



Children's Liver
Disease Foundation

fighting childhood
liver disease

Liver

Disease

A guide for young people.



Introduction

This information covers a range of topics chosen by young people.

The content can't be specific to everyone's different abilities, cultures, religions, sexual orientations or health conditions, but CLDF recognise that everyone is unique. You can always contact CLDF's Young People's Team and there are a number of

links at the end that you can visit for more specific information on anything raised in this booklet. It's also really important to build a positive relationship with your liver team and your local GP as they are there for you too.

No question or concern is too silly and they've probably been asked the same thing many times before. Don't forget, if you want to chat with other young people you can join

HIVE, CLDF's social media platform for 13 – 24 year olds. You can chat, share

stories and experiences and connect with other young people with a liver disease.

Growing up can be difficult for everyone but if you have a liver condition or have had a liver transplant, there are some extra things you may need to think about. This booklet aims to give you information about health choices and decisions related to you.

There's information on areas which may relate to your liver condition BUT there are over 100 different types of liver condition. If you've got specific questions about your condition you can note these down at the back of the booklet and take them to your next clinic appointment.

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Drugs & Alcohol

**The law and alcohol:
It's illegal for anyone under the age of 18 to drink alcohol in licensed premises or public places.**

There are some different laws which state:
It's illegal to give an alcoholic drink to a child under five.

16 – 17 year olds can drink (but not buy) beer, wine or cider with a meal as long as it's served with a meal and bought by someone 18 or over who is with you at the time.

Some towns and cities have local by-laws banning the drinking of alcohol in public places.

As you are probably aware, alcohol can cause liver damage to anyone, whether you have a liver condition or not. Being alcohol free until you are 18 is the healthiest option. If you have a liver disease then you already have some degree of liver damage.

This means that your liver has less reserve to cope with processing any alcohol that you drink. In an ideal world, anyone with a liver condition wouldn't drink alcohol as it could make their condition worse.

With your liver condition there may be added risks to your health so you should talk to your liver team as they can give you the most accurate advice for you.



These are some things to consider when thinking about the negative aspects of drinking alcohol:

- 1. Alcohol is essentially a poison and can make you ill.**
2. Binge drinking can have damaging effects on your body, including your liver.
- 3. Drinking alcohol can lead to weight gain and bad skin.**
4. Drinking too much alcohol can lead you to make bad decisions, such as forgetting to take your medicines and carrying out risk-taking behaviour leading to embarrassing situations.

Top Tips

- 1.** If you do choose to drink, try and drink more slowly than everyone else, so you don't drink as much. Swap between alcoholic and non-alcoholic drinks.
- 2.** Make sure your drink can't get spiked. Keep it with you at all times and make sure it's covered. Don't leave your drink and return to it later, and don't accept drinks from strangers.
- 3.** Additionally it's important for you to know that mixing alcohol with energy drinks can lead to heightened dehydration that will have a stimulant effect on your heart. This means your heart is forced to work harder and your cardiovascular system is put under strain.



Check out the national guidelines on sensible drinking limits and find more information at:

<https://www.drinkaware.co.uk/facts/information-about-alcohol/alcohol-and-the-facts/low-risk-drinking-guidelines>

If you would like to talk through anything you have read, or have any more questions, then your liver team and CLDF's Young People's Team are happy to help.

Illegal Drugs & Legal Highs

For the purpose of this section, when we say drugs, we mean illegal drugs and legal highs, not medicines prescribed by your doctor or recommended by a pharmacist.

There are many risks in using any drug; the only way to avoid the risks is to not take them. This advice applies to everyone. Illegal drugs and legal highs don't come with instructions, therefore you don't know what they are made of and it's unlikely that any two doses are the same. Illegal drugs and legal highs have three main effects:

Stimulants

These drugs raise your heart and breathing rate along with your blood pressure; also known as 'uppers'.

Depressants

These drugs slow down the activity of your central nervous system and can be referred to as 'downers'.

Mind-altering Drugs or Hallucinogenic Drugs

These can trigger disturbing experiences that can lead to dangerous and erratic behaviours, also known as 'trips'.

Legal Highs; Novel Psychoactive Substances (NPS)

These drugs have a variety of effects combining all of the above. Many drugs that were previously sold as legal highs are now controlled under the Misuse of Drugs Act (1971), including mephedrone (meow meow or mcat), naphyrone, BZP and GBL. This means they are illegal to possess or to supply to others.

Combining different drugs can produce unpredictable and sometimes very dangerous effects both on your body and mind.

Even for licensed medicines, pharmacists have to look carefully at the effects they have on each other, so experimenting with illegal drugs, especially when you're taking medicines, can be life threatening.

If someone tells you that they've experimented with drugs and they were fine, don't assume you will have

the same experience. This is especially important when you have a liver condition or have had a transplant because illegal drugs may affect you differently.

Everyone is different so it's not just the quality of the drug you use that will affect your experience, but also:

- **The mood you are in**
- **Who you are with**
- **Where you are**
- **The medicines you are taking**

It's important for you to know that if you are prescribed medicines and are caught giving or selling them to someone else, you can be charged under the Misuse of Drugs Act in the same way

as if you were intending to supply an illegal drug.

If you are caught in possession of an illegal drug you can receive a minimum of a fine or a two year prison sentence, and depending on what classification they are and if you are supplying them, up to 25 years' imprisonment.

It's important to know that legal highs are constantly being made illegal. Not only do you not know what you are taking, you could also be in possession of, or dealing, an illegal substance too.

Puberty

Puberty can start between the ages of nine and eighteen and can continue until your early 20s.

Changes happen to everyone at different times and to different degrees. Some of the changes that happen to boys are that they get taller, grow facial hair and their voices break. Girls' breasts get bigger, they start having periods. Some people may get spots.

As you go through puberty, your feelings may also change. Sometimes you may feel sad and not understood. But equally you may feel happy and relaxed. During this time you may also start to explore your sexual identity. The reason for all these changes is down to your hormones.

So, what are hormones?

They are chemical substances that act like messenger molecules in the body. After being made in one part of the body, they travel to other parts of the body where they help control how cells and organs do their work.

Having a liver condition or a transplant may mean that these changes happen later than they do in others as you need good liver function to get the right level of hormones in your body to start puberty. Your liver team will probably ask you some personal questions relating to puberty at your appointments.

Don't be alarmed or embarrassed, they are doing this to ensure you're getting all the right help you need.

Some key facts you need to know about puberty



Females

who develop a liver condition after puberty has started may find that their periods become irregular or they may stop completely. If this happens, you must speak to someone in your liver team. Don't be concerned if they don't return to normal until after your treatment has started or you've had a liver transplant.



Males

who have a badly damaged liver will often have low hormone levels (see the Pregnancy and Fertility Section on page 14).

If you're concerned about anything to do with this stage in your life don't hesitate to contact someone in your liver team as it's really common to have lots of questions. Don't be embarrassed as your doctors and nurses will have heard it all before.

You might find it easier to talk to a doctor or nurse who is the same gender as you. You can ask for this, although it's not always possible.

Sex & Contraception

Sex and the Law: The age of consent in the UK for any form of sexual activity is 16 for both men and women.

The age of consent is the same regardless of the gender or sexual orientation of a person and whether the sexual activity is between people of the same or different gender. For all sexual interactions you will need to consider the

most appropriate form of contraception for you.

Contraception is a barrier to pregnancy and/or sexually acquired infections (SAI), if used correctly.

It may be a good idea to think about what form of contraception you would want to use before you have any sexual contact rather than at the time, so you're prepared. This is true for both males and females. If you have a liver condition or have had a transplant and are thinking about using another form of contraception as well as a condom then it's important you have specific advice from

your liver team about the type of contraception that's suitable for you. Some forms of contraception may be harmful to your liver.

Remember that only the male and female condom can prevent the spread of sexually acquired infections and other infections such as Hepatitis B, which is another form of liver disease.

If you are on immunosuppression medicines, both males and females are more likely to pick up an SAI, so please plan and consider appropriate contraception for you.

And girls, don't forget smear tests: once you've become sexually active it's important that females have regular smear tests – please speak to your nurse at your local GP surgery about this.

List of contraception methods

Contraception	What it is and how it works	Positives and negatives	If you have a liver condition
Male Condom and lubricant	Very thin lubricated latex rubber or polyurethane sheath that fits over a male's erect penis. They come in a variety of sizes, flavours and textures. You should always use a condom for vaginal, anal and oral sex. It's important to use lubricant for anal sex; again this comes in a variety of flavours.	If used correctly male condoms protect against sexually acquired infections and unplanned pregnancy and are 98% effective .	Condoms are a barrier method so do not interfere with any medication .
The progestogen only pill, POP or 'mini pill'	Small tablet containing progestogen. It stops ovulation and prevents the female from releasing an egg for fertilisation. It also thickens the mucus around the cervix making it difficult for the sperm to get into the womb.	If used correctly this is 99% effective in preventing unplanned pregnancies but it does not protect against sexually acquired infections.	The mini pill can have side effects and is not suitable for everyone. However, it's often the pill of choice if you have a liver condition.
The Combined Pill	This pill contains contains two hormones: oestrogen and progesterone. They are normally produced naturally in a female's ovaries. These hormones prevent ovulation.	If used correctly the combined pill is 99% effective in preventing unplanned pregnancies but it does not protect against sexually acquired infections.	Some females with liver disease may be able to use the combined pill but the final decision is with the liver team, depending on your individual condition.

List of Contraceptive methods (cont.)

Contraception	What it is and how it works	Positives and negatives	If you have a liver condition
Contraceptive implant	Small flexible rod inserted under the skin, containing the hormone progestogen. It's usually inserted in the upper part of the arm and can last up to 3 years, stopping ovulation.	It is 99% effective for protecting against unplanned pregnancy, but it does not protect against sexually acquired infections.	The contraceptive implant is an option, but you should discuss this with your liver team.
The coil (IUD Intrauterine Device)	Small plastic and copper device which is sometimes a T-shape. It is inserted into the womb to prevent sperm meeting the egg or it may stop the egg from implanting in the womb. It can last between 3 to 10 years.	The IUD is 99% effective for protecting against unplanned pregnancy, but it does not protect against sexually acquired infections. It has to be fitted by a medical professional, and can be used as a form of emergency contraception and fitted up to 5 days after unprotected sex.	The IUD should only be given after consulting with your liver team as it may not be suitable for everyone.
Intrauterine system (IUS)	This is similar to the IUD but releases the progestogen hormone (the IUD doesn't). The IUS prevents sperm from meeting the egg or it may stop the egg implanting in the womb. The IUS coil is inserted into the womb and lasts up to 5 years.	The IUS is 99% effective for protecting against unplanned pregnancy, but it does not protect against sexually acquired infections. It has to be fitted by a medical professional.	The IUS is not suitable for everyone so you should discuss the use of the IUS with your liver team.
Injection	Contains the hormone progestogen and works in the same way as the mini pill, stopping ovulation. There are two types of injection, one lasting for 8 weeks and one lasting for 12 weeks.	The injection is 99% effective for preventing unplanned pregnancies, but it does not protect against sexually acquired infections.	The injection can have side effects and is not suitable for everyone. You should discuss the use of the injection with your liver team.

Emergency Contraception

Emergency contraception can prevent pregnancy after unprotected sex or if your contraceptive method has failed, for example, a condom has split or you've missed a pill. There are two types:

- **the emergency contraceptive pill (sometimes called the morning after pill)**
- **the IUD (intrauterine device, or coil)**

There are two kinds of emergency contraceptive pill. Levonelle has to be taken within 72 hours (three days) of sexual intercourse, and EllaOne has to be taken within 120 hours (five days) of sexual intercourse. Both pills work by preventing or delaying ovulation (release of an egg). The IUD can be inserted into your uterus up to five days after unprotected sex, or up to five days after the earliest time you could have ovulated. It may stop an egg from being fertilised or implanting in your womb.

You can buy emergency contraception from the pharmacist or you can access it from your GP practice, an A&E department in a hospital or a GUM clinic. You will be offered information when receiving the medication on how to take it.

Emergency contraception does not protect you against sexually acquired infections (SAI).

Pregnancy & Fertility

Fertility and liver disease in women

Fertility is the ability to have children. Fertility in women with liver disease can be very variable depending on an individual's condition and current health. Your ability to conceive (have a baby) tends to be related to the amount of damage to your liver. Generally, if you are having periods (even if irregular) you should be able to conceive. Even if you don't have periods, you can get pregnant. If you're sexually active and your periods are or become irregular, or stop completely, you should let your liver team know.

Fertility and liver disease in men

Fertility in men with liver disease is also very variable. Your fertility tends to be related to the amount of damage to your liver. Males whose liver is badly damaged and scarred (cirrhotic) will often have low hormone levels. This may mean that they shave less, have problems with maintaining an erection and possibly a lower sperm production and quality. If you're concerned about your fertility you should let your liver team know.

Pregnancy

Remember you can get pregnant the first time you have sex, even if you haven't started your periods.

If you think you may be pregnant you should take a pregnancy test as soon as possible. You can get free tests through your GP, hospital and local family planning clinic. Pregnancy test kits can also be bought from a chemist or supermarket.

Pregnancy can be planned or unplanned. Having a baby is a big step for both partners. You may want to think about your age, the strength of your

relationship and what you and your partner want before trying to conceive or having unprotected sex. If you have a liver condition it's advised that pregnancy is planned and discussed with your liver team.

This is so your medicine plan can be reviewed to keep your liver condition stable throughout pregnancy and birth, and reduce the chances of harm to your developing baby. If you are planning to become pregnant and have had a liver transplant, research suggests that waiting for a minimum of one year after your transplant will lower your risk of having a premature and low birth weight baby.

If you find out you are pregnant, or think you might be pregnant, **DO NOT** stop taking your medicines, speak to your liver team as soon as possible.

Whilst being pregnant

If you become pregnant and have a liver condition, or have had a transplant, there is a slightly higher risk of miscarriage (losing your baby) and a slightly higher risk to your liver condition being unstable.

There may be concern for females who have portal hypertension and varices when they are pregnant as there is an increased risk of bleeding. Ideally, if you have varices, it's best if they are treated before you become pregnant. If you're already pregnant, often your doctor may ask for an endoscopy to check the varices during your second trimester (months 3–6 of pregnancy).

You may also want to know:

- If you have a scar on your stomach, keep it well moisturised during pregnancy. It may change in appearance, but this is normal.
- If you are worried that you may pass your liver condition on to your child, then speak to your liver team as they may be able to put you in touch with a genetic counsellor.

Not all liver conditions are hereditary but there are over a 100 different types so we are unable to be more specific.



Medicines

If you've been prescribed medicines for your liver condition, or after transplant, it's important to take them properly.

There may be times in your life when you resent your liver condition and medication but by accepting that you need medication you can make sure you are in control and

deal with your liver condition or transplant properly to ensure you are as healthy as you can be.

How you could take control of your medicines:

- Understand your liver condition. Ask as many questions as you need and know what your condition means to you.
- **Get to know your GP and your liver team in the hospital and know their names and phone numbers. It will help you feel confident when speaking to them.**
- Make sure you attend all of your clinic appointments because even if you feel well, it's really important that you attend.

• Know your medicines – understand why you take them, what they are called, their side effects and the right dosage.

• Pick up your own prescriptions – put a reminder on your phone before they run out, or even download an app. There are lots around that can help you manage your medication and your life.

• Have a set time to take your medicines. Set yourself a daily reminder on your phone or use an app and it will soon become automatic and part of your daily routine.

If the time you are meant to take your medicines doesn't fit in with your daily routines, talk to your liver

team, as you may be able to choose a time that you will more realistically be able to keep to.

- Use a special container or dosette box to separate your medicines and arrange them for the week.

There are different sizes of containers; some are designed for days out to fit in your pocket or bag. (However, not all medicines can be kept this way so read the storage instructions.

This is especially true of liquids. Liquid medicines may also be available in tablet form. Speak to your liver team for more information.)

It's important to remember to take your medicines regularly as, although missing one or two doses may not affect how

you feel straight away, by the time you do feel unwell from missing doses, your liver may already be damaged. Be in control of your medicines and your health.

Taking other medicines

Herbal medicines and alternative therapies - there is little research to show the effects when taken alongside your prescribed medicines. They may interfere with medicines you are already taking so talk to your liver team about these if you want to know more.

Over the counter medicines

Always check with a pharmacist before taking any

additional non-prescribed medication and let them know about your other health conditions.

Vitamins & supplements

Vitamins may be helpful but are not always necessary and in some situations may be harmful.

You may want to consider: Buying a **MediAlert** bracelet or necklet if you have a medical condition and are on any medication.

It's an internationally recognised emblem that gives 24-hour access to medical information, hospital details and your next of kin should you need any medical attention.



Tattoos & Piercings

There is no legal age of consent for most body piercings, so it's legal for someone under the age of 18 to have a piercing as long as they have consented to it.

Children under the age of 16 can't legally consent to a genital or nipple piercing, as it's considered to be

indecent assault. There are no plans to introduce an age of consent for body piercing in any areas other than the genitals, although some local authorities have introduced recommendations about the ages at which a person can have specific body piercings.

The Tattooing of Minors Act 1969 makes it illegal for anyone to tattoo you if you are under the age of 18, although the offence is with the person who carries out the procedure, rather than the person who has the tattoo.

If you decide to have a tattoo

or piercing, make sure the local council licence is displayed. If they are not displaying a licence then they may not necessarily be using good hygiene standards and this may put you at risk of HIV and other blood-borne viruses such as Hepatitis B and C.

Living with a liver condition and considering a tattoo or piercing

involve putting needles into your skin. Piercing guns can generally only be used safely in ear piercing. If you're having a tattoo or body piercing, you must be vaccinated against Hepatitis B and know that it's been successful. When having a tattoo or body piercing, there is a risk that you might get a skin infection.

It's important to follow the advice of the person who has done it. Large amounts of bacteria and blood vessels which are present in areas like your tongue or belly button make piercing in these areas more risky than your ear lobes.

If you want a tattoo or piercing it's always best to check with your liver team first.

Smoking

The law and smoking: In England and Wales it's illegal to sell tobacco to anyone under the age of 18.

The minimum age to smoke in public is 16, and authorities have the duty to seize any tobacco or cigarette papers in the possession of any person under the age of 16.

In Northern Ireland and Scotland the minimum age for buying cigarettes is 18.

It is now against the law to smoke in virtually all 'enclosed' and 'substantially enclosed' public places and workplaces. If you don't comply with the smoke free law, you will be committing a criminal offence which may result in a fine.

Smoking is one of the biggest causes of death and illness in the UK. Every year around 100,000 people die from smoking, with many more deaths caused by smoking-related illnesses.

Smoking increases your risk of developing more than 50 serious health conditions - some may be fatal and others can cause irreversible long-term damage to your health.

**Passive smoking/
second-hand
smoke**

There are also the "invisible dangers" of breathing in smoke from other people's cigarettes - this is called passive smoking. Second-hand smoke stays around for 2½ hours even in a ventilated room and may not smell or be seen. Young people are particularly affected by second-hand smoke because their bodies are still growing.

People who breathe in second-hand smoke are at risk of the same diseases as smokers because second-hand smoke also contains 4000 toxic chemicals, including:

- **Acetone** which is nail varnish remover

- **Arsenic** which can be used as a rat poison

- **Cadmium** which is an element that particularly affects the liver

- **Formaldehyde** that is used to preserve dead bodies

Important news for you and your liver

If you smoke and you have a liver condition, have had a transplant, or are on immunosuppression medicines you have an increased risk of getting diseases such as cancer and heart disease.

Some liver diseases are associated with respiratory problems, for example Cystic Fibrosis and Alpha-1 Antitrypsin Deficiency (Alpha-1). If you have either

of these conditions, you should avoid smoking or passive smoking as there is an increased risk to your health.

Electronic cigarettes/ Vapour alternatives

An electronic cigarette or e-cig does not contain tobacco or produce physical smoke. The e-cig is not governed by the smoking ban or restricted by tobacco laws.

In terms of the law, it's legal to smoke or 'vape' electronic cigarettes virtually anywhere although some restrictions are now in place locally, however always check changes in the law as this may change again at any time.

It's important for you to know that...

Early studies highlighted that vapour cigarettes have an effect on lung function. Therefore you should really consider the additional risks to you if you use one. However, there is not enough research available yet to know of any long term health problems.

Shisha smoking

Evidence states that Shisha smoking is as addictive and dangerous as smoking cigarettes along with an increased risk of infection due to sharing the shisha.



School, College, University & Work

Your Education: Your Rights

There may be times when your education might have to take a back seat because of your liver condition.

You might be in hospital, at hospital appointments, or take time out due to how your liver condition makes you feel.

Schools and colleges have a responsibility to make sure you have everything you need to thrive and do your best.

In 2014 there were new statutory responsibilities placed upon schools to ensure you get the right service for you.

Section 100 of the Children and Families Act 2014 places a duty on governing bodies of maintained schools, proprietors of academies and management committees of pupil referral units to make arrangements for supporting pupils at their school with medical conditions.

Key things to know:

- Pupils at school with medical conditions should be properly supported so that they have full access to education, including school trips and physical education.
- Governing bodies must ensure that arrangements are in place in schools to support pupils with medical conditions.
- Governing bodies should ensure that school leaders consult health and social care professionals, pupils and parents to ensure that the needs of young people with medical conditions are effectively supported.

If you are concerned about school or college, know you have legal rights and seek the support you need. If you want more information you can access this through local education boards in your area or you can contact CLDF.

Moving on from school

When thinking about careers it's important to think carefully about your options.

It can be difficult to know where you are heading and what you want to do after school. It may be useful for you to consider the following:

- **What interests you?**
- What excites you?
- **How physically active are you, or can you be?**

• What medication do you take? Are you on immunosuppression?

• **Do you need to attend hospital regularly?**

• Think about subjects at school you like and which qualifications you have

• **Think about taking a part time job alongside your studies to gain insight into an industry**

• Talk to your family and friends; what do they think you are good at?

• **Talk to teachers and career advisers**

• Organise work experience or look at volunteering opportunities

• **Talk to other young people with liver disease**

The world after school can be very scary but also very exciting. Research all your options – think outside the box when looking at careers, there may be something that really excites you that you had not thought of.

After researching your options you will then be able to gain insight into the qualifications you need.

Always look at the different routes you may be able to take to get you there. There are many routes into higher education and there will be one for you!

Moving into the world of work

Selecting a career or job of choice can be a challenging time and ensuring you have the right qualifications and experiences can itself offer restrictions.

Additionally, it's important for you to research any further barriers that may be presented due to your liver condition and/or medication that you take.

Access support from a careers adviser and spend time researching what career you want to develop and what requirements are needed for you to go down that path. DO NOT see your liver condition as a barrier but be realistic and honest when researching.

There are certain known restrictions within some career opportunities – these are just a few:

Royal Navy

There are pre-existing medical conditions and ongoing medical illnesses that may prevent you from joining the Royal Navy.

British Army

Medical conditions and ongoing illnesses can stop you from joining. A full medical examination is part of the application process. They have a list of what will prevent you from joining the British Army and having a transplanted organ is on this list.

Royal Air Force

There are medical conditions which prevent you from becoming a Royal Air Force

pilot. Again, this includes having a transplanted organ.

Ambulance & Fire Service

There are no restrictions, just a medical examination to decide if you are suitable for the role.

Police service

You need to be medically fit for the job.

When applying for a job it's important that if you are asked about your health, you are honest. However, you DO NOT have to add health issues onto your CVs.

If you are unsure about any career choices seek advice.

Bullying

Someone might be bullying you if they are:

- Calling you names
- Spreading lies about you
- Teasing you
- Hitting or kicking you and causing you physical pain
- Taking your money or possessions
- Leaving you out or excluding you
- Threatening or intimidating you
- Texting you horrible messages

• Filming you on their mobile phone and spreading it around

• Sending you horrible emails or messages on Facebook and other social networking websites

Everyone has rights – including the rights to:

- **Express your thoughts and feelings freely as long as you don't take anybody else's rights away or bully them in the process**
- **Live your life without being bullied**
- **Tell somebody if you feel unhappy or are being bullied**

• **Be treated well and to feel safe in your surroundings**

• **Be YOU**

What can you do if you are being bullied?

• Don't ignore bullying – it won't go away. If you are being bullied, it can be making your life miserable. The best thing you can do is talk to someone about what's happening.

Ideally you should talk to your parents/carers. If you find it difficult to talk to them then it's important to find someone else you trust.

• **Speak out!** It's important to keep telling people until it stops. The bullying may not stop the first time you tell someone, so keep ensuring you let people know what's happening.

• If you are being bullied online on websites such as Facebook you can report it using the CEOP (Child Exploitation and Online Protection Centre) button. No one should experience bullying. Seek support, do not cope alone and remember there is always someone there to listen.

Being bullied isn't anything to be ashamed of and by talking about it, it shows that you're not intimidated by it.

Keep a diary about how you are feeling.

Try to write down your thoughts and feelings; it may help you to get things out so that you don't bottle things up inside.

Keep a diary of the facts. Write down what, when and where the bullying happened and don't delete any evidence of being cyber bullied as it can be proof if the bully denies their behaviour at a later date.

Communication is really important. If you think you know why the bully is picking on you (for example, because you're off school quite a lot or because of your liver condition), sometimes taking action and sitting down with the bully is scary but if there is an independent adult you can ask, they could act as

a mediator and the issue may be resolved by talking it through.

Try ignoring the bully's comments/actions as it may take them by surprise. If you respond, you may be encouraging the bully to do it again, as they may want to get a response from you.

Don't overshare information. Protect yourself by not sharing information, such as your mobile phone number or online details, with people you don't really know or trust.

Remember it's not your fault. No-one deserves to be bullied.



Going on Holiday & Travelling

Going on holiday and travelling are an important part of life. Whether it's a few days with your mates or a longer trip you're planning, it's important to be prepared.

Before booking your holiday...

Before you do anything, talk to your liver team and ask whether they think it's advisable for you to go on holiday.

Details of where you are thinking of going and what you are thinking of doing are important for them to know.

It may be that a break in this country is okay, but flying or travelling abroad may not be advised.

It's important to know that many young people with liver diseases are still able to go abroad and go travelling but you do need to talk to your medical team to see if it's possible for you at that time.

Flying

There may be limitations to flying with a liver condition or transplant and checks should always be made with your liver team.

Travel Insurance

It's really important to always have travel insurance. There are many different types of travel insurance so use the checklist below to make sure you are getting the best policy for you.

Travel Insurance Policy Checklist:

- Does the quote cover your medical conditions?

• **If there is cover for chronic illness, does it cover: Loss of medicines? Hospital treatments whilst away?**

• Repatriation (sending an individual, some, or all family members home)? Is there an excess and at what level of care?

• **What treatments are covered and is there a maximum cost allowed for treatment (capping)?**

• Are there any countries that aren't covered?

• **Is there a cancellation penalty?**

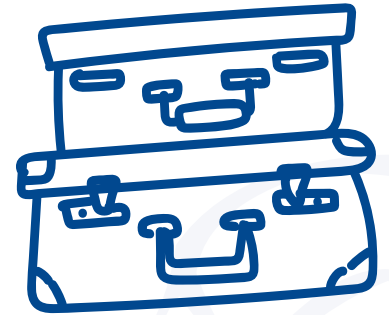
• Would you have to pay for treatment, and then return to the UK and provide proof of care given with receipts?

• **If you are going to a number of countries, confirm with the insurer that cover applies to all destinations.**

Beware if you have not fully disclosed any illnesses and any medicines used, as well as any change in your condition or medication before departure, your cover may be void.

• If you are travelling within the EU you can apply for a UK Global Health Insurance Card (GHIC), as well as having your travel insurance.

Visit childliverdisease.org/ travel for links to insurance companies others have used.



Medical Information on Holiday

You will need to carry an up-to-date letter from your consultant or GP for insurance purposes, which contains details of your medical conditions, including whether you have had a transplant.

It's also useful to take information regarding your medicines and dosages. In some cases it may be useful to explain why the medication is being taken as well.

Make sure you include the contact name, address and telephone/fax number of hospital unit(s) and any individual hospital reference numbers you might have. This information must be up to date as medicines and dosage may change.

Take two copies of any paperwork; one for your hand luggage and the other you

should pack in your main luggage.

Medicines on Holiday

Check that there are no restrictions on the medicines you are taking into the country you are visiting.

Be aware that if you are travelling for more than three months you may also need an export/import licence for any medicines.

Also consider if there is anything special you should take with you on your trip.

Your doctor may advise that you carry a supply of antibiotics for traveller's

diarrhoea or an oral rehydration solution, for example.

If syringes are needed make sure you take an adequate supply, together with sterilising tablets for use with anything that is reusable.

Packing for your holiday

As security measures change and can be different depending on the airport and the airline, check the current situation regarding carrying medicines in your hand luggage before you fly. All prescription medicines should be carried with you, but you will need to ensure that:

- **The medicines are in a bottle or package with prescription labelling.**

- Medicines are clearly marked with your name.

- **The name of the medicine and the dosage are clearly stated.**

- Any medicines are always accompanied by up-to-date documentation identifying the diagnosis and treatment of any liver disease or transplant in case of queries.

- **Look at the instruction leaflet on any medicines. Some may need storage at specific temperatures etc.**

Sun Protection

Some medicines to treat liver conditions or transplants can cause increased sun sensitivity. Buy sun lotion with a protection factor of at least SPF 25+ and follow the instructions.

When You Arrive

Find out where the nearest doctor/medical help is available, so you know where to go if necessary. If you are in Great Britain, you can temporarily register with the local doctor if you need to.

It's not uncommon to develop diarrhoea whilst travelling abroad. Be particularly careful and try to avoid:

- **Uncooked or unpeeled food**
- **Shellfish**
- **Salads**
- **Ice cubes**
- **Tap water** (use bottled or boiled water at all times, even for cleaning your teeth if the water isn't suitable for drinking)

Healthy Body, Healthy Mind and a Healthy You

To help you lead a healthy life, here are some more general tips

Make sure you get your vaccinations

As you grow up you are offered different vaccinations against a variety of illnesses. It's important to be aware of which vaccinations you have received – ask your parents if they have kept a record.

Annual flu vaccination is recommended to all patients with a chronic illness.

It's important to liaise with your GP's surgery to ensure you receive this each autumn.

During adolescence the following vaccinations are recommended by the Department of Health: between 13 and 14 years of age – Diphtheria, Tetanus, Polio and Men C. Girls should also receive the Human Papillomavirus (HPV) vaccination.

The World Health Organisation (WHO) recommends that all young people with liver disease should receive a course of Hepatitis B vaccination. You will need to have your antibodies checked 12 weeks after completing the course to ensure you have developed immunity.

Please remember that if you are taking immunosuppressive medication, you should not receive live vaccinations. Talk to your practice nurse or the person giving the vaccination for further information.

If you have any queries about vaccinations, your practice nurse at your GP's surgery is a good person to talk to.

Eat well

Eating a healthy and balanced diet is really important for maintaining good health and can help you feel your best. Eat a wide range of foods to ensure that you're getting a balanced diet and that your body is receiving all the nutrients it needs. We need to drink about 1.6 to 2 litres of fluid every day and when the weather is warm, or when we get active, we may need more fluids.

If you are under a dietitian they will give you specific information for you and your body; it's important that you follow their advice.

Exercise

To stay healthy or to improve health, young people are advised to do three types of physical activity each week, however, it's important to listen to your body. If you're feeling unwell or tired don't push yourself.

Check out the links at the back of the booklet to find out how you could benefit from being more physically active and talk to your liver doctor about the types of exercise that are safe for you.

Healthy Mind: Five Ways to Positive Wellbeing

There are times in everyone's lives when we find it tough and hard to cope.

Being a teenager, going through puberty, peer pressure, friendships, relationships and deciding your future can add extra stress. It's normal that sometimes we feel low, but if you are feeling low for long periods of time you may need some support.

It's important at times like this that you surround yourself with friends and loved ones.

If you've had long periods off school or college due to being in hospital, or illness, find ways to keep in touch with friends. Use social media, Skype or Facetime and invite friends round to visit you – they may not want to presume it's okay to come and see you, so let them know when it is.

CLDF's social media platform 'Hive' is an ideal place to talk to other young people who also have a liver condition and make new friends.

At times when you feel low it's important to seek support. You can also take steps to manage this yourself by developing a positive attitude.

Having a positive attitude can be tough, especially if you're going through a tough time, but it can help you to manage these times better. Many people benefit from positive thinking. It's worth the time and effort to attempt to see your world from a positive perspective.

ways you can maintain a positive attitude:

1. Be open to positivity Positivity is not about pretending. It's about seeing what's happening around you and striving to make the best of it. It's much easier to become a positive person if you allow yourself to be open to the idea of positivity.

2. Be aware of your thoughts Our minds are amazing things. So amazing, in fact, that sometimes we're not even aware of what we're thinking. Sometimes our minds have a default setting and it's important to make sure the default isn't a negative one. To do that, pay close attention to what you're thinking. Being mindful of your thoughts gives you an opportunity to shift them in a more positive direction.

3. Surround yourself with positivity It's very easy to become negative if you're surrounded by negative people and engaging in negative activities. Who makes you feel good? What do you enjoy doing? The more time you spend with people and activities that make you feel positive and enthusiastic, the easier it will be to maintain a positive attitude.

4. Focus on the present moment One of the ways negative thoughts creep into our minds is when we worry too much about what could happen in the future or dwell too much on what has happened in the past. If we want to stay positive, it's essential to focus on what's happening right now. When you allow yourself to stay fully in the moment, negativity has a much tougher time making its way to the forefront of your mind.

5. Develop gratitude It's probably not the first time you've heard the importance of gratitude in living a more positive life, but it's a vital aspect of having a positive attitude. It's almost impossible to be negative at the same time you're being grateful so if you want to be positive, focus on what you're fortunate to have in your life right now. If it's useful to you, make a list of what you're most grateful for and keep it in your purse or pocket so you can take a peek at it when you feel negative thoughts arising.

Most importantly: remember you are a fabulous, unique person and you deserve to be happy and healthy – always seek support when times are tough.

Helpful links for further information...

Here are some helpful links for further information:

Emotional and Mental Health

youngminds.org.uk

A charity committed to improving the emotional wellbeing and mental health of young people. Their website provides accessible, down-to-earth information on everything you may want to know

about mental health through online resources and personal stories along with a link to their **HeadMeds** website which focuses on mental health medication and the issues this can have.

mind.org.uk

A charity which provides advice and support to empower anyone experiencing a mental health problem. On their website you can access information on mental health alongside advice and tips on everyday life, and a confidential helpline to speak with an adviser via phone, email or text.

Sexual Health

brook.org.uk

Brook offers free and confidential sexual health services to young people, as well as education and support.

There's information on a variety of sexual health topics such as pregnancy and contraception as well as the opportunity to ask for advice via their web and textchat services.

Smoking, Alcohol and Drugs

drinkaware.co.uk

This website has useful facts and information on current drinking guidelines, alongside offering expert advice and tips on how to drink more responsibly. You can also download helpful apps and order factsheets and leaflets to take steps to limit your alcohol intake.

www.nhs.uk/smokefree

Smokefree provides expert support information and advice on quitting smoking.

talktofrank.com

Talk to Frank gives you essential information on the side-effects, risks and law

concerning different types of drugs alongside giving you the opportunity to receive friendly, confidential drugs advice in the form of live chat, personal stories and FAQs.

Education and Work

nationalcareers.service.gov.uk/

The National Careers Service gives you a wide range of support and advice about the world of work by offering personalised help from careers advisers, course and job searches to find career opportunities right for you, and essential help with CVs, personal statements and interviews.

General Support

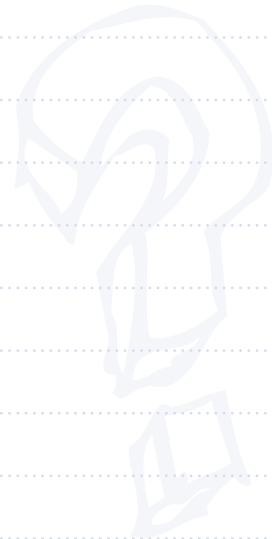
childline.org.uk

Childline is a free and confidential helpline available for young people where you can contact an adviser via message board, email, telephone or online chat to ask for help with a range of issues.

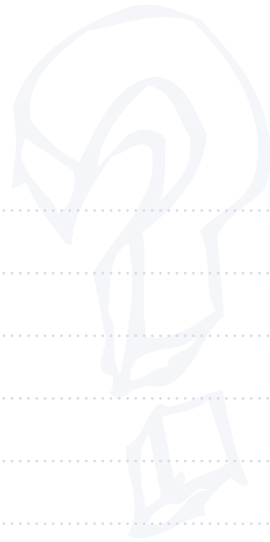
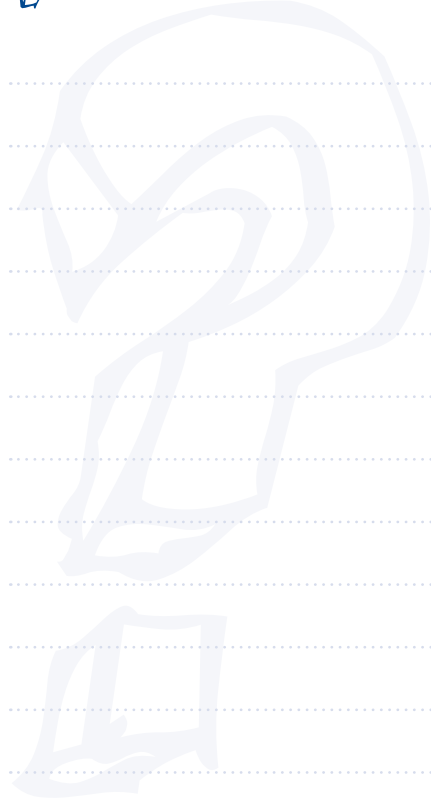
Essential information on topics like peer pressure, bullying and self-esteem are also available, along with interactive games and videos.

Notes

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Notes



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Tel: 0121 212 3839
Email: info@childliverdisease.org
www.childliverdisease.org