needs as a parent/carer, whether your child has a diagnosis or not.
- you are entitled to apply for benefits such as Disability Living Allowance (DLA) even if your child does not have a diagnosis. It is sufficient that they have some form of disability even if this has not yet been formally diagnosed.
- if required, your child may be entitled to extra support to help them at school.
- it may be more difficult to find travel insurance if you are unable to name your child's condition. Syndromes Without A Name (SWAN) UK is a national network for families with children with undiagnosed genetic conditions. This community may be able to signpost you to helpful insurance services.

How do you cope without a diagnosis?

When we encounter a difficult or stressful life situation, we react in various ways to try to make the situation better or to decrease the difficult feelings that the situation has created. These reactions are called coping responses.

There are two main types of coping strategies: emotion-focused and problem-focused.

Emotion-focused coping strategies involve anything a person does to feel better or less stressed in order to decrease the negative feelings. This may include:

Expressing feelings to a friend



Taking medication to reduce anxiety

Meditation

Going shopping



Going to the movies

Problem-focused coping strategies involve anything a person does to try to change and improve a situation. This may include:

Creating a to-do list



Preparing questions

Asking friends for help or advice



Contacting people for information

Making a compromise

If you are in a relationship, you may find that you and your partner cope in different ways, or even similar ways but at different times. This can be frustrating or difficult to understand. It is important to try to respect and understand how the other person is coping and allow them the space and time to do things in their way and time.

There are no right or wrong answers to the way in which we cope. It may be helpful to think about or even keep a diary of your feelings and the coping strategies that you adopt.

What can parents do?

Hospital appointments and investigations

Tests and investigations may be carried out in order to eliminate or provide evidence for a range of possible conditions. Each test result is like putting a piece into a jigsaw puzzle. On its own it will give some information but putting it together with other test results, the history of your child's condition and how they are in themselves, will be much more useful.

Hospital appointments also provide the opportunity for you and your child to ask questions. Children's Liver Disease Foundation provides further information on preparing for an appointment online.

"Try to be as involved as possible with your child's care — ask lots of questions and don't feel overawed by doctors." – Parent

"Make sure that you attend all check-ups, even if your child seems well." – Parent

Find out who's who

Whilst trying to find a diagnosis you may find that you come into contact with a wide range of professionals. As you meet each professional it may be helpful to write down their name, contact details and profession. This will help you to contact them, should you have any more questions.

Keep records

Keeping up-to-date medical records and taking them along with you to each appointment, especially if you have a shared care programme, can help your local hospital to understand. Keeping a diary as an ongoing picture of your child's development may not alter how things are, but it may give a perspective to health professionals and others who monitor your child. Writing down your own thoughts and feelings may also help to release some of your frustrations. Keeping a list of all the ways your child is affected and taking copies to professionals involved in the care of your child can also save you from repeatedly having to explain your child's medical problems.

"Keep detailed records about how the illness affects your child so that you can be exact about what happened and when." – Parent

Persistence and speaking up

We know that this is a very anxious time for you. It is easy to become confrontational and frustrated. It is helpful if you can find ways of working in co-operation with professionals. At the same time, you may have to be politely persistent. Often parents feel they have received help because they were prepared to speak up. If you feel strongly that all avenues to try to get a diagnosis

have not been explored, you should discuss this with your child's doctor or paediatrician. You know your child. If something doesn't feel right or if you are uncertain then say so.

Part of CLDF's role is to empower you as a parent. You may like to contact CLDF's Families Team to talk through your concerns. Details can be found further on in this booklet and on the back page.

Accurate information

You may want to find written information about your child's condition and the internet is an important information source. It is important to remember that anyone can upload information to the internet. The information you find may not come from a reliable source or could be out of date, so it is worth checking with a medical professional. Researching every condition that is being investigated can be very time consuming and may cause unnecessary concern and confusion. Medical professionals may be eliminating conditions in order to get closer to finding the right diagnosis.

Children's Liver Disease Foundation has an extensive range of literature available for families, friends, relatives and young people. Each of these leaflets has been carefully written with assistance from appropriate specialists.

You don't have to do this alone

Without a diagnosis you may not know who or where to turn to for support leading to feelings of isolation.

CLDF is here to help. Support is not a one-size-fits-all area and you may find that you gain support from talking to other parents through Facebook, talking to a member of the Families Team or meeting other families at CLDF events.

"CLDF's website has been great and looking at it makes you realise you have not been the only family going through all the stress. You find out that children are doing well and there are many liver diseases where the cause is never known." - Parent

Research

Through research new diagnoses are being made all the time. In order to do so, hospital teams often ask parents to give permission to take excess tissue from tests such as a liver biopsy or blood samples so they can be stored and used for research years later. You can help by giving consent which may help other families and/or your own child in the future.

Additional help and information

Your child's hospital team

Your child's hospital team can be contacted for additional help and information. They may be able to signpost or refer you to specific support to help your individual circumstances. The people available will vary in each hospital but possible team members you can speak to are:

- clinical nurse specialist/liason nurses
- play specialists
- psychologists
- specialist social workers
- family support workers

Children's Liver Disease Foundation

CLDF has a wide range of information and services which you may find helpful. These include:

- An extensive range of literature for parents, young people, relatives and friends
- CLDF website
- CLDF Facebook
- CLDF dedicated online forum run through **HealthUnlocked**
- Family events
- The CLDF Children and Families Officer who provides support to parents and relatives affected by a childhood liver condition

If you would like to talk or find out more, the CLDF Families Team can be contacted on **0121 212 6023** or by email

families@childliverdisease.org

Contact a Family

This is a charity providing support and advice to parents whose child has a medical condition or disability. Contact a Family can provide financial and benefits advice, information leaflets, information on support groups, contact with other families and other sources of support.

Free phone: 0808 808 3555

Website: contact.org.uk

Genetic Alliance UK

A national alliance of organisations. The group's primary goal is to promote awareness and understanding of genetic disorders so that high quality services for people affected by genetic conditions are developed and made available to all who need them.

Website: geneticalliance.org.uk

Rainbow Trust Children's Charity

A charity that supports families with a seriously ill child aged 0–18 years who are in the greatest need and require bespoke support. They offer family support workers in nine locations across the UK who provide emotional and practical support for families at home, at hospital and in the community.

Website: rainbowtrust.org.uk

SWAN — Syndromes Without A Name

This is a group providing support and information to families who have a child with an undiagnosed condition.

Phone: 020 7704 3141 **Website:** undiagnosed.org.uk

Financial support

Support can be gained from your local Citizens Advice Service. The direct government website provides a list of all public services all in one place.

Website: citizensadvice.org.uk **Website:** direct.gov.uk

Counselling services

British Association for Counselling and Psychotherapy (BACP) or Counselling Directory can be helpful if you feel psychology and counselling services would be beneficial for you and your family

Website: bacp.co.uk

Website: counselling-directory.org.uk

You can also contact your GP and request free counselling through the NHS. This may be difficult in some cases due to waiting lists and prioritising those most in need but it is always worth enquiring.

There may also be local charities/voluntary organisations/schools who can offer low cost or free counselling services in your area. CLDF's family support team can help you to find these if you require assistance.

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 and Research Hub Manager by email at irhm@childliverdisease.org or call **0121 212 6029**.

Thanks

This booklet has been written, edited and reviewed with the help of staff at each of the specialist paediatric liver centres: Birmingham Women's and Children's NHS Foundation Trust, King's College Hospital and Leeds Children's Hospital as well as parents/guardians and young people. Thank you to everyone involved who has 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 March 2020. It is due to be reviewed by March 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 has a social media platform called 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 and fundraising. 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/get-involved**. Alternatively, you can email the Fundraising Team at **fundraising@childliverdisease.org** or call them on **0121 212 6022**.

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