

Thinking ahead: Planning for your future with advanced liver disease



Pioneering Liver Health

Thinking ahead: Planning for your future when you have advanced liver disease

It's important for those with advanced chronic liver disease to talk about how the condition affects their lives, and to think about their wishes for the future.

This publication will help you talk to your hepatology team, GP, relatives and carers about how you would like your future care to progress, and encourage you to start those conversations early so you can make your preferred care options clear. In some cases, you may be referred to a supportive and palliative care team, who are experts in this area. The information here helps you to understand their role.

This publication also covers end of life care in a separate section that can be looked at when you feel ready.

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 greater awareness around liver disease, leading to swifter diagnosis and treatment.

All our publications are reviewed by medical specialists and people living with liver disease. Our website provides information on all forms of adult liver disease and our Helpline gives information and support on general and medical enquiries. Call us on **0800 652 7330** or visit **www.britishlivertrust.org.uk**.

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Planning for your future care

Chronic liver disease is an unpredictable condition and the course of the disease varies greatly – each person living with it will experience it differently. This can make it difficult for your healthcare team to know when it's a good time to talk about your future care. However, there are some symptoms that indicate the liver has become so badly damaged it can no longer work properly (this is known as 'decompensated cirrhosis' – see below). It's important for patients with decompensated cirrhosis to have the opportunity to talk about the impact of their condition, and to think about their wishes for the future. Feeling able to talk about what is important to you and your family in the advanced stages of liver disease is an essential aspect of your care.

Although these conversations can be difficult, patients and their families or carers often find that planning ahead brings them peace of mind. Your healthcare team and loved ones need to understand your wishes and be aware of your thoughts and preferences.

In some cases, you may be referred to a supportive or palliative care team. This is because they are experts in managing the symptoms that may occur with advanced liver disease, so please don't worry if this happens. A common misconception is that palliative care is only provided at the end of life. In fact, palliative care can be provided at any stage of a life-limiting illness. The earlier you access these services, the better they can support you.

What is best supportive care?

You may hear your healthcare team use this term when they discuss the most appropriate care for you. It simply means looking at the best ways to manage your symptoms and ensure quality of life, and how best to provide your care, such as organising a district nurse to visit you at home so you can stay in your own surroundings.

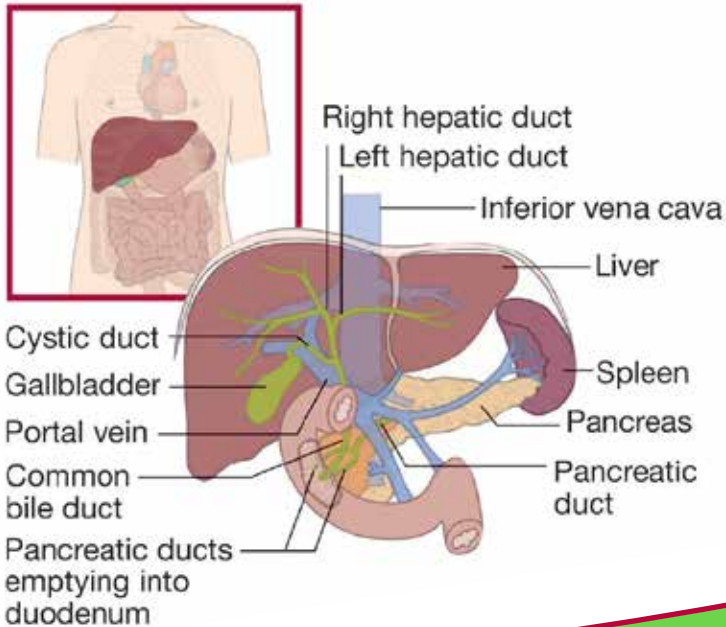
How liver disease develops

Liver damage develops over time. Any inflammation of the liver is known as hepatitis, regardless of its cause. Sudden inflammation of the liver is known as acute hepatitis. Where inflammation of the liver is present for months or years, it is known as chronic hepatitis.

Fibrosis is where scar tissue is formed in response to the inflamed liver. The liver can work reasonably well despite the presence of scar tissue, and treating the cause of the inflammation may prevent further liver damage and may reverse some or all of the scarring.

The term cirrhosis refers to very advanced scarring that has spread throughout the liver and may show up on an ultrasound scan. Even when cirrhosis has occurred, the liver may still continue to function normally and even at this stage, there might be few or no symptoms of liver disease. This is known as **compensated cirrhosis**.

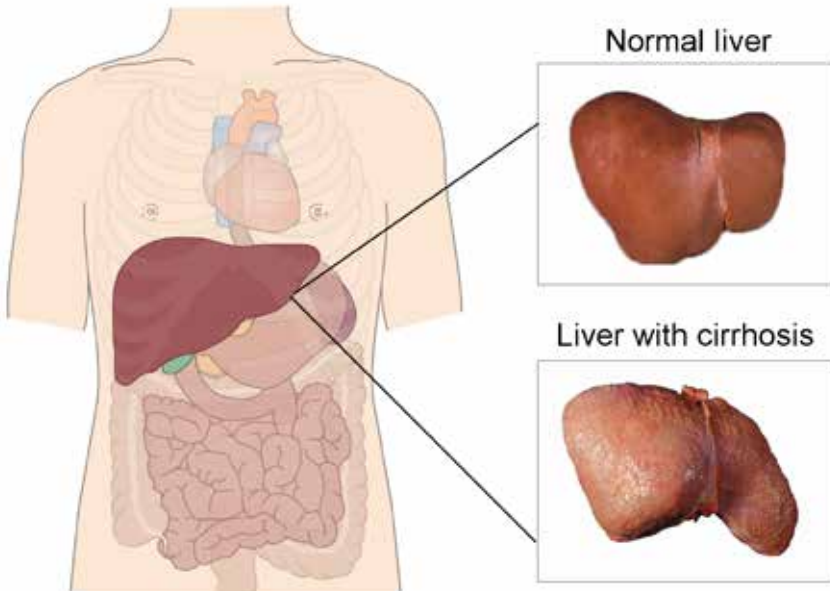
In most patients with cirrhosis, however, there does come a time when the liver stops working properly and symptoms occur. This is known as **decompensated cirrhosis**.



Common symptoms of decompensated liver disease are:

- Bleeding from varices (enlarged blood vessels in the gullet or stomach)
- Ascites (fluid building up within the tummy/abdomen)
- Spontaneous bacterial peritonitis (infection in the ascites)
- Hepatic encephalopathy (confusion and drowsiness due to the liver not working properly)
- Jaundice (yellowing of the skin and whites of the eyes)
- Kidney failure (sometimes called hepatorenal syndrome).

As the liver fails, the chemicals and waste that a healthy liver would normally process build up in the body and become toxic. **This is known as end-stage liver disease.** In the final stages of liver disease the build-up of waste products affects many organs. This is known as multiple organ failure, and sadly, loss of life is likely to follow.



Can decompensated cirrhosis be cured?

Liver transplant offers a potential cure for some people with advanced liver disease. Unfortunately, many people cannot have a transplant because they are too unwell for the operation. There are many other factors that may affect suitability, including whether there is enough support at home, or whether the person living with liver disease is alcohol-dependent. The number of people who need a transplant is also greater than the number of livers available. Some people will die on the transplant waiting list each year, while others will have to be taken off the waiting list because they have become too unwell. For patients who are not suitable for a transplant, whatever the reason, it is important to recognise that their liver disease will shorten their life. This can help with planning for the future.

Why should I plan ahead?

- Understanding your illness, thinking about the future and what is important to you, can help plan care that aims to achieve your wishes
- Thinking about what is important to you can also help you to make the most of the good days, but also plan for the times when you are feeling less well
- Having conversations with your family, friends and carers about your wishes for the future means they will know what you want to happen if you become less well and are unable to state your wishes yourself. You may want to decide on treatments you would or would not want, or where you would prefer to be cared for.

What is supportive and palliative care?

Supportive and palliative care teams aim to improve the quality of life of people with an illness that will shorten their lives, enabling them to live as well as possible for as long as possible. Supportive and palliative care teams can help by managing any symptoms you might have, as well as providing psychological, social and spiritual support.

They can also make sure your family is supported and help you to access any financial help you may be entitled to as a result of your illness. This care may be provided in hospitals, in your home, in the community or in a hospice. Supportive and palliative care teams work alongside your GP and hospital team to improve your wellbeing by treating you as a whole person, not just looking at your medical condition.

What is hospice care?

Hospice care is specialist supportive and palliative care that is linked to a specific hospice organisation. However, you don't need to be in the hospice itself to receive care from the people who work there. Hospices provide different services – many run community and day services so you don't need to be admitted to a hospice to benefit from the care it offers.

A hospice may have some NHS funding, but usually relies on charitable donations. Volunteers often assist at hospices, but clinical care is always provided by medically trained professionals. Hospice care is simply one way of providing supportive and palliative care services.

Common misunderstandings about palliative and hospice care:

- **Palliative care is only for people in the last days of life**

Many people think palliative care is only provided at the end of life. However, palliative care can be provided at any stage of a life-limiting illness. The earlier you access these services, the better they can support you.

- **Palliative care is only for people with cancer**

Palliative care teams used to see mainly people with cancer. However, they now see increasing numbers of people with life-limiting illnesses, whatever the cause.

- **Hospice care is only for people who are dying**

Lots of people think that hospices are just places where people go to die. Some patients are admitted to hospices in their last days of life, but many people use hospice services to get help in controlling their symptoms or to find out more about care in the community or day care services.

People can be admitted for last days of life, symptom management or respite. Community services aim to keep people as well as possible for as long as possible. They may also offer exercise classes, complementary therapy, carer support groups and more.

Questions you might find helpful:

How can supportive and palliative care teams help me?

People with advanced liver disease often experience uncomfortable symptoms that affect their quality of life. Palliative care specialists are experts in pain and symptom management and may be able to help improve your quality of life so that you can make the most of every day. They can also:

- Tell you about other services that might be helpful to you, such as community services and support groups
- Assist with any psychological, social and/or spiritual concerns you may have
- Provide information and advice about your care and treatment, including financial and benefits advice
- Support your family, friends or carers
- Give practical advice on medication management
- Help you plan ahead to ensure your wishes are known by those caring for you.

Palliative care teams also help support patients at the end of life to make the last hours/days of life as comfortable as possible and to help them to die with dignity. They can also provide support to your family and loved ones at this difficult time.

When should I think about being referred to supportive and palliative care?

This depends very much on individual circumstances. Some situations in which you may benefit from discussion with your GP or hospital team about referral to palliative care are:

- If you have been admitted to hospital with problems from decompensated liver disease and have troubling symptoms that affect your quality of life
- If you have ascites (build-up of fluid) that needs to be drained regularly
- If your ascites has ever been infected (called spontaneous bacterial peritonitis)
- If you have been told you have problems with your kidneys as a result of your liver disease

- If you have had an episode of hepatic encephalopathy, even if you have made a full recovery. Having discussions with your family and healthcare team about what you want in the future will help them to know what to do if you become confused again
- If you have been told that you are not able to have a liver transplant
- If you are undergoing treatment for liver cancer
- If you are being considered for a liver transplant (see below).

It may seem odd for people who are being considered for a transplant which could possibly cure them to think about palliative care. However, people who need a transplant are often unwell, suffer with difficult and unpleasant symptoms and may also benefit from specialist input to improve quality of life while they are waiting for the operation.

How do I access palliative and hospice care?

Your GP, or another member of your health and social care team, such as your liver doctor (hepatologist), can refer you to these services. Your GP or hospital doctor will then work together with them, trying to keep your liver working as well as possible, while at the same time looking after other needs you and your family may have.

It may be necessary to travel to where the service is being provided, for example to a local hospice. However, if you struggle to get out and about, palliative care can be provided at home by community palliative care nurses, as long as this service is available locally.

The services offered by supportive and palliative care teams will vary depending on where you live. To find out what is available in your area, contact your GP or social care team.

Is palliative care just for patients?

Supportive, palliative and hospice care teams provide support for families and carers too. This may include psychological and emotional support, social opportunities, bereavement support and counselling. In some cases they may help to arrange extra care for you to enable your family to take a break from the caring role, giving them more time and energy to do the things you all enjoy.

What should I discuss with my supportive and palliative care team?

The types of things that you may wish to discuss with your care team will vary from person to person. Your care plan should be written down and be reviewed on a regular basis so that it meets your current needs. Remember that it is flexible and that you can change your wishes at any time.

Some examples of the things that you may wish to discuss include:

- Your treatment choices
- Managing your symptoms
- How to manage your diet and fluids
- Where and how you wish to be cared for should your condition deteriorate
- How to ensure the support you have meets your needs
- Who you would like contacted and who you would like to make decisions on your behalf.

**The following section includes information about end of life care.
You may not want to read any more at this stage.
You can refer to this section when you feel ready.**

What does end of life care planning mean?

It is important for your healthcare team to have open, honest conversations with you and your family, particularly when you are coming to the end of your life.

End of life conversations may feel difficult, but planning ahead can make it easier to arrange things as you wish in the future. Talking to your healthcare team early on will enable them to make every effort to respect your wishes should you become too unwell to tell them what you want at a later stage.

Things people with advanced liver disease sometimes want to think about are:

- Whether you want to continue having invasive tests such as gastroscopies (camera test to look into the stomach)
- Whether you want to be admitted to hospital or remain at home when you become more unwell
- Your thoughts about resuscitation if your heart stops or you stop breathing
- Where you would prefer to be cared for, if possible, in the last days of life
- If there are any affairs you need to get in order to make things easier for your family e.g. ensuring you have an up to date Will
- Appointing someone you trust to make decisions about your medical care, and/or manage your finances if you become too unwell to do it yourself. This is called appointing a Lasting Power of Attorney (LPA) in England and Wales, Power of Attorney in Scotland and Enduring Power of Attorney (EPA) in Northern Ireland (it only applies to financial matters in Northern Ireland and does not include medical care).

It is important to know that you can change your mind about your wishes at any time. It is very difficult to know in advance what you will really want if you become more unwell. For example, even if you tell your healthcare team you plan to stay at home, you can change your mind and ask them about going back into hospital, especially if things change quickly and you are not managing at home.

Why is end of life care planning important?

Writing down your wishes in advance means you can explain how you would like your future care to be provided. This can be beneficial if those involved in your care need to act on your behalf. Having these difficult conversations early can also help reduce concerns and uncertainty.

You may find the process gives you a sense of control, knowing that those involved know exactly how you would like your care to be provided. Knowing what your wishes and preferences are may also give your loved ones a sense of comfort and reassurance. It may also prevent doubts or disagreements about what would be best for you if other people, such as family members or trusted friends, need to help make these decisions for you.

For patients with liver disease in particular, having early conversations about their wishes can be particularly important. One of the complications of decompensated liver disease is **hepatic encephalopathy** (HE) which causes people to become confused and drowsy, so planning and making decisions can be more difficult. Ensuring your family and healthcare team know your wishes in advance means that, if you develop hepatic encephalopathy, there is no confusion about what care you would or wouldn't want to receive.

How can I plan ahead?

When you feel ready, ask your health and social care team about your options for future care and planning. This doesn't mean you have to make immediate decisions, but being informed can help you discuss your needs, preferences and wishes.

Your GP or palliative and hospice care professionals, as well as your wider health and social care team, can help you with making decisions. You can write down instructions about the medical and social care you would wish to receive or not receive in certain situations.

Creating an **Advance Care Plan** enables you to write down your preferences for your future care. It is not legally binding but helps guide choices on your behalf if you become unable to make decisions or communicate for yourself.

An **Advance Decision to Refuse Treatment (ADRT)**, in England and Northern Ireland or **Living Will** in Scotland, enables you to write down decisions to refuse or withdraw specific treatments in advance. These documents must be written in a particular way, and it's a good idea to ask your care providers for help if you feel you need it. As long as they've been completed correctly, these are legally binding documents.

How do I find out more?

There are lots of organisations available that provide information and support to patients with life-limiting conditions and it would be difficult to cover all of them here. The specific palliative and end of life care services available to you will vary depending on where you live so if you think you may benefit from being referred to a palliative or end of life team, speak to your GP or hospital team to find out what is available near you.

Sources of general advice:

Conversations for Life

Help for families, professionals and communities to start discussions about end of life care.

Telephone: 01539 821420

Email: info@conversationsforlife.co.uk

Website: www.conversationsforlife.co.uk

Dying Matters

A membership organisation offering a wide range of resources to help people start conversations more easily about dying, death and bereavement.

Telephone: 0800 0214466

Website: www.dyingmatters.org

Good Life, Good Death, Good Grief (Scotland)

Set up by the Scottish Partnership for Palliative Care, this organisation is working to make Scotland a place where there is more openness about death, dying and bereavement. They aim to help people feel better equipped to support each other through the difficult times that can come with death, dying and bereavement.

Website: <https://www.goodlifedeathgrief.org.uk/>

Hospice UK

Charity which supports hospice care providers to deliver high quality care and support for people with life-limiting illnesses and their families.

Telephone: 020 7520 8200

Website: www.hospiceuk.org

British Liver Trust

Telephone: 0800 652 7330 between 10am and 3pm

Monday to Friday (not bank holidays).

Email: helpline@britishlivertrust.org.uk

Website: www.britishlivertrust.org.uk

Your care team will be happy to discuss any of the topics covered in this leaflet with you – please ask them if there is anything that you don't understand.

Special thanks

Dr Hazel Woodland, Clinical Research Fellow in Hepatology, University Hospitals Bristol NHS Trust

Dr Fiona Finlay, Consultant in Palliative Medicine, Queen Elizabeth University Hospital, Glasgow

Professor Karen Forbes, Professorial Teaching Fellow and Consultant in Palliative Medicine, University Hospitals Bristol NHS Trust

Sue Goodall, Renal Supportive Care Clinical Nurse Specialist, St Barnabus House Hospice, Worthing

Kim Batchelor, Liver Clinical Nurse Specialist, St Barnabus House Hospice, Worthing

Anthony Moffat, Consultant Nurse Hepatology, Derriford Hospital, Plymouth

Terry and Mike, lay reviewers

Sylvia and Doug, lay reviewers

Anne Lewis, lay reviewer.

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 to 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**

Remember to indicate your Gift Aid preference.

By texting LIVR10 £10 (or other amount) to 70070

Via post to British Liver Trust, 6 Dean Park Crescent, Bournemouth BH1 1HL

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

Call us: 01425 481320

Helpline: 0800 652 7330

Email us: info@britishlivertrust.org.uk

Visit our website: britishlivertrust.org.uk

Write to us: **British Liver Trust**, 6 Dean Park Crescent, Bournemouth BH1 1HL



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