

A guide to understanding
advanced liver disease

Information for patients and carers about hepatocellular carcinoma (HCC)





Introduction

Welcome to your guide to understanding advanced liver disease and **hepatocellular carcinoma**. Throughout this guide, any unusual terms are highlighted in bold and explained at the end of this leaflet in the glossary. If you have any questions, remember to ask your doctor or nurse at your next appointment. We hope you find it informative and useful – it should help you to feel more in control of your condition.

There are five other booklets available in this series which cover a range of topics including general health and wellness, **varices** and **variceal bleeding**, **ascites**, **hepatic encephalopathy** and nutrition. If any of these interest you, be sure to ask your doctor about them.

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What is liver cirrhosis?

When a healthy liver gets injured by a virus, a toxin like alcohol or another specific liver disease, it repairs itself by replacing damaged cells with new ones. This is usually an efficient process but, when too much damage occurs and/or lasts a number of years, some of this repair work can leave scars. This is known as **'cirrhosis'**. At this point, if care is taken, the liver can usually cope with the damage and maintain its important functions. During this period, which can last years, there can be very few symptoms or even none at all.

In advanced liver disease, the scarring can become so great that the liver can no longer repair itself or function properly.

This can cause associated conditions like ascites, variceal bleeds, hepatocellular carcinoma or hepatic encephalopathy. In this booklet, we focus on the associated condition hepatocellular carcinoma, a type of primary liver cancer.

Advanced liver disease and cirrhosis can have several causes including long term alcohol abuse, viral infection such as **hepatitis B or C**, metabolic diseases such as **non-alcoholic related fatty liver disease (NAFLD)**, or other conditions such as autoimmune hepatitis.



Why can cirrhosis lead to hepatocellular carcinoma (HCC)?

Hepatocellular carcinoma (HCC) is the most common form of liver cancer and literally means cancer of the liver cells.

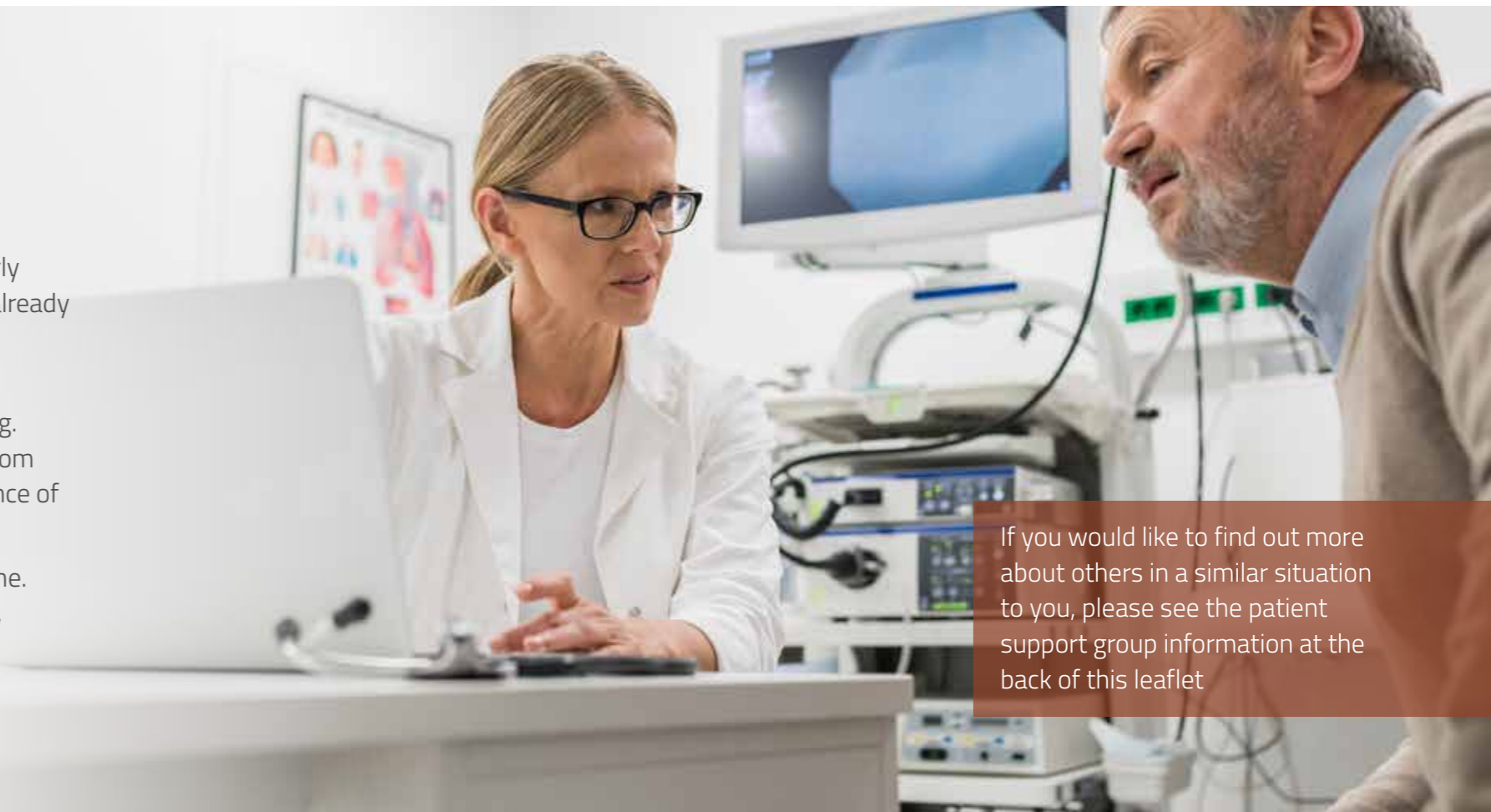
We do not know the exact cause of HCC, but it is thought that the conditions that cause cirrhosis increase the risk of developing HCC.¹

It starts when the main cells of the liver get damaged and die due to chronic liver disease, scar tissue may then form in place of the missing cells. This can lead to the development of cancerous **nodules**.²

Sometimes, HCC is detected at quite an early stage of the disease because patients are already receiving treatment for their liver damage, including regular blood tests or scans.

Knowing that you have HCC can be worrying. Being well informed and following advice from professionals should give you the best chance of managing your HCC successfully.

It's important to remember you are not alone. Talking about your condition can often help, particularly to those in a similar situation.

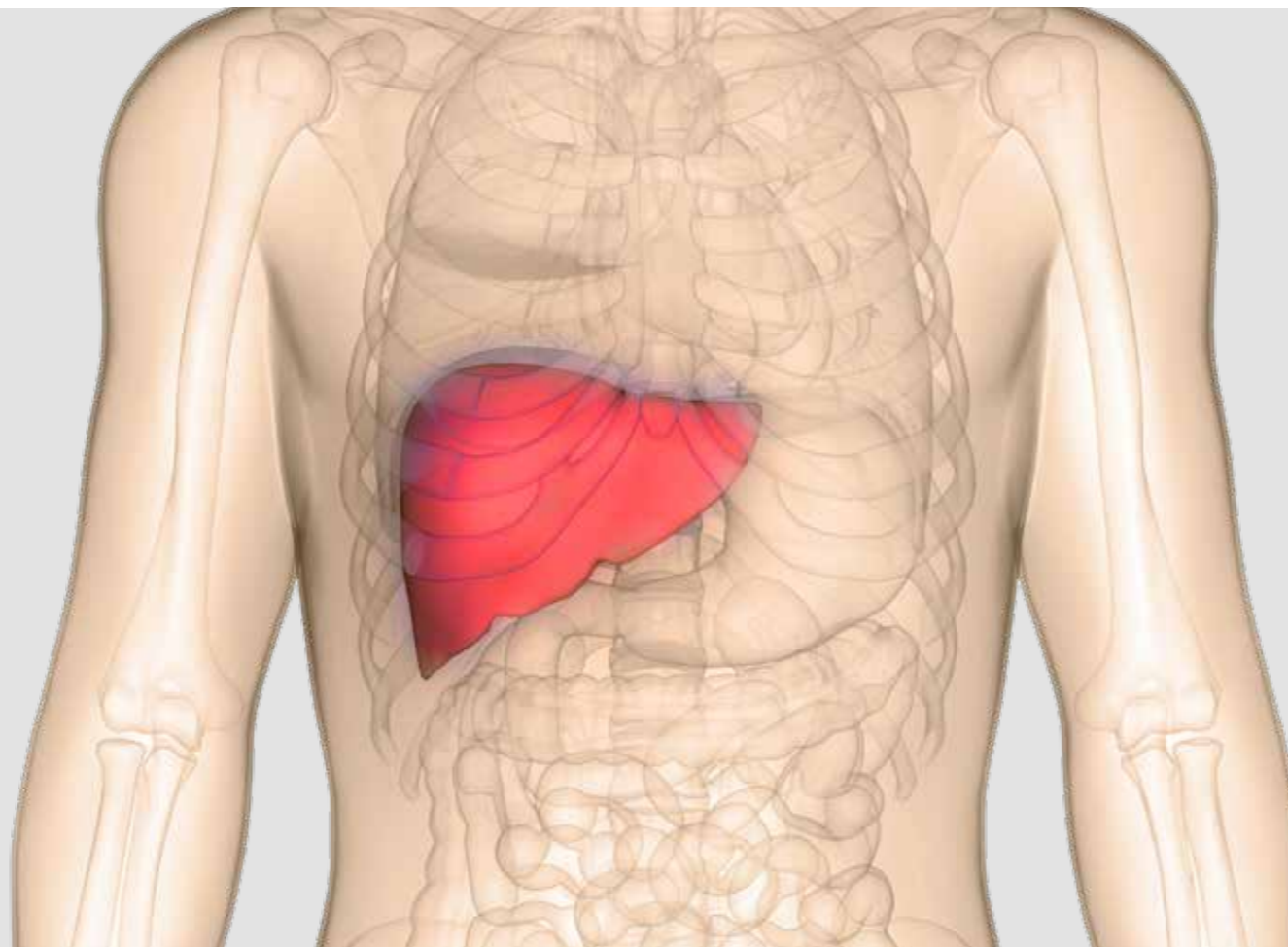


If you would like to find out more about others in a similar situation to you, please see the patient support group information at the back of this leaflet

Tell me more about HCC

HCC is known as a 'primary' cancer because it starts in the liver, rather than spreading there from another part of the body. It is by far the most common form of liver cancer and is much more likely to occur in people with severe liver damage.³

Normally, the cells in our bodies are continually renewed. Old cells naturally die off and are replaced with new cells at the same rate.



However, with cancer cells, this balance has gone wrong – the natural renewal of cells in the liver becomes increasingly out of control.

The cancer cells constantly grow and multiply until they eventually form a **tumour**.

What are the main symptoms of HCC?

In the early stages of HCC, there may be no symptoms at all. However, as the cancer progresses, the following symptoms may appear:¹

- **Abdominal** (tummy) pain or tenderness
- Nausea or vomiting
- Bruising or bleeding easily
- Weakness or tiredness
- Yellowing skin and eyes (jaundice)

If you do think you are experiencing any of these symptoms, let your doctor know straight away. The earlier cancer is diagnosed, the more chance there is of successful treatment.



How is HCC diagnosed?

Blood tests

As previously mentioned, because of your cirrhosis, your doctor will already be performing regular blood tests. If these tests show the presence of a protein called **alpha-fetoprotein (AFP)** in your blood, it can be a sign of liver cancer.

Scans

A **CT** and/or **MRI scan** enables your doctor to get a detailed image of your liver from outside your body. It will show if there are tumours in the liver and if so, how large they are. It will also show if the tumour has spread to other parts of the body.



Biopsy

This is where a tiny piece of the liver is removed for closer inspection under a microscope. This can be done by inserting a small needle through the abdomen and into the liver. The doctor will give you a local anaesthetic first, so it won't be painful. Alternatively, the doctor will insert a tiny tube with a camera attached to the end (called a laparoscope). In this case, you will be given a general anaesthetic, so you won't be awake during the procedure. This procedure is not that common if your scans show typical HCC signs as there are some risks associated with it.

If your doctor does find evidence of HCC, they will then give the cancer a grade, between 1 and 4, with 4 being the most advanced cancer.

How is HCC treated?

Treatment for HCC can slow its progression, prolong your life and provide symptom control. A cure may even be possible if the cancer is not too advanced. The most appropriate treatment for HCC depends on many factors. These include:

- How advanced the cancer is (the size and number of tumours)
- Where the cancer is in the liver – there may be several different areas
- Whether the cancer has spread beyond the liver
- Which of your conditions is most serious (cirrhosis or HCC)
- Your preference and general health

Tumour ablation and cryo-ablation (heat and cold treatment)

These treatments use hollow tubes, like straws, to apply extreme heat or cold directly to the tumour site to destroy the cancer cells. Ablation is performed under local or general anaesthesia, so it's always painless. Cryo-ablation is performed under general anaesthesia, so you are unconscious during the operation.

Chemotherapy

Chemotherapy is an aggressive form of cancer treatment that kills cancer cells, but some healthy cells too. They are usually delivered in the form of an injection, so a hospital stay may not be needed. Chemotherapy can be effective, but it can also cause some unpleasant side-effects and sometimes infections.

Surgery (resection or transplant)

In most new cases of HCC, surgery is not an option due to the severity of the underlying disease. However, if the damage to your liver is minimal and the cancer is contained in a small part of your liver, it may be possible to remove the cancerous cells during surgery. This often depends on the severity of your cirrhosis and your liver's ability to regenerate itself. If a liver resection is recommended, it will be carried out under a general anaesthetic, which means you'll be unconscious during the procedure and won't feel any pain.⁴

On rare occasions, a liver transplant may be suggested by your doctor. A liver transplant is a major operation, which carries many risks in itself. Unfortunately, the waiting list is usually

very long. Also, it is only possible if the cancer has not spread to other parts of the body. The liver itself needs to come from somebody with the same blood type and a similar body size to the person receiving it.

This is a lot to think about and take in, so make sure you have a good conversation with your doctor, and perhaps someone close to you, to decide what is best.

There are many other treatment options, so make sure you discuss these in depth with your doctor, and remember it is okay to ask questions.

Can I get any more support?

Keeping positive

It's normal to feel overwhelmed when you're told that you have HCC, so emotional support can help you keep motivated. Ask your doctor about special groups you may be able to join. It can really help to talk with other people going through the same experience. Your doctor can also recommend places you could get specialist advice.

Looking to the future

Alongside conversations about your experience with HCC, you may want to start thinking about your wishes for the future. A **palliative (or supportive) care** team can help you start these conversations early and make sure that those around you know about your preferred care options. You can also discuss treatments to make you more comfortable.



Glossary

Abdomen: This is a space in your body (often known as the tummy) that holds a number of organs, including the liver and stomach.

Alphafetoprotein (AFP): A protein that can be a sign of liver cancer when found in the blood.

Ascites: A build-up of fluid in the abdomen.

Cirrhosis: Where healthy liver cells become damaged and are replaced with scar tissue.

CT scan: This is a painless scan where multiple x-rays are used to create a 3D image of the inside of your body.

Hepatic encephalopathy: A change in the brain that can occur in patients with advanced liver disease due to high levels of toxins in the brain.

Hepatitis B and C: Two conditions that cause inflammation of the liver due to viral infection.

Hepatocellular carcinoma: A type of liver cancer that is common in people with cirrhosis.

Liver: The largest organ inside the human body. Among other things, it is responsible for removing toxins from our blood, producing certain molecules like hormones and storing and releasing energy from food.

MRI scan: This is a painless scan that uses strong magnets and radio waves to create images of the inside of your body.

Nodules: An abnormal growth of tissue.

Non-alcohol related fatty liver disease (NAFLD): NAFLD is when you get a build-up of fat in your liver.

Supportive or Palliative care: Keeping people as comfortable as possible when they have a terminal illness.

Toxins: Harmful chemicals that enter the body through our normal daily activities such as eating, drinking and breathing. A healthy liver helps to remove these toxins from the body.

Tumour: Growing lumps of cells that can be cancerous, or can be harmless (benign).

Variceal bleed: when small veins (known as varices) burst, causing serious bleeding.

Varices: Small veins that have become larger, twisted and swollen due to blood being redirected to them.



Reporting of side effects due to prescribed medicines

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at www.mhra.gov.uk/yellowcard.

By reporting side effects, you can help provide more information on the safety of this medicine.

References:

1. A practical guide to understanding cancer: Understanding primary liver cancer. Available at <http://be.macmillan.org.uk/Downloads/CancerInformation/CancerTypes/MAC11917liverE4lowres-pdf20170614LK.pdf> [Accessed January 2019].
2. Sanyal A, *et al*. The etiology of Hepatocellular Carcinoma and consequences for Treatment. *The Oncologist* 2010; 15(suppl 4): 14-22.
3. Balogh J, *et al*. Hepatocellular carcinoma: a review. *Journal of Hepatocellular Carcinoma* 2016; 3: 41-53.
4. NHS choices. Treatment: Liver cancer. Available at <https://www.nhs.uk/conditions/liver-cancer/treatment/> [Accessed January 2019].

Disclaimer:

The images are being used for illustrative purposes only. Any persons depicted are models.

Suggested reading:

- <https://www.webmd.com/cancer/hepatocellular-carcinoma#1>
https://www.medicinenet.com/liver_cancer_hepatocellular_carcinoma/article.htm
<https://www.healthline.com/health/treating-hcc/treatment-options>
<https://www.healthline.com/health/cancer#growth>

Support groups:

European Liver Patients' Association:
<https://www.elpa-info.org>



Norgine has organised and fully funded the production of these patient leaflets as a service to medicine.

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