

## Primary liver cancer (HCC): The care to expect

If you are worried you might have liver cancer or have just been diagnosed, you may have a lot of questions about what will happen next. As with any cancer, no patient's journey will be exactly the same. There are different types of tumour and different types of treatment, and your doctor or specialist healthcare team will always be the best people to answer any questions you have. However, it can be difficult to know what to ask – especially when you're feeling anxious or don't quite know what to expect.

Liver cancer can either be primary (that is, it originates in the liver itself) or secondary (where the cancer has spread from another organ). The most common form of primary liver cancer is hepatocellular carcinoma or HCC (sometimes called hepatoma) which originates from cells in the substance of the liver.

This factsheet gives you an indication of what might happen during the different stages in the diagnosis and treatment of hepatocellular carcinoma (HCC). It also includes suggestions for questions you might ask your doctor or healthcare team at each stage, as well as signposts to more information. Your specialist team should also have lots of information they can give you about your diagnosis and treatment – and if you feel you don't have enough information, don't be afraid to ask.

### 1. Surveillance and symptoms

The majority of people with HCC at an early stage have no symptoms. This is why surveillance – that is, monitoring people who might be at risk – is so important.

#### a. Surveillance

In the majority of cases, HCC develops in a liver which has been damaged and scarred, usually over many years. If someone has cirrhosis (a term used when the liver is significantly damaged) there is a risk of HCC developing, so surveillance tests should be carried out. These are tests that are performed to try and diagnose cancer at an early stage, when more treatment options are available. If you have cirrhosis, you should be having an ultrasound scan every six months with a blood test called AFP as surveillance (see the section on 'Tests and diagnosis' below).

#### b. Investigation of symptoms

Often there are no symptoms in the early stages of liver cancer and if you do notice symptoms, they may be similar to those seen in other liver conditions. However, the earlier liver cancer is diagnosed, the better the chances of successful treatment, so if you're at all worried or think something isn't right, talk to your doctor. Possible symptoms can be very vague but could include:

- A general feeling of poor health
- Loss of appetite
- Fatigue and weakness
- Nausea and vomiting
- Loss of weight
- Discomfort over the liver area (upper right-hand section of the abdomen)
- Itchy skin
- Pale or grey poo
- Dark urine.

See the next page for symptoms that might indicate more advanced liver disease. >>>

If you have any of the following symptoms, you should **always** seek medical advice straight away, as it may indicate more advanced liver disease:

- Jaundice (skin and eyes turning yellow) – often associated with very dark urine even if you are drinking plenty of fluid
- Swelling of the abdomen
- Fever with shivers
- Vomiting blood
- Dark black tarry poo which is often smelly.

These symptoms will prompt your doctor to check your liver blood tests, which are likely to be abnormal. Further investigations will include a liver scan (see 'Tests and diagnosis' below).

### c. Incidental diagnosis

Sometimes, tests will be performed to investigate a seemingly unrelated problem, such as kidney pain. These tests then identify an unexpected abnormality in the liver which can lead to a diagnosis of liver cancer.



#### Questions for your doctor

If you have symptoms of primary liver cancer, your GP should take your medical history and perform a detailed clinical examination. They will usually then recommend a series of appropriate tests (see 'Tests and diagnosis' below). At this stage, questions you might ask your doctor include:

- Can I have a blood test to assess my liver's health?
- How and when will I get the results of the test? Who can I contact if I don't get them?
- If the blood test is abnormal, are there more tests I can have to investigate further – for example, an abdominal ultrasound scan?
- I have liver disease - when is my next ultrasound due?
- What can I do myself if I'm worried about my liver health? Are there changes I can make to my lifestyle to help?

## 2. Tests and diagnosis

The two key initial tests in diagnosing HCC are:

- A **blood test called alpha-fetoprotein (AFP)**, which is elevated in 60% of patients
- A **liver ultrasound scan**, which can show a lump or other abnormality.

If the ultrasound highlights any areas of tissue that are concerning, or if the AFP is elevated, you should be referred to a specialist liver unit for a **CT or MRI scan**. These are used to give detailed images of the inside of the body. Occasionally a **liver biopsy** may be required to confirm the diagnosis.

Additional investigations will help plan the most appropriate treatment, and will include a comprehensive set of blood tests to help doctors understand how well the liver is functioning.

When all the tests have been completed, your consultant will review your results with a medical team (see 'Who will be providing my care?' panel on page 3). As well as diagnosing the presence of cancer, the tests will provide information on how advanced the cancer is (including the size, number of tumours and location), referred to as 'staging'. This will help to determine what kind of treatment you should be having. For more information on staging, see our longer leaflet about HCC available at [www.britishlivertrust.org.uk/publications](http://www.britishlivertrust.org.uk/publications)



### Questions for your doctor or healthcare team

If you have been referred for specialist tests following an initial blood test and ultrasound, your questions might include:

- Which imaging test will I have next (for example, CT or MRI) and why?
- Where will I need to go for the tests (you may have initial tests at your local hospital; if you are diagnosed you should be referred to your nearest specialist liver unit - find a list of these at [www.britishlivertrust.org.uk/liver-transplant-units](http://www.britishlivertrust.org.uk/liver-transplant-units))
- How quickly will the test(s) be arranged? (You should be seen by a specialist within 2 weeks)
- How long will I need to wait for the results and how will you contact me? What should I do if I haven't heard anything within a particular timeframe?
- Who should I contact if I have any questions? Who is the named contact that I can speak to throughout my treatment pathway?

## 3. Treatment

A number of treatment options are available for HCC. The aim of some is to remove the cancer completely. If this is not possible then treatment will aim to stabilise or shrink the size of the cancer in order to delay progression, reduce symptoms or make other definitive treatments such as surgery possible.

Treatment options will depend on the size, number and position of tumours, the overall condition of your liver and your general health. Effective treatments include **liver transplant**, for which you will need to meet certain UK criteria (find out more at [www.britishlivertrust.org.uk/liver-transplantation](http://www.britishlivertrust.org.uk/liver-transplantation)), **resection surgery**, which involves removing the part of the liver affected, and **ablation therapies**, which work by targeting the cancer with micro or radio waves placed directly into the tumour. This can destroy the cancerous cells.

A number of other treatments may be used to stabilise the cancer and delay its progression. These include **embolisation** (sometimes called **transarterial embolisation**), **transarterial chemoembolization (TACE)** and **systemic anti-cancer treatments (SACT)**. Targeted cancer drugs may also be used, including **Sorafenib, Lenvatinib and Regorafenib**.



### Who will be providing my care?

When cancer is diagnosed, a team of specialists will be involved in your care (often referred to as a 'multidisciplinary team' or 'MDT'). The team will include a liver disease specialist (also known as a 'hepatologist') and cancer specialist (also known as an 'oncologist'), and usually a liver surgeon, specialist radiologist and specialist liver nurse.

The specialist nurse will support you in your cancer journey; if you aren't given the name of a specialist nurse at the point of diagnosis, ask for one as soon as possible, or at least a named person who can support you throughout your treatment.

For more on other treatments, see our longer leaflet 'Primary Liver Cancer'



### Questions for your doctor or healthcare team

If you are undergoing treatment for liver cancer, you are likely to have a lot of questions about what the treatment will involve and how it's going to affect you. Your questions might include:

- What stage is the cancer at?
- What is the management plan for my cancer?
- Who will be providing my care? (See panel above right)
- Who should I contact if I have more questions? Is there a specialist nurse or named person I can contact for further advice and support?
- How will the cancer affect me physically?
- What are the side effects of any treatments and how can they be managed?
- What are the likely outcomes of treatment and what are my chances of recovery?
- Is there anything I can do myself to help my overall health?
- Where can I find additional support and information?

## 4. Follow-on care

During and after your treatment, your healthcare team should keep you updated about what happens next, as well as the support that is available. After any treatment or surgery, the team will provide you with information about follow-up appointments, which should take place regularly and include appropriate scans and blood tests. Similarly, if you have a liver transplant, you will be given detailed information about follow-up care and how to look after yourself following your operation. You can also find more information about recovering from a liver transplant in our booklet 'Life After Liver Transplant', which can be downloaded from [www.britishlivertrust.org.uk/publications](http://www.britishlivertrust.org.uk/publications)

For some patients, liver cancer can be devastating and the prognosis is very poor. If this is the case, you may wish to talk to someone about your preferred care options and future wishes. It can be helpful to have these conversations early. Supportive and palliative care teams can help by managing symptoms you might have, as well as providing psychological, social and emotional support. You may find the information in our booklet 'Thinking Ahead' helpful – download it at [www.britishlivertrust.org.uk/publications](http://www.britishlivertrust.org.uk/publications)



### Questions for your doctor or healthcare team

If you have undergone successful treatment for liver cancer, you might ask the following:

- What is the follow-up plan for my care?
- How often will I have follow-up appointments and what will happen at those appointments? What tests and scans will be carried out?
- Where will I go for follow-up appointments and scans?
- Who can I contact in the future if I'm worried about my liver health?
- Is there anything I can do myself to look after my liver health in the future?

If your cancer cannot be successfully treated:

- Is there someone I can talk to about planning for my future and end of life care?

### Liver cancer and COVID-19

If you or a loved one has liver cancer, you are likely to be very worried about the impact of COVID-19. Some people with liver cancer are more at risk of becoming seriously ill if they contract COVID-19. You are more at risk if you have an underlying chronic liver condition and/or are undergoing active chemotherapy, are having immunotherapy or other continuing antibody treatments, have secondary cancers or are having other targeted cancer treatments which can affect the immune system.

Make sure you talk to your healthcare team about extra precautions you may need to take to look after yourself, and ask them any questions you need to about how your treatment may be impacted by the coronavirus pandemic. You can also find up to date information and links on the British Liver Trust website at [www.britishlivertrust.org.uk/coronavirus-covid-19-health-advice-for-liver-cancer-patients](http://www.britishlivertrust.org.uk/coronavirus-covid-19-health-advice-for-liver-cancer-patients)



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### More information and support

#### British Liver Trust website

Read more about liver cancer diagnosis and treatment, and download our longer publications on HCC and liver transplant. You'll also find information on other types of liver cancer including cholangiocarcinoma and fibrolamellar cancer  
[www.britishlivertrust.org.uk/liver-cancer](http://www.britishlivertrust.org.uk/liver-cancer)

#### Macmillan

Macmillan provides information and advice on all aspects of cancer care  
[www.macmillan.org.uk](http://www.macmillan.org.uk)