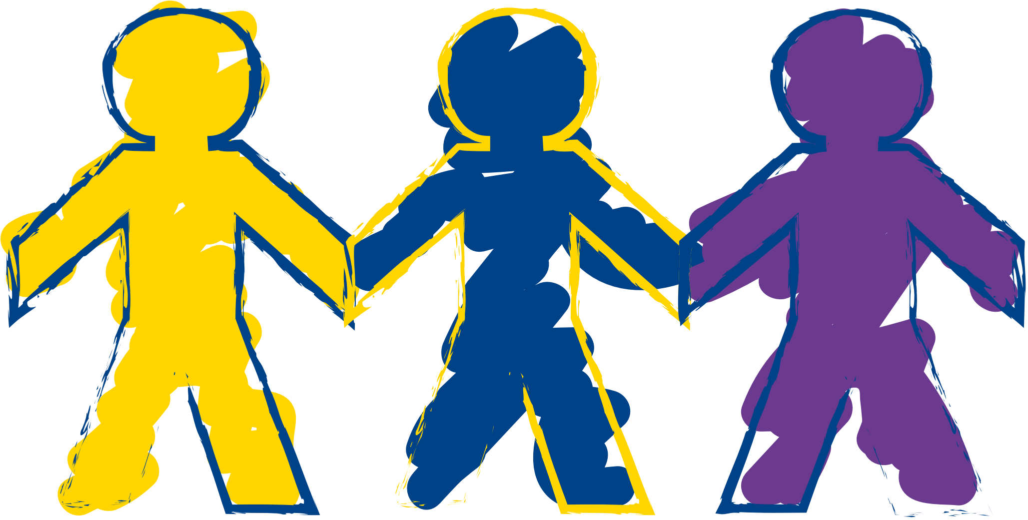
Children's Liver
Disease Foundation
fighting childhood
liver disease

Supporting Young People

A guide for parents and guardians



Information and helpful tips on supporting young people with a liver condition

This leaflet has primary been written for:

- Parents/guardians 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 social and psychological impact of childhood liver conditions during adolescence

It provides information on:

- Supporting your child as they grow up
- University and careers
- Benefits
- Prescription charges
- Moving into adult services (transition)
- Support services available
- Hint and tips from other parents and young people

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

- Liver Disease: A Guide for Young People
- Inspirational Young People
- Support Through Your Child's Liver Journey

Supporting your child as they grow up

During the teenage years there is a period of change as your son or daughter moves from being a child to an adult. There are several key transitions that take place such as moving schools, entering further education, taking more responsibility for decisions and starting a job.

A child with a liver condition must contend with growing into adulthood with their disease. This can affect the whole family.

There are a number of ways you can support your child to take responsibility for their condition and allow them to experience growing up just like any other teenager wherever possible:

Understanding their condition

Support your child to understand their condition, including the implications for their future, to the best of their ability.

Medication responsibilities

Encourage them to be responsible for their medicines. You may need to supervise at first but also learn to trust them once they feel confident in managing their medication. Be aware that problems taking medicines (non-compliance) can happen at any time and therefore it may be helpful to talk through the implications of not taking medicines.

Socialising with friends

Allow your child to stay over with friends because this will encourage them to organise their own medicines as well as mix with their peers.

Lead role at consultations and appointments

Allow them to speak for themselves at consultations and/or encourage them to have discussions with the doctor without you present. You may want to suggest writing down questions before their appointment.

If you find that healthcare professionals address you first, direct them to your child so that they are included in the discussions.

Be aware that your child may want some privacy, e.g. if they are having a physical examination.

Part-time/holiday jobs

If your child is well, allow them to take on other responsibilities such as a part-time or holiday job. Check with your hospital team that the work they want to do is suitable for them given their specific liver condition.

School trips

As long as your child is well, the hospital are aware and with good communication with the school, there is no reason why your child should not take part in school trips (both in this country and abroad). However, it is always best to confirm this with their medical team. CLDF has useful information online about going on holiday.

Medical alert devices and peace of mind

Register your child with MedicAlert or a similar scheme. This allows your child to wear an identifying piece of jewellery with emergency contact details and important information about their condition and medication. 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.

University, careers and finances

When your child has needed more support than most and has faced many challenges, the task of letting them go is often much harder. It is normal to feel concern, anxiety and even a sense of loss when your child starts to become more independent. Remember that independence is vital for a child to develop. It may help to encourage young people to discuss their wishes and plans for the future. Help them to be realistic without damaging their aspirations and dreams. There is a lot of help out there to prepare young people for these decisions.

Careers

There are number of support and guidance services available to help young people with careers advice such as:

- Schools career service
- National careers service
- Job Centre Plus
- Work experience
- Voluntary work

Universities and discretionary grants from local authorities

Always research the UCAS information available from schools and colleges. Consider what provision is best for your child, e.g. campus universities that provide accommodation close to lecture venues may work better for young people who experience fatigue/tiredness. They are also more likely to have a medical centre nearby.

It is important that your child registers with a new GP as soon as possible and that the practice is updated with their health needs. At this stage young people should be well versed in managing their medication and will need to ensure they are able to access a supply of medication while at university.

Young people with a liver condition may be able to access extra help in examinations, such as rest periods and/or extra time, if their tutor thinks that this is appropriate.

Socialisation is also a very important part of university and college life. Make sure your son or daughter has had the opportunity to discuss safe sex, contraception and safe limits for alcohol use. CLDF has a leaflet which may be useful called 'Liver Disease: A Guide for Young People.'

There may be grants and local authority funding available for non-advanced college courses, especially for families with a low income. Grants for disabled students may also be available to help support students with special needs. These grants cover personal support needs or provide equipment such as computers. Advice on Disabled Students' Allowance and associated support can be accessed via **dfes.gov.uk/studentsupport**.

A useful website for those moving on to work or higher/further education is the National Bureau for Students with Disabilities at skill.org.uk

Benefits

Once a child turns 16, the Department of Work and Pensions will pay any benefits they are entitled to directly to them. There may also be a change to the benefits they receive. For example, if they receive Disability Living Allowance (DLA) they will continue to receive this until they are invited to apply for Personal Independence Payment (PIP) after the age of 16. It is important to ensure your child has a suitable bank account and understands how to manage their money. Ensure they check with Job Centre Plus to make sure they are receiving everything they are entitled to.

Prescription charges

In England, young people over the age of 18, or over 16 and out of full-time education, have to pay for their prescriptions. A prescription prepayment certificate (PPC) can reduce the cost of prescription charges if you need multiple medications.

There may be help with prescription charges if a young person receives benefits. For example, they may be able to apply for an exemption certificate if they are on a low income. Parental income is not included in the assessment.

Prescription charges were abolished in Wales in 2007, Northern Ireland in 2010 and Scotland in 2011.

You can find further information online at
nhsbsa.nhs.uk/check-if-youre-eligible-help

Moving into adult services (transition)

Transfer to adult care occurs at the end of a transition process that is personalised for each patient. It takes into account all aspects of growth and development. Good communication with the young person, family and adult hepatologist is essential so that anxieties are addressed. Attention should be paid to psychological and social issues to address non-compliance with treatment, which is particularly prevalent in adolescents. The young person must have self-management skills (which should be assessed) and there should be plans for long-term social support before transfer. Transition should be a positive process.

You and your child will notice many differences between the children's hospital/ward and adult services. The table outlines some of the changes that you may need to adjust to or prepare your child for.

Paediatrics	Adult services
Family consultations	Individual consultations
A team of different professionals and types of support available such as family support worker, play worker, psychologist, dietitian and a specialist nurse	Limited team support
Fewer patients	Large patient numbers
Treatment by a medical team with specialist knowledge of childhood liver conditions	Staff may have less experience of rare childhood liver conditions
Medication is usually free	Prescription charges apply
	Procedures may be done differently in an adult unit

The process and time (12–36 months) for transition varies in each hospital and for each child but discussions may start taking place as early as 12 years old. Your child will see some or all of the following people:

Paediatric Clinical Nurse Specialist, Adult Clinical Nurse Specialist, Consultant Paediatric Hepatologist, Consultant Adult Hepatologist, Key Worker, Child Health Adolescent Worker or Youth Worker.

Your child may have joint clinics where members of both the paediatric and adult teams are present.

What does it mean for me and my family?

The experiences and feelings about transition to adult services will be different for everyone. Transition can often be talked about in a negative way due to the change and anxieties that it often presents. However, for many young people and families, transition has been a positive experience of development and independence.

Teenager/young person

Given Choices

Excited

Sad to leave the team they have grown up with and having to build trust with a new team

Develop confidence

Lost

Feel listened to

Vulnerable

Greater independence

Accountable

Uncomfortable

Parent/guardian

Less reliance on parents/guardians allow everyone more freedom

Practical concerns

Child develops own friendships and networks

Loss of control

Sense of loss

Worry

Left out

Child develops self-management skills – less worry for parents/guardians

As a parent/guardian you may find it difficult to cope with your reduced role in the medical care of your child. Remember you should still be actively included where and when appropriate.

The medical team may feel your child is ready to be seen independently at an earlier age than you feel is appropriate. The most suitable age for transition to adult services is different for each child and it is important that both medical professionals and parents/guardians appreciate this. Don't be afraid to question doctors and ask for further clarification or support during these discussions. You should feel you are able to advocate for your child if they want somebody to accompany or support them during an appointment. Your medical team will want to make the change as easy as possible for you and your child to ensure that it is a positive process.

Support for young people

Children's Liver Disease Foundation (CLDF)

Young people, aged 11–24, can contact CLDF's Young People's team, if they want to talk about issues affecting them, meet and share with others or belong to a group who care and understand what it is like to live with a liver condition. They can attend young people's events organised throughout the year and join a dedicated Facebook page called HIVE/HIVE+ for 13–24 year olds to connect and share stories at childliverdisease.org/young-people/hive.

If you are concerned about a young person, you can also contact CLDF's Young People's Digital and Engagement Officer:

Email: youngpeople@childliverdisease.org

Call: 0121 212 6024

Text: 07928 131 955

If you are a relative of a young person with a liver condition who would like direct support for yourself, you can contact CLDF's Families Officer:

Email: families@childliverdisease.org

Call: 0121 212 6023

Online contact form:
childliverdisease.org/cldf-support-service-form

Hospital teams

Young people can ask their medical or transition team for support through the process of moving to adult services. If they are based at a regional centre, they may be able to access youth work services. There may also be peer support available for young people at their hospital if they are attending transition clinics. Please contact your child's medical/transition team to discuss this.

Other families

Contact with another family can be of great help and an exchange of shared experiences lessens isolation and anxiety. CLDF may be able to help put you in contact with other families who are best suited to your needs through introductions at events, or where appropriate, through telephone/email contact.

Talk Tell Transform

This is a project where 16–18 year olds are given the opportunity to create films and share an aspect of their liver disease journey. These films provide great insights into the thoughts of many teenagers during adolescence and transition to adulthood and adult services.
childliverdisease.org/talk-tell-transform-films

Hints and tips

- Think about how and when you want to say goodbye to the children's team, allow yourself time to come to terms with this
- Get to know the new teams
- Think about how you and your child will negotiate your new roles
- Familiarise your child with their medical history and other important health information
- If you are worried, raise it with the team – if you are not supported it will make it harder for you to positively support your child through the transition period
- Arrange for part of their appointments to take place without you as they get older
- Empower your child to advocate on behalf of themselves
- Educate yourself and your child about the adult facility (with consideration of location, parking, travel and pharmacy)
- Encourage your child to learn about their medications – names, purpose, dosage and frequency
- Find out about practical issues relating to your child's needs; appointments, supply of medication and supply of essential medical items and equipment
- Show your child early on how to access information, resources and equipment
- Health and well-being knowledge – educate your child about more than just their liver and talk about emotional health, nutrition, fitness and personal safety

Advice from other parents/ guardians and young people

Here are some things that other parents/guardians want to share:

It's important for your child to know when and how to request a repeat prescription through their GP, including important details such as allowances for Bank Holiday closures

Although it is scary allowing your child to organise themselves, it is really important to start this at an early stage so you can tackle a little at a time

It might be helpful to have an alarm on their phone to remind them to take their medication. It may have a different ringtone to their other alerts, so they know what it's for

Encourage them to take the lead at their hospital appointments. It might help to talk to them in advance about how they have been health-wise to give them time to prepare for the discussion with their medical team. Ask them to write down notes if it helps them to remember everything or get over any initial nerves they might have

Find out if your child's specialist hospital has a consultant/clinic dedicated to transition. Ask if your child can be seen there if they aren't already, as this will help support them on their journey

Remember that they won't be able to apply to a wish charity once they are 18

Get them involved in planning their journey to appointments

Start talking about some of the changes early on, e.g. blood tests without numbing cream, biopsy with local rather than general anaesthetic, endoscopy with throat spray. This way it's not a shock when it happens

Here are some things that young people want to share with parents/guardians:

There's a different atmosphere in adult services that you need to prepare for. It is very matter-of-fact in adult services

Parents – it is not your fault

Transition is like moving from junior to senior school, it's terrifying, it's bigger, you don't know anyone and they don't know you...but just like senior school you get used to it

Sometimes I am too tired for family things, it's not that I'm avoiding them

Recognise that I do have bad days and that is OK

Encourage me to do things I want to do and reassure me that it will not hold me back

Thank you for being strong

Let me take responsibility for my illness

You've taught me about how to care for myself, so trust me to use your lessons.

It's good for us to have our own independence

We appreciate all your support and help

Trust that I know my body and can have responsibilities

If I say I'm OK, I'm OK. Don't worry too much.

Biopsy – I need you to be reassuring for me. In adults, you must have it when you are awake but it's not painful and can be over quite quickly.

Although your child is starting transition, they may still need you there at appointments for support.

Although I am older it doesn't mean I don't still struggle

Keep pushing me to do things that are out of my comfort zone as they end up being really good

Don't push me to talk

Thank you for all the time you give up for appointments and for always being there

Notes

Notes

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 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 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/guardian 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 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/get-involved**. Alternatively you can email the Fundraising Team at **fundraising@childliverdisease.org** or call them on **0121 212 6022**.

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0121 212 3839 info@childliverdisease.org
Main site: childliverdisease.org

Registered Charity Number: 1067331
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