

Living with liver disease



Pioneering Liver Health

Living with liver disease

The British Liver Trust works to:

- support people with, and affected by, liver disease
- improve knowledge and understanding of the liver and related health issues
- encourage and fund research into new treatments
- campaign for better services and improved patient care
- increase awareness of the risk factors of liver disease and promote earlier diagnosis

All our publications are reviewed by medical specialists and people living with liver disease. Our website provides information and our Helpline gives advice and support on enquiries about liver health. Call the Helpline on **0800 652 7330**, general enquires on **01425 481320**, or visit **britishlivertrust.org.uk**

For the latest updates to this information, please refer to our website **britishlivertrust.org.uk**

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The liver

Your liver is your body's 'factory' carrying out hundreds of jobs that are vital to life. It is able to repair itself (even renewing large sections). **However, the liver's ability to repair itself is limited and continuous harm can lead to permanent scarring.**

Your liver is very tough and able to function even when some of it is damaged, which means you may not notice any symptoms until your disease is quite advanced and noticeably affecting your health.

Your liver performs hundreds of functions. Importantly it:

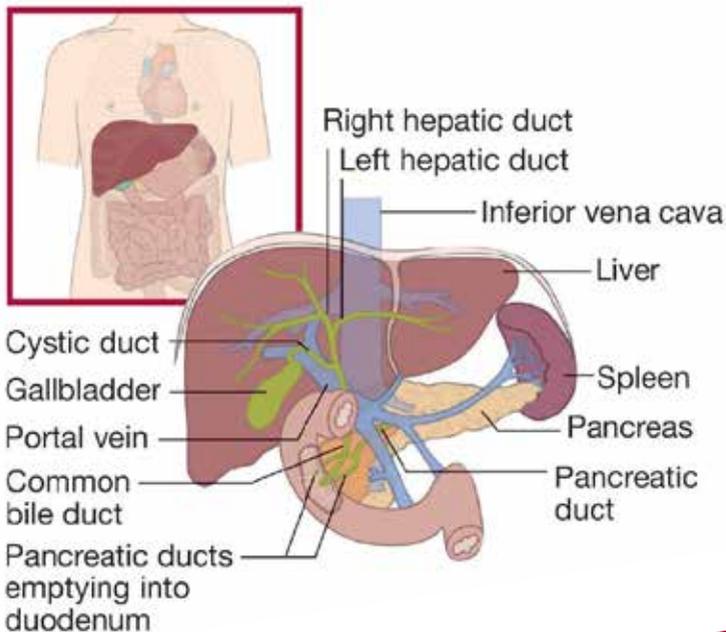
- filters and cleans the blood
- fights infections and disease
- deals with and destroys poisons and drugs
- makes vital proteins which make your blood clot when you cut yourself
- produces bile to help break down food in the gut
- processes food once it has been digested
- stores energy that can be used rapidly when the body needs it most
- regulates fat breakdown and distribution in the bloodstream
- stores sugars, vitamins and minerals, including iron
- gets rid of waste substances from the body
- produces and maintains the balance of some hormones
- produces chemicals – enzymes and other proteins – responsible for most of the chemical reactions in the body, for example repairing tissue
- repairs damage and renews itself (up to a point).

How liver disease develops

Your liver responds to harm by becoming inflamed. Any inflammation of the liver is known as hepatitis, whatever its cause. Sudden inflammation of the liver is known as acute hepatitis. When inflammation of the liver lasts longer than six months, it is known as chronic hepatitis.

Inflammation is part of the process of repairing damaged tissue. In a similar way to a scab forming over a skin wound, a temporary fibrous 'scaffold' forms while new liver cells regenerate. If your liver is repeatedly harmed, new liver cells cannot regenerate fast enough and the fibrous scaffold remains as a scar. This is called fibrosis, and can take a variable amount of time to develop.

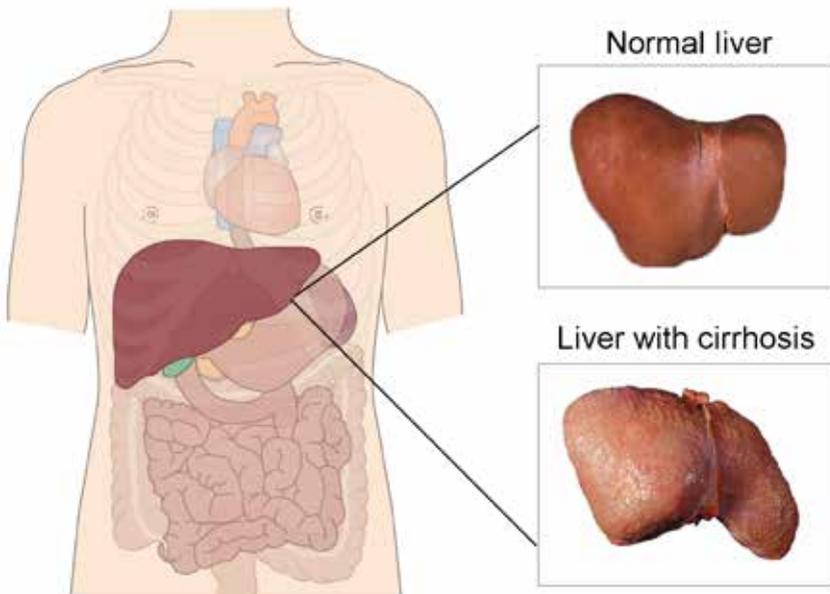
When fibrosis is present, your liver may be able to keep functioning quite well. Removing or treating the cause of the inflammation may reverse some, or all, of the fibrosis and prevent further liver damage.



If the harm to your liver continues, the inflammation and fibrosis can spread throughout your liver, changing its shape and affecting how well your liver cells work. This is known as **compensated** cirrhosis. Even at this stage, people can have no obvious signs or symptoms.

The scar tissue in cirrhosis interrupts the blood flow through the liver. As a result, the blood pressure in the veins in your abdomen is increased and may result in bleeding. Scar tissue in cirrhosis is difficult to remove and may be permanent. However, further progression can be halted and your cirrhosis stabilised, if the cause of the liver damage is removed.

Cirrhosis increases your risk of liver cancer and can lead to liver failure. If damage to your liver continues, it will become unable to function sufficiently (**decompensated** cirrhosis) and start to fail; this is sometimes referred to as 'end stage liver disease'. At this stage chemicals and waste products can build up in the body, commonly causing jaundice, ascites (a build-up of fluid in the abdomen) and hepatic encephalopathy (confusion and memory loss). In the final stages of liver disease the build-up of waste products may lead to multiple organ failure and loss of life.



Managing your liver condition

Liver disease is complex, varied and fluctuates, meaning that no one person's experience of liver disease is the same as another's. Your experience of liver problems may vary from day to day. This is partly because the liver has a huge number of functions and so liver failure can affect almost every part of your body and the way you feel.

This publication is for people living with a liver problem and their families, to explain some of the emotional, physical and practical problems of the disease. It will help you to manage your condition by suggesting questions to ask, choices which you can make for your care and highlighting the help and services which are available to you.

More detailed information on specific liver diseases is available in the British Liver Trust patient guides which are listed under 'further information'.

Some sections contain information for people with advanced liver disease and serious symptoms. It is important to remember that many people do not experience severe problems from their liver disease and much of this information may not apply to your condition. If you have concerns about the information in this publication, please discuss this with your medical team.

“Treat every day in as positive a manner as you can. Don't ask yourself 'Why me?' as you can not change the past.”

Phil, Hants.

“I always find when talking to people about my own liver condition, I refer to how I live around and with it.”

Judith, Birmingham.

Being diagnosed with liver disease

Most people learn they have a liver problem from their GP, often as a result of routine blood tests. Abnormal liver function tests are relatively common, so the doctor will look at other symptoms and test results before reaching a diagnosis.

It is quite common for the GP to simply ask you to return in a few months for a repeat test. It is essential that you do follow-up or request a repeat test. Many treatments for liver disease are more effective if the problem is diagnosed early.

Deciding who to tell

Being diagnosed with a liver disease can be upsetting and worrying. It can be very comforting to talk to close friends and family. Discussing your condition with people you are close to can help them to understand some of the lifestyle changes you may need to make and allow them to offer support.

However, you will want to think carefully before sharing the news too widely.

Consider how the person may react – are you confident that they will be supportive and respect your confidentiality? It is often better to gather more information about your condition and take some time to consider what it means to you and your family, before taking this step.

It is sadly true that people with many medical conditions can suffer discrimination in work or social settings. This can be an issue in liver disease because some people have preconceived ideas, particularly around alcohol or viral hepatitis. By first understanding your condition you will be able to address any concerns which may be raised.

There are some people who you may need to tell so that they can take precautions to protect your health or their own. It is important to tell any medical practitioner about your liver disease before they offer treatment or give you any medications. If you have viral hepatitis, medical practitioners need to know so that they can take additional precautions to prevent crossinfection of other patients. As hepatitis B and C can be transmitted through sex, you have a legal obligation to protect your sexual partners, through practicing safer sex and/or disclosing your status.

“ I think it would have made it easier on myself if I had told my friends the real reason why I was so ill...a lot of my stress was hiding it from people.”

B.B., Hep C Nomad.

Insurance and mortgages

Diagnosis of a liver disease may affect your ability to obtain a life insurance policy or a mortgage linked to a life policy, or the premium may increase. If this happens, it is worth talking to your doctor as many consultants are willing to write to a mortgage or insurance company stating your health and life expectancy. Travel insurance may also be more difficult to obtain.

It is important that you tell insurance companies about any pre-existing conditions or conditions which develop while you have cover, as this could affect your entitlement if you need to make a claim.

Not all insurance companies are the same and so it is worth trying several. The British Liver Trust can provide a list of insurance companies who have indicated they will cover people with liver disease.

Employment and occupational issues

It is best to refer to your company's policies and guidelines for sickness and disability before deciding whether to tell your employer of your illness. It may be necessary to tell your employer if your condition could pose a risk to other people, for example, if you are a healthcare professional and carry viral hepatitis, or if your symptoms make certain work dangerous, such as operating machinery.

Although there are certain legal protections against discrimination, telling your colleagues or your employer may not be necessary or helpful for you. It is important to think carefully before making this decision and perhaps to discuss it with your healthcare team.

Accessing the right care

Choosing the right medical team

Once your GP, or another medical professional, suspects you have a liver problem, they will usually refer you to a liver specialist doctor called a hepatologist. Alternatively you may be referred to a gastroenterologist (a doctor who specialises in diseases relating to the digestive tract) with a liver specialism. In some cases, you might be referred directly to a specialist liver nurse or an infectious diseases specialist.

Patients have the right to choose which hospital or healthcare provider their GP refers them to. This is a very important decision, as it will determine which team of healthcare professionals look after you, the equipment they have, the wards you might have to stay on and the facilities that will be available.

You may want to consider the following:

- Does the hospital have a dedicated liver unit?
- How many specialist liver consultants are there at the hospital?
- How complex or rare is your liver condition?
- How far is the hospital from friends and family?
- Can you be treated at the hospital where you are already receiving care for another condition?

Hospitals with a dedicated liver unit will have the greatest concentration of liver specialist knowledge and may be particularly suitable for patients with rare or complex conditions, or those with advanced liver disease. They see large numbers of patients with different types of liver disease and build up considerable expertise in treating them. They often have a medical team including doctors, specialist liver nurses and others, such as dietitians and pharmacists with liver expertise. The British Liver Trust can advise you which hospitals have specialist liver units near you.

Even if you are being treated in hospital, your GP is a very important member of your medical team. When you are discharged by the hospital, your GP is responsible for your care. It is important to have regular

appointments with your GP to monitor your condition – ask for these if they are not offered. Make sure your GP is aware of any treatment you have received in hospital and speak to them if you develop any new symptoms or are having difficulty with lifestyle changes.

Many patients benefit from an excellent long-term relationship with their GP. If you have questions or concerns about what is happening to you or want more information, often your GP can help to explain things. **If you do not have a good relationship with your GP, you have the right to find a new one.** Don't be afraid to say how you feel or ask to see another GP at the surgery who may be more sympathetic to you. The NHS Choices website gives details on how to change your GP (nhs.uk).

“ Make sure you are sent to the appropriate consultant by your GP, and find out what lifestyle changes you can make to help with your liver disease.”

Linda, Berks.

“ Many people out there want to help; dedicated doctors and nurses who deal with the medical and mental issues you may have.”

Phil, Hants.

Being assessed

When you are referred to hospital, usually the first step is specialist assessment of the health of your liver. This is very important to determine how much liver damage you have experienced (referred to as ‘staging’ your liver disease) and to decide what treatment is most appropriate for you. You are likely to have regular blood tests to monitor your condition. You can ask for copies of the computer print outs of these results, and keep these safe so that you can track your condition.

Getting the most out of your doctor's appointment

Before each appointment with your doctor, it is a good idea to prepare by:

- thinking of all the questions you have
- thinking about the symptoms you've experienced (include what might seem like minor things, such as itching, nose-bleeds, change in your stool colour, swelling, sleepiness and twitching)
- thinking about what information you want from your doctor
- writing these down so that you can give a copy to your doctor.

During the appointment:

- tell the doctor how you feel. Don't be afraid to say what you think is causing your problem or making things worse
- if you can, take along a friend or relative who can listen and take notes of what the doctor says, and perhaps remind you of any points you would like to raise
- check your list at the end of the appointment to make sure that you have covered all the points
- if anything the doctor says concerns you, if they have not answered all your questions or you do not understand the answers, do not be afraid to question them and ask for a more detailed explanation
- it is also a good idea to ask the doctor what symptoms you should look out for and what you should do if they occur, for example, whether you should come back to the hospital as an emergency; adjust your medication; phone the liver unit or make another appointment
- find out what happens next, for example, do you need to book another appointment?

You have an important role in looking after yourself between appointments and asking questions will help you to manage your condition.

Keeping records

You have a right to a copy of any letters your liver specialist may send to your GP and from your GP to your specialist. You can also request a copy of test results and of your prescriptions. It is often useful to file these together with details about your condition, so that you can refer to them later if needed.

*“ Understanding your own liver condition
will help you live your daily life.”
Judith, Birmingham.*

Things to consider about treatment

There are many different options for treating liver disease and its symptoms. Your doctor will discuss which are most suitable with you and seek your consent. It is important that you ask questions about the treatment before you give your consent.

- What are the risks and benefits of each option to me?
- Are there any potential side effects?
- Which is the most suitable for me and why?
- How long will the treatment last?
- What is the success rate?
- What role can I play in making the most of the treatment?
- When and how should I take particular medications?

If you are in any doubt, ask your medical team to explain. If you would like more time to consider a treatment, perhaps to discuss it with family, mention this to your doctor.

Relieving symptoms

There are treatments for many of the symptoms of liver disease, such as itching, ascites (fluid retention in your abdominal area), and hepatic encephalopathy (sleepiness, shaking and other symptoms that can affect your mental health). Tell your doctor if any symptoms are troubling you so that they can arrange effective treatment.

It is important to remember, however, that there is no simple cure for most liver diseases. **Your doctors will do their best to find the most effective treatments for your condition. Be patient and work with them to manage your condition as much as possible.** Understanding your own liver condition will help you to manage your daily life.

New treatments

There are new medicines and treatment options in development for many liver diseases. Before these can be used routinely they have to go through rigorous tests for safety and to check they work. In some cases, it may be possible to be part of a clinical trial. This carries certain risks and you should discuss these carefully with your doctor.

An organisation called NICE (National Institute for Health and Clinical Excellence) looks at new medicines and other treatment developments, and produces recommendations to the NHS. It has produced guidance on several treatments for hepatitis B and hepatitis C. If one of these treatments is recommended by NICE and is suitable for you, you are entitled to be prescribed it regardless of cost. There are other bodies producing guidance for Wales (All Wales Medicines Strategy Group) and Scotland (Scottish Medicines Consortium).

Patients often find information about treatments on the internet or in the media. It is important to be cautious about the promises these make. Some have not passed the tests for safety, quality and effectiveness that the UK requires. In other cases, the treatments may not be safe or appropriate for your condition. **If you find information about a treatment which you have not been offered but you think could help, discuss it with your medical team.**

Medicines

Your liver processes all the medicines and drugs that come into your body.

Medicines that are normally safe can be dangerous to someone with liver problems because the liver is not able to cope. Always check with your liver specialist and the pharmacist whether a medicine is safe for you.

- It is essential that before taking any medicines, whether prescribed by your doctor or bought 'over the counter' from a shop, that you tell the pharmacist you have a liver problem and check they are safe for you to take.
- If you were prescribed any medicines before you were diagnosed with liver disease, your doctor should review whether these are still safe for you to take.
- If you are seeing a dentist, or a doctor for another health problem, they would not necessarily know that you have liver disease, unless you tell them, and could prescribe something that is dangerous for you.
- It is particularly important not to share someone else's medication.

Pain killers

Even common pain killers such as aspirin and ibuprofen can be dangerous for people with liver disease. These can sometimes be found in creams for muscle aches, cold remedies and cough syrups. It is a good idea to ask your doctor what medications you can take for pain relief and check the content of any medicines that you buy with the pharmacist.

Often people, particularly those with advanced liver disease, are prescribed a number of different medications. It can be quite complex remembering what dose to take, when to take them and what each is for. This can be a particular problem when the packaging, appearance of the tablets and even the brand name may change with each prescription.

Tips for taking your medicines:

1. It can be a good idea to write out a table of all the medicines you are taking, their name (the long chemical name and the brand name), the dose, when you take them and what they are for. There is an example table that may be helpful at the end of this publication, your doctor or nurse can help you complete it.
2. If you go into hospital, see a pharmacist or a different healthcare professional, always give them a list of your medications so they can see clearly what medicines you are taking. It is a good idea to take this information with you if you plan to travel away from home.
3. It is important that you take all your regular medications at the right time. You may find it helpful to buy a pill dispenser box (available from pharmacies) so you can load up your medicines for the week. You can then easily see if you have remembered to take each dose. It also prevents you from taking too many if your memory is poor.
4. If you miss a dose, take the next one as soon as you remember, but do not take a double dose unless you are told to do so. If there is a problem or you forget more than one dose, ask your medical team for advice. Make sure you have enough supplies of your medicines, particularly over bank holiday periods or if you plan to travel away from home. Order repeat prescriptions well in advance in case the pharmacy runs out of stock.
5. It is also useful to know what side-effects you might experience and whether you should be worried about these. Talk to your doctor about this when the medicines are first prescribed. Mention any side-effects to your doctor at the next appointment, or if these are a problem, call your doctor as soon as they occur. It is important not to stop taking your medicines without speaking to your medical team first.

“ Order repeat prescriptions at least a week in advance in case the pharmacy has to order new stock.”

Lynda, Surrey.

Complementary and alternative therapies

Some people wish to take herbal remedies, particularly to relieve the symptoms of illness. Again, most of these are processed by the liver, so can be toxic to people with liver problems. Some can damage the liver and make you more severely ill.

Some people believe that milk thistle can be helpful for people with liver disease. It is not licensed as a medicine however, and there is also no regulation of milk thistle products, which means you cannot be sure how much of the active ingredient you are getting and how pure it is. It is wise to be cautious about the claims made for herbal remedies, particularly those advertised on the internet, as they can offer false hope. **It is a good idea to discuss the use of these remedies with your doctor and your pharmacist.**

Looking after yourself

Vaccines and protecting yourself from infection

People with liver disease are more vulnerable to infections, and if they do get an illness, are more likely to become severely ill. As a result, it is really important to keep up-to-date with vaccinations. As with medications, it is important to make the doctor or nurse aware of your liver condition and tell them if there have been any changes in your condition, before having treatment.

- Flu: visit your GP for a flu jab every autumn.
- Pneumococcal infection: get a jab to protect against this major cause of chest infection, when you are diagnosed with liver disease and then every 10 years.
- Hepatitis A and B: these infections are much more serious in people who already have another liver disease, so visit your GP for the full course and the booster when due.
- If you are travelling abroad it is important to make sure your vaccinations are up-to-date. If you are immunosuppressed, for example due to taking steroids for autoimmune hepatitis or following a liver transplant, you should avoid 'live' vaccines such as MMR, TB, yellow fever and oral typhoid vaccine. In these circumstances it is important that family members do not receive live vaccines either. Your doctor can advise on how best to protect yourself.

There are also a number of fairly simple precautions you can take to avoid infection.

- Avoid close contact with adults and children carrying infections – from the common cold to chicken pox.
- Avoid inhaling dust particles or smoke.
- Keep good standards of hygiene – for example, washing your hands after going to the toilet or changing a baby's nappy.
- Brush your teeth after every meal and floss daily.
- Visit the dentist every six months.
- Keep toenails and fingernails clean and trimmed.
- Thoroughly clean all cuts and grazes before applying a clean, dry dressing or plaster, and keep an eye on them to make sure they are healing.
- Do not clean out the cat litter or bird cages, or go near animal excrement, without gloves.
- For women, use only small tampons, change frequently and do not use overnight.

Managing fatigue and sleepiness

Many people with advanced liver disease feel very tired and have low energy levels. This can be due to your medical condition, external stresses or a combination of the two. Fatigue affects people differently and can come and go. One day you may feel able to live normally and the next you may have difficulty getting the energy and strength to do even the smallest tasks.

Planning your day and the week ahead is very important if you experience fatigue.

- Plan in time to rest during the day.
- Think about which things are the highest priorities for you and your family, and make sure these get done first.
- Be realistic about what you can do and don't try to do too much.
- Ask for help, not just from your family, but think about which tasks a friend or neighbour might be able to do for you.
- Explain to people that you need to be flexible, so that you can leave early from a party or social engagement.

Some people also experience sleepiness, and can even fall asleep when talking. This can be due to fatigue, but it can also be a symptom of hepatic encephalopathy, which can be more serious. If you experience this sleepiness, talk to your doctor about it. They may prescribe medication such as lactulose, and you may be able to adjust the dose yourself until you get the best effects. You may also need to be admitted to hospital.

Is it OK to drive?

If you experience sleepiness, confusion or severe fatigue, it is important to think about whether some activities put yourself or others at risk. For example, it may not be safe to drive, operate machinery or do other things where you are exerting yourself or carrying responsibility for others.

Some people experience sleep problems. This can mean that you need to sleep during the day, or perhaps that you have difficulty sleeping through the night. Plan your day to suit your body's needs, taking naps during the day if you need to.

There are many sources of help if you are suffering from fatigue or sleepiness. There may be a hospital social worker who can direct you on to help or you can contact your local authority's social services department. They can organise things like meals on wheels, home help, childcare or transport. You may have to pay for some of these services.

Diet

Eating a good, balanced diet is one of the most important things you can do to keep yourself well. Regular meals containing protein (such as meat, fish or beans), starch (such as bread, potatoes or rice) and vitamins (in fruit and vegetables) are the best approach. It is particularly important to make sure you are getting enough protein in several meals throughout the day. Many people with advanced liver disease find that they have a small appetite or cannot manage normal sized meals. This can be a problem if you are unable to take in all the nutrients your body needs.

- Try smaller, more frequent meals and snacks.
- Include protein in these, such as a boiled egg, cheese or beans on toast, or fish fingers.
- You may also benefit from being prescribed a supplement or a special food drink.
- Talk to your medical team and ask to be referred to a dietician. Some people with advanced liver disease are advised to follow a low-salt diet. This can be very important in managing the impact of liver failure and preventing serious complications.
- Some salty foods have to be avoided altogether, such as crisps, cured meat (like bacon and ham) and cheese.
- Many foods contain 'hidden' salt, such as bread, biscuits, sauces and cereals. Check the labels of any bought food so you can see how much salt, often called sodium, they contain.
- Avoid using salt in cooking – microwave or steam vegetables to retain flavour.
- It is also helpful to get the advice of a dietician who can offer tips and meal plans tailored around your food preferences.

Alcohol and smoking

Alcohol is processed by your liver, and as a result, it can be dangerous for anyone with liver problems. Check with your doctor whether it is safe for you to drink any alcohol, and if so, how much.

Alcohol dependency

If you are, or have ever been, alcohol dependent or an alcoholic, discuss this with your doctor. In these circumstances it is important to get medical help to give up drinking, as stopping suddenly can, in some cases, lead to severe withdrawal symptoms, including hallucinations and seizures. There are many sources of support and help they can give you or direct you to.

It is important to be honest with your doctor about how much alcohol you drink. This will help them give you the right advice and care for your liver problem.

Smoking is dangerous to everyone's health. People with liver disease are more vulnerable to infection and to poor health overall, so smoking or exposure to passive smoking is not advisable. There is good evidence that it has a particularly damaging effect on people with hepatitis C, speeding up liver damage. If you smoke, speak to your doctor about what help is available with cutting down and giving up.

Drugs

Illegal drugs such as cannabis, ecstasy and cocaine are all broken down by the liver. These can be particularly dangerous in people with liver disease and should be avoided completely. **As with alcohol, if you have become dependent on a drug it is important to discuss this with your doctor and get medical help with withdrawal.**

Emotional issues

Having liver disease is not just a physical problem. It can place a huge burden on your body and mind.

- The physical tiredness and sleep problems that go with many liver diseases make it even harder to cope with the emotional burden.
- Many people with advanced liver disease find themselves feeling more emotional than normal.
- Fatigue can make people seem impatient and demanding.
- It can also make people withdraw from socialising and relationships, as they can be too much effort.
- Liver disease often fluctuates, meaning that one day you could feel well and the next be severely ill or too tired or sleepy to do anything. This makes it hard to predict and plan your life.
- Uncertainty is a big feature of liver disease. Waiting for a liver transplant is a particular strain, as people are left worrying and anxious on the transplant list.

All of this can leave patients and their families frustrated and anxious and results in additional stress. Try to explain to those close to you how you feel so they can help you plan your day and your week, and be sympathetic if plans need to change. **Talking about your worries and how you feel can help them feel less overwhelming and allows your family to feel more involved, and voice their own anxieties if they need to.**

Side effects of treatment

Some medications, particularly those for treatment of hepatitis C, can have side effects which affect people emotionally. Some people experience headaches, fatigue, depression, anxiety, sleep disturbance and poor concentration. There is some comfort in knowing that these side effects are not unusual and it is 'not just me'. It is also important to remember that treatment is for a limited time and many symptoms subside after the first month or so.

However, for some people, these side effects are too severe or too dangerous to put up with. It is important to talk to your doctor about side effects and how they are affecting you. Don't just stop taking the medicines. It may be that the doctor can give you another medicine or prescribe something to help with the side effects such as antidepressants.

You may find it helpful to use a journal to record how you are feeling each day. This can act as a reminder of things to discuss with your doctor and can also show patterns in symptoms which it may be possible to address.

Sex

Advanced liver disease can also reduce your sex drive (as can some of the medications used to treat it) and make it difficult to have sex. This is a sensitive area but one you and your partner should not be afraid to discuss with your doctor. Counselling, for you and your partner on the impact of liver disease on your relationship, may be helpful.

Serious illness can bring people closer and hugging or cuddling can be very comforting, especially if you don't feel up to talking.

Hepatic encephalopathy

Many people with advanced liver disease have some degree of hepatic encephalopathy. This may be so subtle that only someone close to you can tell that it is affecting you. It can affect you in a huge range of ways.

Mild symptoms can include:

- being slightly sleepy
- disturbed sleep patterns – sleepy during the day but awake at night
- having difficulty concentrating or remembering things
- seeming a bit less ‘with it’ and alert
- slightly lower performance in word games or calculations
- less clear or shaky writing
- perhaps a bit teary or more emotional than usual.

More advanced symptoms can include:

- a tremor that prevents you holding a drink without spilling it
- confusion
- personality changes
- paranoia
- staggering or falling.

For example you may find yourself getting very irritable or even unkind with your close family. It is important for you and them to recognise that this is a symptom of encephalopathy, rather than a real change in the affection between you.

“ The thing that upset me most was when my partner developed encephalopathy and I didn’t realise. If I had known about encephalopathy and its effect on personality I could have coped far better.”

Lynda, Surrey.

Problems such as encephalopathy can be a sign of worsening liver function so it is important to discuss this with your doctor as soon as possible.

It is important to get both medical help and other sources of help for these symptoms and emotional issues. This can include help from mental health professionals, counsellors, social workers and social care staff which your medical team or GP practice will be able to direct you to, as well as from friends, family and organisations listed on the British Liver Trust website.

Sharing your concerns

Attitudes to liver disease can make people even with only mild, or no symptoms, withdraw from friends and family, and make it hard to talk about how it affects you. This is one reason that support groups for people affected by liver disease can be a great comfort; you can meet and discuss how you feel with people going through the same experience. Support groups provide an opportunity to share tips and thoughts with sympathetic people in a safe environment. Visit the Trust website for information on support groups in your area:
britishlivertrust.org.uk/liver-disease-support-groups/

It is also worthwhile thinking of other sources of support, including those in your local community. Some people find great comfort from the hospital chaplaincy service or from ministers of religion.

“ The people close to you are affected by your illness too. They can become sidelined if you leave them out of your day to day worries and concerns.”

Phil, Hants.

Looking after someone with liver disease

It can be very worrying, upsetting and tiring to look after someone with liver disease. If you are a carer, whether a close friend or relative, it is important to look after yourself as well, and consider what support you need to enable you to look after someone else. In addition to support through family and friends, there are carer's helplines and also counselling services that can offer help. Please refer to the Trust website for further information: britishlivertrust.org.uk/liver-information/useful-links/

The person with liver disease will be the first concern of their medical team who have to respect the confidentiality and views of the patient. But hospital staff should also inform and involve carers in decisions on the patient's care, with the patient's consent.

You have certain rights, for example:

- to be involved in planning the patient's discharge from hospital into your care
- you are entitled to an assessment of your needs as a carer from the local council
- if you have to give up work to look after someone, you may be entitled to a carer's allowance or other financial support.

You also have an important role to play in helping the person with liver disease with their diet and fluid intake. Ask to be present when they see the dietitian and review their diet sheet, so you can follow this when they leave hospital.

By being better informed about liver disease, its symptoms and how to manage them, you can help the patient and also find reassurance about how it affects them.

Knowing when to seek medical help

Certain symptoms of liver disease, such as hepatic encephalopathy, can be a particular challenge. This can affect patients by making them sleepy, anxious, paranoid or result in other personality changes. You can get advice on how these symptoms can be managed, and when you should get medical intervention, from the patient's medical team.

“ Being able to let our loved ones know that we understand what is happening to them, is one of the most important things we can do. ”

Lynda, Surrey.

Understanding your rights

Not satisfied with your care? What are your rights?

If you have concerns about the medical judgements your doctor has reached, the treatment options they are putting to you or how effective their treatment is, it is usually best to make an appointment and discuss this with the most senior doctor looking after you.

- It is a good idea to take notes of your concerns beforehand.
- Ask a friend, relative or member of staff you trust to be present.
- Let the doctor know how you feel and what your concerns are, being as specific as you can be.

Bear in mind that the vast majority of staff are striving to help you to the best of their ability. There may be very good reasons behind their judgements, but too often there is not enough time for them to explain themselves to patients, leaving patients unnecessarily anxious. If your doctor is not willing to discuss your concerns, or if the relationship breaks down, you should consider seeking a second opinion or lodging a complaint.

It is important to remember that you have the right to make choices about your medical care. Ask the medical team what choices are available and what are the advantages and disadvantages of each option. They will also need to seek your informed consent before giving you any treatment or procedure.

You also have a right to be treated with dignity and respect (and you have obligations to treat staff likewise). If you feel there are shortcomings in the way you have been treated, the hospital environment, or other issues (such as staff not washing their hands), you have a right to raise this. It is often easiest and most effective to simply ask to speak to the nurse in charge if you are a patient on a ward, or the department manager if you are an outpatient. It is usually best to make a complaint as soon as possible after the incident has occurred, while it is still possible to investigate the complaint and gather evidence. There are more details about the complaints procedure below.

If you are concerned about your treatment or are making a complaint, you have a right to access to your medical records and the results of any tests and investigations. Again, it is usually easiest to simply ask to see these rather than take formal action, which can take time and be stressful.

Making a complaint

When you make a complaint, it is important to think about what you would like to achieve from it. In many cases, patients would like to:

- alert the hospital/GP practice to something that went wrong and learn from it
- improve procedures in the future
- be provided with a simple apology.

There is a time limit on raising complaints of six months, although this can be extended in some circumstances.

The Patient Advice and Liaison Service (PALS) which is located in each NHS trust, can advise you on how to take your complaint forward or help you to resolve it informally.

If you wish to make a complaint:

1. You have to make it first to the hospital or GP practice concerned. You can simply write to the manager, and they will forward it to the person responsible for managing complaints. You should receive a response within a reasonable time period, usually about a month. Most complaints are resolved at this stage.
2. If you are not satisfied with this response, you have the option to get back in touch with them or refer it to the Health Service Ombudsman. In Scotland, complaints not resolved locally should be referred directly to the Scottish Public Services Ombudsman. There is also the option of taking legal action through a solicitor.

An independent complaints advocacy service (ICAS) is available to provide advice and support to people who wish to make a formal complaint about the NHS and you can also get advice on complaints from NHS Direct.

The NHS complaints procedure also applies if the NHS has paid for you to be treated privately, and to some aspects of your care if you are in a pay bed in a private hospital. Every private healthcare provider should have their own complaints procedure.

There are different procedures in place for complaints about local authority or social services care. Please refer to the Trust website for further information - britishlivertrust.org.uk/liver-information/useful-links/

If you choose to consult a lawyer or start legal action, the NHS may refuse to continue treatment or to start their own investigation, or respond to your complaint.

If your complaint is about the competence or behaviour of a healthcare practitioner, this could be a matter for the professional regulators. NHS Direct can provide the contact details for the relevant healthcare regulator.

Dealing with discrimination

People with liver disease can sometimes face stigma or discrimination due to its perceived association with alcohol and drug abuse. There is a large amount of public ignorance about liver disease and some negativity towards it that other conditions do not seem to receive:

- there are over 100 types of liver diseases and there are many different causes – some are genetic, inherited or congenital
- you do not need to be an ‘alcoholic’ to develop alcohol-related liver disease – one in three people in the UK drink alcohol at levels that put their liver at risk
- nearly a third of UK adults are overweight or obese which is one of the key risk factors for developing non-alcohol related fatty liver disease
- it is not known why some people who drink heavily or who are overweight develop liver disease and others do not
- many people have contracted viral hepatitis from sharing personal items or from unprotected sex
- everyone with liver disease – whatever the cause - should be treated with care and respect.

People with liver disease have rights. The Disability Discrimination Act protects people with disabilities that are likely to have a substantial or long-term negative effect on your ability to carry out normal day-to-day activities. Long-term is defined as disabilities that have been present for at least 12 months and will likely be present for the next year. Examples of activities that may be affected include getting out and about, driving and performing everyday household chores, as well as your ability to look after yourself properly should your physical or mental health start to suffer.

It is unlawful for your employer to discriminate against you, or treat you or someone close to you less favourably, because of your disability. They have to make 'reasonable adjustments' to help you do your job. Public services, shops and places of entertainment have to ensure that you have reasonable access to services.

Social care

If you need ongoing health and social support after leaving hospital, a multi-disciplinary team, which may include a consultant, doctors, nurses and local social services, will carry out an assessment of your needs. Local councils each have their own set of 'eligibility criteria' for care services and services may incur a charge.

You should be fully involved in the assessment process and informed of the complaints procedure in case you are not happy with the outcome. Most teams will have a social worker who will make sure social services know about any extra support you will need at home. Other specialists may also be part of the team, such as occupational therapists.

If you were receiving services before entering hospital the existing services may simply need reinstating when you leave hospital. You should not be discharged from hospital before the services you need have been arranged.

Financial support

There are a number of sources of financial support available for patients and carers. It is a good idea to ask about and apply for this support, even if you are not sure whether you are ill enough to qualify, as many people overestimate how ill they have to be to be eligible. Remember to ask your GP or the hospital ward for a medical certificate.

You can also ask the medical team, particularly a specialist nurse or social worker, for advice on completing the forms with information about your condition. Many people with liver disease have unpredictable symptoms and good days and bad days. Try to give as much information as possible about the number of days you have symptoms and how bad you are on your bad days.

It is also important to highlight that your symptoms can deteriorate rapidly. If your condition is severe and life expectancy is less than six months, there is a special rapid assessment procedure under 'Special Rules' – ask your doctor to instigate this procedure by completing the form.

The names of benefits and eligibility change frequently, so check with the Benefits Enquiry Line, your local Job Centre Plus, Citizen's Advice Bureau, a social worker attached to the hospital or local council for more information and help with applications.

You may be entitled to one or several of the following:

- **Statutory Sick Pay:** if you are in work, your employer can pay this for 28 weeks. They may offer you a period on full or part pay instead.
- **Disability Living Allowance (DLA):** this is paid to help with personal care, whether or not you are in work, if you are under 65. There are several different rates, depending on how severe your disability is. You can also claim a mobility component if you need help getting around.
- **Attendance Allowance (AA):** if you are over 65, you may be entitled to this allowance which is similar to DLA but has no mobility component. It is tax free and is not usually affected by any savings or income you may have.
- **Employment and Support Allowance:** this is financial support if you are not working. People who are too ill to work or who have caring responsibilities are entitled to supplements on top of this, and there are different bands of support depending on how disabled you are.
- **Carer's Allowance:** this is financial support for your unpaid carer, including your spouse (although they do not need to be related to or live with you), if they are not able to work, or study, because they are looking after you for at least 35 hours a week. They are also entitled to a carer's assessment from the local council to look at the support they may need.
- **Direct Payments:** if you have been assessed as having a need for social services, you may be offered a payment to organise care for yourself. You can get information on this from your local council.

There are other benefits that you might be entitled to if you are on a low income, such as free prescriptions, housing benefit, income support, council tax benefit or tax credits. If you experience a sudden drop in your income, for example, if you give up work, you might also be entitled to a tax rebate. It is also worth checking if you have a pension, life assurance or income protection policy, whether they will offer a payout to help financially.

Help with getting about

Liver disease can make people feel very fatigued and some people with advanced liver disease can have trouble walking even short distances. If this is your experience, you are entitled to a variety of financial and other support.

- Help with travel to hospital: you can apply for financial help for this, or use a local scheme such as a dial-a-ride service. Ask your hospital for details on what services they offer.
- Disability Living Allowance mobility component: this is paid as part of your DLA to help with your mobility needs. This is paid at two rates. The lower rate is paid if you can walk but might need some help. The higher rate is paid if you can't walk, if the effort might be dangerous for you, or if you can't walk well or beyond a very limited distance.
- Blue Badge parking: this gives you a permit to park in disabled bays and on many yellow lines, or in on-street pay and display parking zones for free. It also gives you exemption from the London congestion charge (you have to register in advance) and from certain road and bridge tolls. You can also use the badge in the EU and some other countries. This is administered by the local authority.
- Road tax exemption: cars used just for disabled people who are in receipt of DLA (higher rate mobility component) can be registered as exempt from vehicle excise duty. You will need to apply for an exemption certificate from the agency that issues your benefit.
- Disability equipment: your local council can help with things like home modifications and walking frames.
- Free local bus travel: if you are disabled and live in England, you can apply for free off-peak bus travel from your local bus pass provider.
- Freedom Pass: in London this scheme gives you free travel on public transport. You can apply from the Post Office or from your local council.
- Disabled person's railcard: offering you discounts of rail fares after a one-off fee.

It is worth checking with your local council, social worker, Job Centre Plus or the Benefit Enquiry Line that you are getting all the support, both financial and otherwise, that you are entitled to.

Hoping for the best, planning for the worst

Many people with liver disease live for many years, often without serious symptoms. However, a serious diagnosis such as liver failure means that it is a sensible idea to plan for what could happen if you become increasingly ill. Patients are often worried about what could happen to them if they are not able to make their own decisions. They want to be sure that their wishes will be followed and that their loved ones are looked after.

It is a sensible idea to sort out paperwork at an early stage. Make a list of all your assets and/or debts, and file these carefully. Include things like property deeds and investments, as well as details of bank and savings accounts. Think about who you would like to take care of your affairs if you were not able to look after them yourself. If you feel able, ask their permission and tell them where you keep your files. If you have young children, pets or other caring responsibilities, think about what arrangements should be made for them if you became more unwell.

It is very important to make a legally valid will, witnessed by two people who are not relatives or benefiting from the will. It should set out who you want to leave your assets to, if you have any preferences for funeral arrangements and who you want to sort out your affairs after your death. It is best to consult a solicitor for legal advice, and it's a good idea to make your will while you are still well. If you need to take strong medication later on, or become mentally incapacitated for any reason, you may not be considered legally competent to make a will at that time.

Some people want to have a say in medical decisions made for them when they are too ill to consent at the time, for example because they are unconscious or during an operation. You can make a legally binding decision called an advanced directive (sometimes called a living will). This can include your wishes about your treatment and even the circumstances where you would like to refuse treatment. You can get a legal document, called an enduring power of attorney, that will enable someone you nominate to take legal decisions, including on your care and treatment, on your behalf. Setting up a power of attorney is important if you would like someone to be able to administer your financial affairs for you. These are major steps, and it is important to consider them carefully. If you feel able, discuss them with those closest to you, your medical team and a solicitor, if possible.

Useful words

Acute – a short sharp illness that may be severe but from which most people will recover in a few weeks without lasting effects.

AFP – alpha-fetoprotein, a protein produced by liver cells normally found only in tiny traces in your body. The AFP blood test is a common test for liver cancer.

Albumin – the main protein in human blood, manufactured by the liver. Low albumin levels are an indication of liver damage.

ALT – alanine aminotransferase, a liver enzyme that enters the blood following liver damage. An ALT test is used, for example, to monitor and assess the degree of damage in patients infected with chronic hepatitis B and other types of hepatitis.

Anaemia – a condition where there are not enough red blood cells taking oxygen around the body, causing symptoms like fatigue and shortness of breath.

Antigen – a foreign, invading protein. When recognised by the body as foreign, the body's immune defence will react to the antigen by producing antibodies.

Antibody – a specific immunoglobulin (protein) produced by your body as part of a defence reaction against an invading substance (antigen).

Ascites – accumulation of fluid in the abdomen (peritoneal cavity) which surrounds the bowel, leading to enlarged, swollen and tender abdomen.

AST – aspartate aminotransferase, a liver enzyme but less specific to the liver than ALT (see above). A raised AST level may follow a heart attack, for example.

Auto antibodies – abnormal antibodies that attack your own body tissues because it has mistaken them as foreign.

Autoimmune disease – a type of disease where the body's defences attack another part of the body.

Bile – a yellow-green fluid produced by your liver to aid digestion. It contains chemicals as well as waste products and plays a central role in helping the body digest fat.

Bile ducts – the tubes linking your liver to your gut (also known as your intestine or bowel). The bile ducts carry bile from your liver to your gut.

Biliary – anything to do with the bile duct or bile.

Blood markers – substances measured in blood which may increase if infection or disease is present or suspected.

Blood serum – the clear, liquid part of your blood. Serum will separate from blood during clotting.

Cholestasis – a condition where the flow of bile from the liver is reduced.

Chronic – an illness that lasts a long time (more than six months), possibly for the rest of a person's life.

Cirrhosis – where inflammation and fibrosis have spread to disrupt the shape and function of the liver. Even with no signs or symptoms of liver disease, the working capacity of liver cells has been badly impaired and they are unable to repair the liver. This is permanent cell damage and can lead to liver failure or liver cancer.

Creatinine – a waste product from protein in the diet and from the muscles of the body. Creatinine is removed from the body by the kidneys. Measuring the creatinine level in the blood gives an indication of how well, or poorly, the kidneys are working.

Compensated cirrhosis – a stage at which the liver is severely scarred but there are enough healthy cells for the liver to perform all of its functions adequately. People who have compensated cirrhosis may feel quite well.

Decompensated cirrhosis – where the liver is not capable of performing all of its normal functions. People may experience a variety of symptoms, including ascites, bleeding varices, jaundice and hepatic encephalopathy.

ELISA – enzyme linked immunosorbent assay, a biochemical test used to detect the presence of an antibody or an antigen in a sample.

End-stage liver disease – another term used for cirrhosis and indicates that a person is in poor health. It can be more useful to describe a person's cirrhosis as either 'compensated' or 'decompensated'.

Enzyme – a substance, usually a protein, produced by the body to help speed up a chemical reaction (which can be measured with liver function tests).

Fibrosis – where scar tissue is formed in an inflamed liver. Fibrosis can take a variable time to develop and, even with scar tissue present, the liver keeps on functioning quite well. However, continued building up of scar tissue may lead to cirrhosis.

Gastroenterologist – a doctor who specialises in problems of the digestive tract including throat, stomach, bowel (gut) and liver.

GGT – gamma-glutamyl transferase, a liver enzyme in your blood that is measured to check for liver damage.

Glomerular filtration rate (GFR) – a test of kidney function that measures the effectiveness of the glomerulus, a small, entwined group of tiny blood vessels (capillaries) in the kidneys, to filter urine from your blood. A reduction in the GFR increases the risk of renal failure.

Hepatic – anything relating to the liver.

Hepatic encephalopathy (HE) - disturbed brain function leading to mental confusion, drowsiness and memory loss due to waste products which the liver is no longer able to process being carried to the brain.

Hepatitis – any inflammation of the liver is known as hepatitis, whether its cause is viral or not. A sudden inflammation of the liver is known as acute hepatitis. Where inflammation of the liver lasts longer than six months the condition is known as chronic hepatitis.

Hepatocellular cancer (HCC) – cancer of the liver cells.

Hepatocyte – a liver cell.

Hepatologist – a doctor who specialises in liver diseases.

Hyperlipidemia – having excessively high levels of fats (triglyceride and cholesterol) in the bloodstream.

Immunoglobulins – also known as Ig, these are large proteins that act as antibodies, found in body fluids and cell tissues. They will bind to invading organisms, such as bacteria or viruses, to destroy them.

Immunosuppressant – a drug that dampens down the body's defences (immune system). Usually used after an organ transplant to stop the body rejecting the donor organ.

Inferior vena cava – the large vein that carries blood back to the heart from the lower part of the body.

Inflammation – the body's protective reaction to injury, involving swelling, pain, redness and heat.

INR time – international normalised ratio, a term used to describe how quickly your blood clots and your risk of bleeding. As the liver makes clotting factors and platelets, it is a useful indicator of how well your liver is functioning. Normal INR is around 1 and a higher INR indicates increased risk of bleeding and poorer blood clotting.

Intravenous – injection of a fluid into a vein via syringe or catheter (a long narrow tube inserted into a vein to allow intravenous injection).

Jaundice – yellowing of the skin and whites of the eyes caused by the yellow pigment bile, which is normally got rid of by the liver, surfacing in the blood.

Liver blood tests – several blood tests analysed together to indicate whether your liver is inflamed (hepatitis), damaged or not working properly. They measure levels of certain enzyme and protein substances in your blood that may alter when liver damage is present.

Metastasis – the distant spread of a malignant tumour from its site of origin.

ME (myalgic encephalomyelitis) – also known as chronic fatigue syndrome, a condition in which a person always feels tired without a clear-cut medical reason.

Metabolic – relating to the break down and processing of substances in your body for growth and vitality.

Oncologist – a doctor who specialises in understanding and treating cancer.

Pathogenesis – the development of a disease or illness.

Protein – a large molecule made from amino acids (peptides) required for the structure and working of your body's cells, tissues and organs. Most proteins are made in the liver.

Resection – removal of some of a body part by surgery.

RIBA – recombinant immunoblot assay, a sensitive test used to detect the presence of Hepatitis C virus (HCV) antibodies in your blood.

RNA – ribonucleic acid plays an important role in translating the genetic information (DNA) into protein production (synthesis)

Seroconversion – the point when the body starts to make antibodies in response to the presence of an antigen (a foreign body), such as a bacterium, virus or vaccine.

Stent – a small, thin wire-mesh or plastic tube used when treating obstructions in the bile ducts. Where there is a narrowing (stricture) in the bile duct the doctor will insert a stent to open up the duct to keep it from collapsing.

Tumour markers – substances found in blood, urine or body tissues which may increase if cancer is present or suspected. Alpha-fetoprotein (AFP), for example, is a protein that is a tumour marker for liver cancer.

Viral load – the amount of virus in your blood.

Virus – a microscopic particle that infects living cells by getting inside them and reproducing (replicating). Viruses cannot reproduce by themselves and can only multiply from within the cells of their living host.

Further information

Please refer to the Trust website for details of patient organisations and support groups specialising in specific liver conditions, that you may find helpful.

The British Liver Trust publishes a large range of leaflets about the liver and liver problems written for the general public.

Leaflets that you may find particularly helpful include:

- *Alcohol and liver disease*
- *Autoimmune hepatitis*
- *Benign tumours and cystic disease of the liver*
- *Budd-Chiari syndrome*
- *Cirrhosis of the liver*
- *Diet and liver disease*
- *Directory of liver specialists*
- *Non-alcohol related fatty liver disease*
- *Gilbert's syndrome*
- *Haemochromatosis*
- *Hepatitis B*
- *Hepatitis C*
- *Hepatitis D and E*
- *Life after liver transplant*
- *Liver cancer*
- *Liver disease tests explained*
- *Liver transplantation*
- *Intrahepatic cholestasis in pregnancy*
- *Porphyria*
- *Primary biliary cholangitis*
- *Primary sclerosing cholangitis*
- *Wilson's disease*

Contact us for more information:

Tel: 01425 481 320

Tel: 0800 652 7330

Email: info@britishlivertrust.org.uk

Web: britishlivertrust.org.uk

This leaflet is for information only. Professional, medical or other advice should be obtained before acting on anything contained in the leaflet as no responsibility can be accepted by the British Liver Trust as a result of action taken or not taken because of the contents.

Special thanks

Dr Toby Delahooke, Consultant Hepatologist, Leicester Royal Infirmary, Leicester.

Dr Steve Ryder, Consultant Physician in Hepatology and Gastroenterology, Nottingham University Hospital NHS Trust

Phil, B.B., Linda, Judith, Lynda.

Important medical information

(take this with you when you travel, go into hospital or see another medical practitioner)

Name: _____

Date of birth: _____

Home address: _____

GP: _____

Hospital consultant name: _____

Hospital: _____

Your hospital number: _____

Hospital telephone number: _____

Next of kin name: _____

Next of kin contact number: _____

Allergies: _____

Medical condition/s: _____

Other information: _____

Usual medications:

Name (chemical and brand)	What for	Dose	When taken am, pm or as required	Date started	Date stopped

Usual medications:

Name (chemical and brand)	What for	Dose	When taken am, pm or as required	Date started	Date stopped

We hope you have found this publication helpful

All our publications are reviewed by medical experts and people living with liver disease. If you have any feedback on this publication please email the Trust at **info@britishlivertrust.org.uk**

The British Liver Trust is proud to be recognised as a provider of expert liver health information, but to do this we must depend on the kind donations of our supporters. The Trust receives no government aid, yet strives to fill the growing need for liver health information in the UK.

We are a small charity, and your donation can make an important difference.

A gift of £5 could help us answer patient calls to our helpline

A gift of £20 could help us set up a new patient support group

A gift of £50 could support the costs of a new patient guide or leaflet

Gifts can be made:

Online at **britishlivertrust.org.uk/donate**

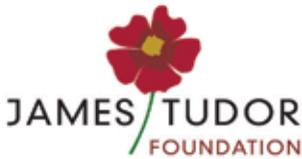
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By texting LVR10 £10 (or other amount) to 70070

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Please consider supporting The British Liver Trust today.

If you have questions about making a donation,
please call **01425 481320** or email **fundraising@britishlivertrust.org.uk**



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Contact details

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