



Cholangiocarcinoma (Bile Duct Cancer)

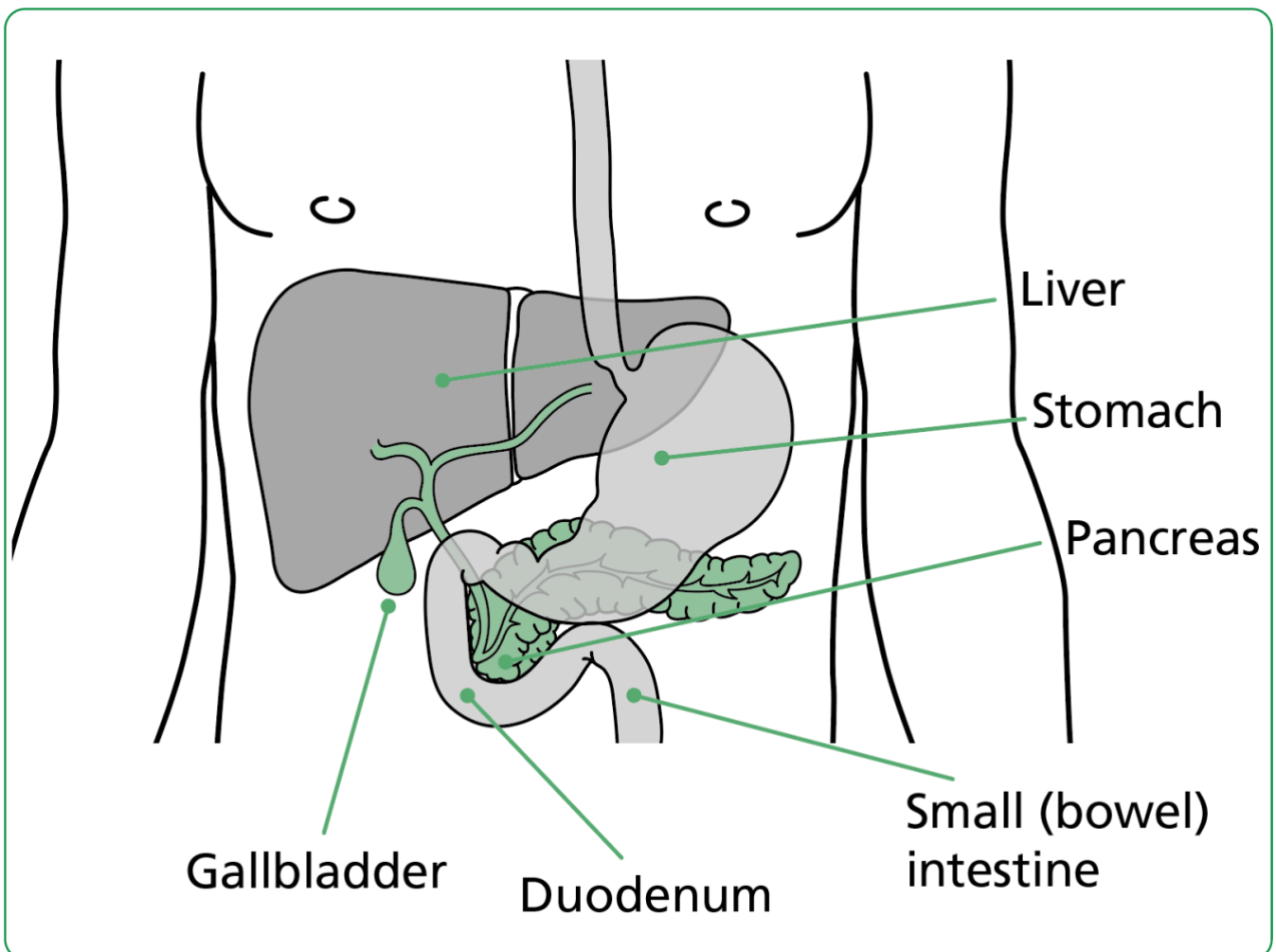
This booklet contains information about Cholangiocarcinoma (bile duct cancer). Please remember this booklet is not a substitute for asking questions of your doctor and specialist health care team. You are always welcome to ask questions and we would encourage you to do so.

What is cholangiocarcinoma or bile duct cancer?

Cholangiocarcinoma is cancer that has started in the bile ducts.

Bile ducts are narrow tubes found inside and outside the liver.

Bile ducts carry bile and connect the liver and gallbladder to the small bowel.



The liver produces bile whose main function is to help break down fat in the digestive system.

What causes cholangiocarcinoma?

We are not sure what causes cholangiocarcinoma. We do know that people who have a liver problem called primary sclerosing cholangitis (PSC) are more likely to develop cholangiocarcinoma and people with ulcerative colitis (UC) are more likely to develop primary sclerosing cholangitis.

What are the symptoms of cholangiocarcinoma?

Please remember you may not experience any or all of the following symptoms.

The cancer in your bile duct may stop your flow of bile. Instead of bile passing through your bile ducts into your bowel, bile flows back into the bloodstream. This can cause you to become jaundiced; your skin and the whites of your eyes may become yellow.

Jaundice may also make your urine a dark colour and your stool pale.

Jaundice may cause your skin to itch, antihistamines or other medication may help.

You may also show signs of infection in your bile ducts, such as high temperature and shivers and shakes like bad flu.

The reason for infection in your bile duct is stagnant bile in your blocked ducts encourage infection.

You will probably be started on antibiotics.

You may also experience weight loss, nausea and fatigue.

How is cholangiocarcinoma diagnosed?

Your X-rays and scans will have been sent to us before we see you in clinic. Our specialist team of surgeons, oncologists (cancer doctors), hepatologists (liver specialists) and radiologists (X-ray doctors) will review the X-rays.

Looking at your X-rays will give us a lot of information about your cancer.

We are then able to make a provisional plan about the treatment we can offer you.

We will be able to discuss this plan with you when we see you in clinic.

Treatment options

Surgery

This is the most effective form of treatment for cholangiocarcinoma and the only treatment option that offers a cure. Surgery for cholangiocarcinoma may involve exploring and removing the bile ducts affected by the cancer and may also involve removing 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 positions of your cancer or if the cancer has spread outside the liver.

If the portion of liver needed to be removed is too big, it may risk not leaving enough liver behind to fulfil the body's needs - this can result in liver failure. To help reduce this risk some patients will be offered a procedure called Dual vein embolization (DVE). The aim of this procedure is to increase the size of the liver that will be left behind. It is carried out in the Radiology Department and is usually done 4 to 5 weeks before a liver resection. DVE involves blocking the blood supply to the part of the liver that is to be removed and redirecting it to the healthy part of the liver which is to remain after the liver resection. The aim is to shrink the part of the liver affected with cancer whilst allowing the remaining healthy liver to grow bigger making future surgery safer. A CT scan will be arranged about 4 to 6 weeks after the procedure to assess the result.

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 the liver.

If your cancer has spread outside the liver, 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 the liver we would then plan for your surgery to happen very shortly afterwards.

Your hospital stay after surgery can be up to two weeks, but 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 an operation not possible. In these circumstances we will bypass your cancer. The purpose of this bypass is to prevent your duodenum (part of your stomach) becoming blocked by the cancer.

This involves connecting a piece of small bowel to your stomach creating a bypass of the duodenum.

You will then have a biliary stent placed in your bile duct to relieve your jaundice. This is explained in detail later.

For most patients with cholangiocarcinoma, if they are able to have an operation this procedure will extend their life and in a minority of patients it will cure them of their cancer.

However, it is also true that for most patients their cancer will return at some time in the future.

Even in a specialised centre there are potential complications of surgery.

Potential complications of liver resection for cholangiocarcinoma 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 15%
- Liver failure (the remaining liver cannot cope) 10%

Unfortunately, there are a small percentage of patients who will die as a result of having this operation, approximately 15%.

The percentage of patients with cholangiocarcinoma developing liver failure or dying as a result of this operation are higher than with other patient groups having a liver resection.

We do not give you this information in order to frighten you but for you to have all the information you need to make a decision about your treatment.

Stents

A biliary stent is a narrow tube that is inserted into a blocked bile duct.

Biliary stents can be placed by endoscopic retrograde cholangiopancreatography (ERCP). ERCP involves a flexible tube that is placed into your mouth and is passed into your stomach and beyond so that the doctor can see the bile duct that is blocked and position the biliary stent. You will be given a sedative for this procedure.

If ERCP is not possible then the stent can be placed in X-ray by the radiologist. This procedure is called percutaneous transhepatic cholangiogram (PTC).

A thin guide wire is passed through your abdomen wall into the bile duct and a stent is passed over the guide wire. Your skin will be numbed with local anaesthetic before this procedure.

Very often a temporary drain will be left in for a short time to drain the bile away into a bag. This drain will be clamped at first. If you do not have pain or fever and the stent is working well the drain will come out.

A biopsy of your cancer may be taken during stenting. You will be asked to sign a consent form for stenting and for a biopsy.

A biopsy involves taking a small piece of your cancer for examination under a microscope. The results will be expected to that the cancer is cholangiocarcinoma.

Chemotherapy

For people who are not able to have an operation, chemotherapy may be an option. Unfortunately chemotherapy will not be possible for everyone. It is important that you are not jaundiced at all. This is because chemotherapy is dangerous for patients who are jaundiced. For this reason it is very likely that you will need a stent that is working well.

Sadly chemotherapy does not cure cholangiocarcinoma but it can help to control and contain the cancer and may help to lengthen your life. Some people respond better to chemotherapy than others and live longer.

Chemotherapy can cause side effects, although we are very often able to reduce or avoid these with medication such as anti-sickness tablets.

More specific information can be given to you about the type of drugs we can use if this is an option for you.

Clinical trials

In a specialist centre, we are always trying to find more successful ways of treating our patients. 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 have 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 dietician for help.

Coping financially

Your Macmillan 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 social worker. We have a social worker available for patients.

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.

Ascites

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

Cancer cells in the lining of the abdomen cause fluid to leak out into the abdomen.

Pressure develops in veins around the liver because of the liver not working properly and this 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. Unfortunately, despite both of these treatments, ascites will very often re-accumulate in the abdomen again.

Pain

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 morphine-based painkiller, such as Morphine Sulphate tablets. Do not worry about becoming addicted to morphine. Morphine taken to relieve pain works in a different way than if it was taken for 'recreation'.

Morphine Sulphate or MST is given in two doses daily, 12 hours apart, 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 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 anaesthetist and other specialist nurses who will be able to offer special treatment.

Clinic

We will see you regularly in clinic. You will always have the option to alter any appointment if you are worried about anything. Contact numbers are on the back of this booklet.

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 the Queen Elizabeth Hospital, 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 more questions you can think of than we would ever be able to answer. Write your questions down and talk to your doctor or nurse or contact one of 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

www.cancerhelp.org.uk
www.macmillan.org.uk

Please write down any questions you may have and bring this with you to your next appointment.

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Liver Services

Queen Elizabeth Hospital Birmingham

Mindelsohn Way, Edgbaston,
Birmingham B15 2GW

Ward 726: 0121 371 7303

CNS team: 0121 371 4652

Accessibility

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