

Primary Liver Cancer or Hepatocellular Carcinoma (HCC)

This booklet contains information about primary liver cancer.

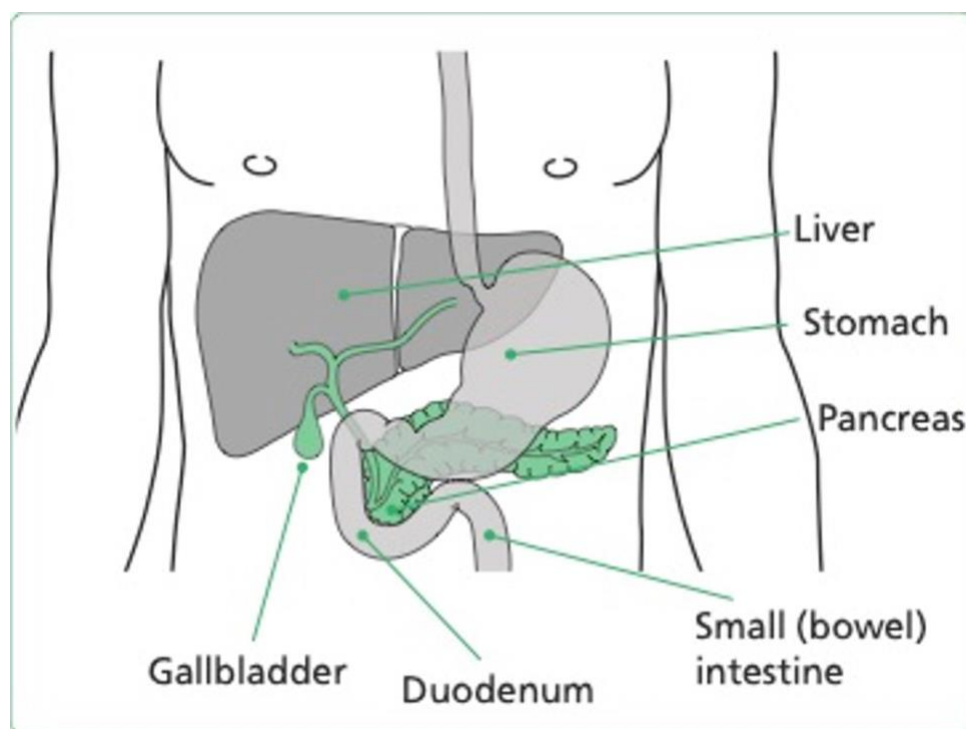
Please remember this booklet is not a substitute for asking questions of your doctor and specialist health care team. You are always welcome to ask questions and we would encourage you to do so.

What is primary liver cancer?

Primary liver cancer means that your cancer has started in the liver and has not spread from another part of your body.

A primary liver cancer, which begins in the liver cells, is also known as a hepatoma or hepatocellular carcinoma (HCC).

Primary liver cancer is relatively rare in the UK.



What causes primary liver cancer?

A lot of people who develop primary liver cancer also have cirrhosis of their liver. Cirrhosis is scarring of liver tissue and can be caused by an underlying liver disease such as hepatitis or excessive alcohol intake, or some rare liver disorders.

However, it is important to remember that not everyone who has cirrhosis will develop primary liver cancer and not everyone with primary liver cancer has cirrhosis. This means that we do not know why some people develop primary liver cancer.

What are the symptoms of primary liver cancer?

Primary liver cancer causes very few symptoms until the disease becomes quite advanced. This means that you can remain well for quite a long time even though you have primary liver cancer. This is because the liver is an organ with a great deal of reserve, and only needs a portion to be working in order to function. As your cancer progresses, the following symptoms may develop.

Jaundice

Bile ducts that carry bile are present both inside and outside of the liver. If a bile duct becomes blocked by cancer, bile flows back into the bloodstream causing your skin and eyes to turn yellow. Jaundice will also darken the colour of your urine and make your stools pale.

Jaundice can also cause itching; antihistamines or other medication as prescribed by your doctor may help with this.

If possible, jaundice can be relieved by inserting a tent (narrow tube) into the bile ducts to re-establish the flow of bile through your system.

Biliary stents are usually inserted in specialised centres such as this by radiologists (X-ray doctors). There is no alternative procedure for relieving your jaundice other than by a biliary stent or external drain if your jaundice is caused by a blockage of your bile ducts.

Placing a stent into your bile ducts carries a small risk of bleeding and infection. The risks for you will be discussed in detail by the doctor performing your procedure.

There is a possibility that the biliary stent can become blocked and/or infected. It is important that you know the signs of this happening, which are explained below.

An infected stent will cause you to develop a fever or high temperature. You may also shiver and shake, a feeling similar to bad flu. You may also develop symptoms of jaundice, such as dark urine and/or pale stools. In both cases you need to contact your GP that day so he/she can make the arrangements needed to help you. If this is problematic then please contact the ward on 0121 371 7303. You will also have the contact details of your specialist nurse.

Ascites

Ascites is a build-up of fluid in the abdomen. There are several possible reasons for ascites, including:

- Cancer cells are in the lining of the abdomen causing fluid to leak out into the abdomen
- Pressure in veins around the liver caused by the liver not working properly causes fluid to leak out into the abdomen

Symptoms of ascites such as a large, uncomfortable abdomen can be helped by taking water tablets or by inserting a temporary tube into the abdomen to drain the fluid. Placing a drainage tube into your abdomen carries a small risk of bleeding and infection. The risks for you will be discussed in detail by the doctor performing your procedure.

Unfortunately, despite both of these treatments, ascites will very often re-accumulate in the abdomen again.

Other symptoms

Other symptoms of primary liver cancer include:

- Loss of appetite
- Weight loss
- Excessive tiredness
- Nausea

How has primary liver cancer been diagnosed?

Your scans will have been sent to us by your referring hospital, even before we see you in clinic.

Our specialist team of surgeons, radiologists, hepatologists and oncologists (cancer doctors) will have reviewed these scans.

Your scans will tell us about your cancer, for example how big your cancer is and where in the liver it is situated.

Looking at your scans will also give us an idea if your cancer has spread outside of the liver.

Blood tests will also give us some information about your liver and sometimes about your cancer.

Sometimes your diagnosis needs to be confirmed with a biopsy of the liver. This is a procedure involving taking a very small piece of liver with a fine needle inserted into your abdomen after your skin has been numbed. This piece of your liver is then looked at under a microscope. The results would be given to you in clinic and can usually confirm if there are cancer cells present or not.

Treatment options

Liver Transplant

For a small number of patients, liver transplant may be considered as the best treatment option. These patients will almost always have an underlying liver disease. The aim of a liver transplant is to cure both the liver cancer and the underlying liver disease. Suitable patients have to undergo a very thorough screening programme and meet strict criteria. If your doctors think that you are suitable, they will discuss this with you in detail.

Surgery

This is the most effective form of treatment for primary liver cancer and the only treatment option that offers a cure for people who aren't suitable for a liver transplant. Surgery for primary liver cancer involves removing the part of the liver affected by the cancer.

You will be given a separate booklet designed to give you more information about having a liver resection if this is the best treatment option for you.

However, surgery is not always possible, depending on the size and position of your cancer or if the cancer has spread outside of the liver or if the rest of your liver would not be able to cope after an operation.

Sometimes if surgery is thought possible a procedure called a laparoscopy is performed. A laparoscopy is keyhole surgery that enables a camera to look inside your abdomen in order for the surgeon to see if your cancer has spread outside of the liver; a biopsy may be taken of your liver at this time. A biopsy involves taking a small sample of the liver to look at under the microscope. A laparoscopy will also tell us how well we think your liver could cope with an operation.

If your cancer has spread outside of the liver or if the remaining liver looks too diseased to cope with an operation then surgery will not be offered to you. This is because we know from experience and from the experience of others that having a major operation such as a liver resection will not benefit you.

A laparoscopy will involve an overnight stay in hospital. If no cancer is seen outside of the liver and the liver looks healthy then we would plan for your liver resection to happen very shortly afterwards. Your stay in hospital after your liver resection would usually be around 5 – 7 days, although everyone is different.

Unfortunately, in some cases even though the surgeon has looked with a camera, more cancer may be discovered at the time of the operation making a resection of your liver not possible. For the majority of patients with a primary liver cancer if they are able to have an operation this procedure will extend their life and, in a minority of patients, will cure them of their cancer. However, it is also true that for a majority of patients their cancer will return at some time in the future.

Potential complications of liver resection for primary liver cancer include:

- Bleeding and having to return to theatre for an operation – approximately 1%
- Chest infection – approximately 10%
- Wound infection – approximately 5%
- Bile leak from the surface of the liver – approximately 10%
- Liver failure (the remaining liver cannot cope) – 1%
- Unfortunately there are a small percentage of patients who will die as a result of having this operation – approximately 8%

We do not give you this information to frighten you but in order for you to make an informed decision about your treatment.

Sometimes, in very specific cases a liver transplant can be considered. This will be discussed with you further if you are within the medical criteria.

Liver Ablation (MVA/RFA)

Liver Ablation is a treatment that uses heat to destroy some types of liver cancer cells. It is performed by a consultant interventional radiologist (IR doctor). It can also be given by a consultant surgeon during an operation.

There are two different techniques - Microwave Ablation (MWA) and radio Frequency Ablation (RFA).

The technique used depends upon which is more technically suitable and the size and position of the tumour. Please ask for the leaflet called "Liver Ablation (MVA/FRA)" for further information.

Stereotactic ablative radiotherapy (SABR)

SABR is an advanced radiotherapy technique for treating liver tumours. The treatment is non-invasive and delivered as an outpatient. It is most often used when other treatments, such as ablation or trans-arterial chemo-embolisation (TACE) have stopped working, or when they are not suitable. Several tumours can be treated at once, and treatment is usually given every other day for five sessions over a fortnight. Side effects are generally mild, although care must be taken to protect the normal liver from radiotherapy to reduce the impact of the treatment on quality of life.

At the Queen Elizabeth Hospital, two techniques are used to deliver SABR. The first is a machine called CyberKnife; for this treatment, gold seeds are inserted into the liver before SABR under local anaesthetic. This helps the machine to track the movement of the liver with breathing.

The second technique is called volumetric arc therapy (VMAT). With this approach the person being treated is placed on flat bean bag and a perspex plate is placed on their abdomen, to limit the movement of the liver with breathing. Whilst this sounds uncomfortable, the vast majority of patients cope with it well. The choice between the two techniques depends on the position of the tumour within the liver, and other factors.

SABR is delivered by a radiotherapy team. The first appointment is with a consultant clinical oncologist, a doctor who specialises in radiation treatment. They will explain the treatment to you, including the possible side effects. You will then have a planning CT scan in the radiotherapy department, and possibly a further MRI scan. The treatment is then planned by the consultant and dosimetrists, who determine how the radiation should enter the body to achieve control of the tumour. SABR usually starts 2-3 weeks after the initial scan; it is delivered by radiographers who guide patients through treatment and operate the radiotherapy equipment. Once treatment is completed you see the consultant clinical oncologist four weeks later for blood tests and a check-up; the first scan is done three months later to assess how effective the treatment has been.

Trans Arterial Chemoembolisation (TACE)

Chemotherapy drugs and a substance called lipiodol, which is an oily dye, are injected directly into the liver via an artery in your groin or arm. This procedure is carried out by your radiologist in the X-ray department. The aim of this treatment is to shrink the size of your cancer. However we know that chemoembolisation cannot cure your cancer.

Chemoembolisation carries some risks such as bleeding, infection and sometimes pain. The risks for you will be discussed in detail by the doctor performing your procedure.

Chemotherapy

There are new anti-cancer drugs on the market that have been proven to help extend life. If any of these drugs are suitable for you, you will be referred to an oncologist to discuss further.

Clinical trials

Your specialist may talk to you about the possibility of entering into a clinical trial. This may involve treatment with new drugs or new ways of using drugs.

You do not have to participate in clinical trials and your care will not be affected if you do not. The doctor involved in the research will give you specific information about any clinical trials.

Supportive care

Sometimes there are no treatment options available to you.

This may be because your cancer has progressed and treatment will not benefit you.

Sometimes people choose not to have any treatment. We would support any decision you make regarding treatment.

Although treatment may not be an option, this does not mean there is nothing that can be done to help and support you and your family.

The following are suggestions about how we can support you and your family. We would recommend that you be referred to a community cancer nurse, usually called a Macmillan nurse. Your doctor or specialist nurse can arrange a referral for you. A specialist community nurse is essential to ensure you and your family has access to help and support at home.

Diet supplements

If you are finding it hard to eat, there are plenty of diet supplements available on prescription. Some are powders you sprinkle on your food and some are drinks that are complete meals in themselves. Sipping a supplement between meals throughout the day can really boost your calorie intake. Ask your doctor or dietitian for help.

Coping financially

Your clinical specialist nurse or GP may be able to help you get grants for aids, heating costs, holidays and other household expenses related to your illness. They can also help you to claim benefits for yourself or for the person caring for you. It may be helpful to see a benefits advisor. Your Specialist Nurse will be able to give you more information about this.

Coping with symptoms

As your illness progresses you may develop different symptoms. It is not certain that you will have all or any of them but the following information may help you to realise that there is usually something that can be done to help you cope.

Pain may develop in the abdomen and sometimes in the back. There are many painkillers or analgesics you can take to control pain. You will probably be started on some simple painkillers such as paracetamol or co-codamol. Some people do not need anything stronger. However, if these are not effective then we can introduce a morphine-based painkiller, such as morphine sulphate (MST) in tablet or capsule form. Do not worry about becoming addicted to morphine. Morphine taken to relieve pain works in a different way than if it was taken for recreational use. MST is given in two doses daily, 12 hours apart. This is usually in the morning and at night before bed. The idea is that the morphine is released slowly into the blood stream and so provides a

background of constant pain relief. You will usually be given liquid morphine or fast acting tablets in a bottle to take to 'top up' your pain relief if you experience a breakthrough in pain control. It is important to make a note of how much liquid morphine you are taking, as this may be an indication to increase your morphine tablets.

Morphine-like drugs can also be given as a patch, similar to nicotine patches. This way of delivering painkillers may be used for patients who are not able to tolerate taking tablets.

Another important factor to remember when taking most painkillers is that they can make you constipated. Constipation is not about how often you go to the toilet but how easily the stool is passed. If you find that you are becoming constipated then you should ensure that you are drinking plenty of water and that you have some laxatives at home ready to help you. Try to avoid becoming constipated as this can increase the amount of painkillers you need and so increases the constipation. This becomes a cycle that you need to break in order to become comfortable again. It is very likely you will be prescribed laxatives when you have your painkillers.

You may also find that painkillers or even your illness on its own may cause you to feel sick. If this is the case then we can give you very good anti-sickness medication to stop this feeling.

Very rarely we are unable to control your pain through the usual methods and so we can refer you to experts such as an anaesthetist and other specialist nurses who will be able to offer special treatment.

Clinic

You will be seen regularly in clinic - this will probably be here at QEHB but for some people we are able to refer back to their local hospital. You will always have the option to alter any appointment if you are worried about anything. Contact numbers will be given to you.

Finding information

If you know what to expect, you may find yourself less anxious and worried. Talk to your doctor or nurse about your illness and treatment. It is important to know all your options.

If you would like to talk to someone outside your own friends and family, there are organisations that can provide information about cancer and treatment as well as cancer support groups, where you can talk to other people who have cancer and may have had similar experiences.

In the Cancer Centre at Queen Elizabeth Hospital Birmingham (QEHB), there is the Patrick Room (telephone: 0121 371 3539) where you can find information and support.

Difficult questions

A diagnosis of cancer may mean you will have all sorts of questions going around in your head that are not only difficult to answer – they are difficult to ask. We have tried to answer some of those questions here but there are probably more questions you can think of. Write your questions down and talk to your doctor or nurse, or contact the specialist nurses on 0121 371 4652.

It is very common in any family for some people to want to ask difficult questions and some not. Try to respect this and give each other the space to ask as much as you want to. This may mean giving your doctor permission to talk to your next of kin alone, or, if you are a relative, giving the patient time to talk to the doctors by themselves.

Please remember that you will undoubtedly have good and bad days and that during the bad days you are not alone but have a team of people, both in the hospital and community, who are there to help you and your family.

Useful websites

<https://livercanceruk.org>

www.cancerhelp.org.uk

www.macmillan.org.uk

Contact information

You can contact us either in person or on the telephone on the following numbers:

Secretary to Oncology doctors

Telephone number: 0121 371 3571 or 0121 371 3441

Clinical Nurse Specialists via their secretary

Monday–Friday: 09:00–16:00

Telephone number: 0121 371 4652

Liver Services

Queen Elizabeth Hospital Birmingham

Mindelsohn Way, Edgbaston

Birmingham B15 2GW

Accessibility

To view this information in a different language or use text-to-speech reader visit **www.uhb.nhs.uk**, click the yellow and black circular icon in the bottom right of the web page to open the ReachDeck toolbar and then use the search bar to search by the name of the leaflet. If you require this information in another format such as braille, please email interpreting.service@uhb.nhs.uk.



How did we do? 😊 😐 😞

If you have recently used our services we'd love to hear about your experience. Please scan the QR code or follow the link to share your feedback to help us improve our services. **Thank you.** www.uhb.nhs.uk/fft

