

Surgical treatment of Bile Duct Cancer (cholangiocarcinoma)

**Information for you
and your family**

Introduction

On the advice of your surgeon, you are coming into hospital for an operation to remove your bile ducts. Specifically this booklet is about surgical removal of the bile ducts.

We appreciate that life may feel like an emotional roller coaster at the moment. You may have many questions and anxieties regarding the operation, your hospital stay, and financial concerns.

This booklet has been prepared to address many of these questions and more. It will hopefully supplement the information given to you by your doctors, ward nurses and specialist nurses. It may not cover all your concerns so if you have any other questions or worries after reading this booklet, please don't hesitate to contact one of the staff listed on the last page.

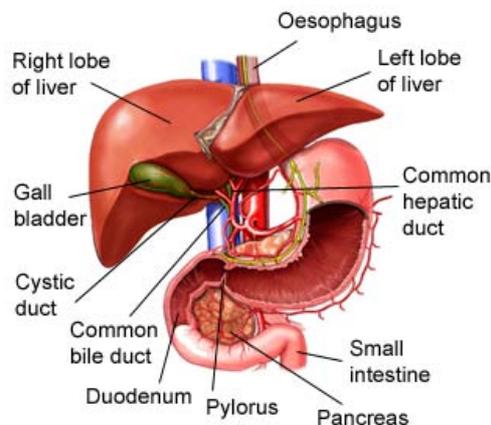
This booklet is also meant for your relatives and close friends, to answer their questions and concerns, and to help them understand the treatment you will be undergoing.

This leaflet is also available in large print and can be translated into other languages on request. Please contact Patient Services

Tel : 01752 763031

What is the Bile Duct?

The bile ducts are the tubes connecting the liver and gall bladder to the small intestine (small bowel). Bile is made by the liver and stored in the gall bladder. Its main function is to break down fats during their digestion in the small bowel. In people who have had their gall bladder removed, bile flows directly into the small intestine. The bile ducts and gall bladder are known as the biliary system.



What is cancer of the bile duct?

Cancer is classified according to the type of cell from which it starts. Cancer of the bile duct almost always starts in a type of tissue called glandular tissue and is known as adenocarcinoma.

Cancers of the bile duct are rare in the Western world. There are approximately 600 people diagnosed with bile duct cancer (cholangiocarcinoma) each year in the UK.

If the cancer starts in the part of the bile ducts contained within the liver it is known as intra-hepatic. If it starts in the area of the bile ducts outside the liver it is known as extra-hepatic. This information concentrates mainly on extra-

hepatic bile duct cancers. Intra-hepatic bile duct cancers may be treated like primary liver cancers.

What are the first signs of cancer of the bile duct?

1. Painless Jaundice If cancer develops in the bile ducts it may block the flow of bile from the liver to the intestine. This causes the bile to flow back into the blood and body tissues, and leads to the skin and whites of the eyes becoming yellow (known as jaundice). The urine also becomes a dark yellow colour and stools are pale. There is sometimes itching of the skin due to the jaundice. This rapidly disappears once the blockage has been cleared or bypassed.

2. Weight Loss The tumour may block the pancreatic duct leading to poor digestion, loose stools and weight loss. This may be relieved by clearing the blockage or by giving pancreatic enzymes.

3. Mild Discomfort in the Abdomen The tumour may cause discomfort in the abdomen because it presses on other organs or nerves near by.

How is it diagnosed?

Your doctor may need to do some tests to find out more about your particular problem. You may have already undergone one or more of them already.

Ultrasound examination (USS)

This is a simple, painless and relatively quick investigation used to obtain pictures of the inside of the abdomen.

These provide useful but basic information about the pancreas, liver, bile ducts and gallbladder.

Computerised Tomography (CAT scan or CT scan)

This is a type of x-ray, which builds up a three-dimensional picture of the bile duct and surrounding organs. It is painless and can take up to 30 minutes.

MRI scan (Magnetic Resonance Imaging)

An MRI scan is similar to a CT scan but uses a magnetic field instead of x-rays to build up an image the bile duct. It is painless and can take up to one hour.

Endoscopic retrograde cholangiopancreatography (ERCP)

This is a special investigation for taking pictures of the bile ducts and the pancreatic duct. It involves inserting a special flexible telescope into the mouth, down the gullet and into the stomach, and then into the duodenum opposite the opening of the bile duct and pancreatic duct. A small tube (cannula) is then pushed into the opening and a contrast (dye) is injected into the ducts. A permanent small tube (stent) may be left in the bile duct to relieve the blockage causing jaundice. This test will be performed under sedation.

Percutaneous Transhepatic Cholangiography (PTC)

This is another procedure by which your doctor can obtain an x-ray picture of the bile duct. An area on the right side of your abdomen will be numbed with an injection and a thin needle will be passed into the liver through the skin. A dye will be injected through the needle into the bile duct within the liver. X-rays will then be taken to see if there is any abnormality or blockage of the duct.

Endoluminal ultrasound (EUS)

This is an endoscopic procedure rather like an ERCP. Instead of x-ray pictures of the bile ducts, EUS takes pictures by ultrasound. This test will be performed under sedation.

Needle biopsy

Occasionally a small piece of tissue from the bile duct needs to be taken to help make a diagnosis. This can be done during ERCP, an ultrasound scan, CT scan or a PTC. During the latter procedures, local anaesthetic is injected into the skin. A fine needle is then introduced and its tip positioned using pictures from the scan before any tissue is taken.

Is needle biopsy safe? This is surprisingly safe but complications such as bleeding or acute pancreatitis can occur, but only very occasionally.

Laparotomy

If the doctor cannot make the diagnosis from the above tests, a laparotomy may be done under a general anaesthetic. This involves making a cut (incision) into your abdomen so that the surgeon can examine the bile duct and the tissue around it for cancer. Sometimes this examination can be done through a tiny cut using a camera called a laparoscope – this procedure is known as keyhole surgery.

What are the treatments for suspected cancers of the bile duct?

The type of treatment that you are given will depend on a number of factors, including your general health, the position and size of the cancer in the bile duct and whether the cancer has spread beyond the bile duct.

- **Surgery**

Surgery may be used to remove the cancer if it has not spread beyond the bile duct. It is not always possible to carry out surgery, as the bile duct is in a difficult position and it may be impossible to remove the cancer completely. The decision about whether surgery is possible or not depends on the results of the tests described above.

There are different operations depending upon how big the cancer is and whether it has begun to spread into nearby tissues.

Removal of the bile ducts

If the cancer is small and contained within the ducts, then a partial liver resection is undertaken and the bile ducts containing the cancer are removed. The remaining ducts in the liver are joined to the small bowel, allowing the bile to flow again.

- **Stent Insertion**

If the tumour has blocked the bile ducts, causing jaundice, and it is **not possible** to undertake surgery, a metal stent (small flexible mesh pipe) may be inserted which will relieve the blockage and allow bile to flow into the small bowel again. The jaundice will then clear up.

- **Chemotherapy**

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy the cancer cells. They work by disrupting the growth of cancer cells.

Chemotherapy is used to treat cancers that have spread, but this would be with the intention of symptom relief and not cure. However, for some people the treatment will have no effect upon the cancer and they will get the side effects without the benefits. Making decisions about treatment in these circumstances is always difficult and needs to be discussed in detail with your doctor and nurse specialist.

Whatever treatment is chosen, alongside it you will have supportive care, with medicines to control symptoms/ side effects and nurse specialists to help look after you and your family.

In simple terms, surgery may be used to remove the tumour completely (if it is small and has not spread beyond the bile ducts).

This booklet will focus on the surgical treatment of the bile ducts. Information regarding Chemotherapy treatment and Stenting can be obtained from your Specialist Nurse (see last page of booklet for contact details).

Risks associated with your surgery

Giving your consent

Before you have any treatment your doctor will explain the aims of the treatment to you and you will be asked to sign a form saying you give permission for the hospital staff to give you the treatment. No treatment can be given to you without your consent and before you are asked to sign you should have been given full information regarding the risks and benefits of the proposed treatment, plus possible alternatives.

Below, is an overview of the risks, in order to help you decide whether to go ahead with any surgery.

Serious complications occur due to the injury to the liver. These include leakage of bile (a yellow liquid produced by the liver) into the abdomen and post-operative bleeding. Bile leaks can usually be controlled by a drainage tube but a technique called ERCP may be necessary to encourage internal drainage of bile.

Bleeding after a liver resection is a serious problem which may require a second operation and the administration of blood products to promote blood clotting.

Occasionally after removal of more than half of the liver a period of liver failure may occur. This sometimes causes a temporary period of jaundice (yellow discolouration of your skin, eyes and urine).

Minor complications are common and readily treated. These include wound infections and infections in the chest and bladder which usually respond to antibiotics. To minimise any risks the physiotherapist will visit you immediately after your operation to help you to cough and breathe properly. It is important to carry out the breathing exercises you are shown.

These complications are rarely serious or fatal. However, like all major operations bile duct surgery with its associated liver resection has a risk of death. This is usually under 5%. In other words one in twenty people will not survive the operation or the post-operative period.

What will happen if I don't have the surgery?

Cancer cells, left untreated, can spread to other organs and grow into secondary tumours. It is therefore a potentially fatal disease. If you decide not to go for the operation, and the tumour proves to be cancerous, it is possible to shrink the tumour by use of chemotherapy, but not to get rid of it completely.

How can I prepare for the surgery?

- Avoid alcohol completely
- Try to stop smoking
- Regular exercise e.g. walking up to 3 miles a day
- Take a healthy diet, plenty of red meats, fruit and vegetables. Avoid fatty foods, e.g. sweets, cakes and pastries.

NB If you are taking Aspirin, Clopidogrel, or Warfarin Please let your specialist nurse or surgeon know as early as possible as sometimes these medicines need to be stopped before surgery.

Admission to hospital

You will come into the ward one or two days prior to the operation. Some of the following tests may be carried out, either at a pre-admission clinic or on the day of admission.

Chest X-ray

This will look at the size and shape of the heart and the general condition of your lungs.

Electrocardiogram (ECG)

This shows the electrical activity of the heart and is routine for anyone undergoing an anaesthetic.

Blood tests

A blood sample is taken from your arm and various tests are carried out including your blood group.

Lung Function Tests

These are breathing tests, which measure how well your lungs are working so that your anaesthetic and operation can be performed as safely as possible.

Exercise tolerance tests

People who you will meet

A Doctor (Surgeon) - Will examine you and ask questions about your illness. He/she will explain the operation to you and ask you to sign a consent form. This indicates that you agree to the operation so make sure you have discussed it fully with the doctor and understand what is involved.

An Anaesthetist- is the doctor responsible for your anaesthetic. He/she will ask you questions about your medical history, what drugs you are on and if you have any allergies. They will also discuss the types of pain control available.

A Liver Nurse Practitioner- She will assess your fitness for surgery and arrange all the relevant tests and paperwork a week or so prior to your surgery date. She will answer any questions you have and provide information on your surgery.

An Upper Gastrointestinal Cancer Nurse Specialist- She will be your key worker throughout your surgical experience and during your follow- up. She is available for

advice and information about any queries you have about your surgical journey. She is the main means of communication between all parties involved.

Ward Nurses - Will show you around the ward, help you settle in. They will also discuss factors regarding preparation for your operation such as when to stop eating and drinking, whether you need to be shaved before surgery, when you need a bath/shower etc. They will provide expert surgical nursing care during your hospital stay and facilitate your discharge home.

A Physiotherapist-Will teach you important deep breathing and coughing exercises, which you will be encouraged to do after your operation. These exercises will help your lungs re-expand and help prevent chest infections from occurring. Following the operation the physiotherapist will also help you mobilise out of bed and assist you with your walking, posture, and climbing stairs. He/she will help you to become as fit as possible before going home.

A Dietitian – can advise you on how to maintain a good dietary intake before and after your surgery. If you would like to see a dietician before your operation let the clinic or nursing staff know.

Your Operation

Your operation will normally happen first thing in the morning. You will not be given anything to eat or drink from 12 o'clock the previous night. You will have a gown to wear for theatre and if you wear a wedding ring it will be covered with tape. If you have dentures they will be left on the ward. Relatives may go with you when you are taken on your bed to the operating suite.

What happens after surgery?

Recovery Area

Your operation will take approximately 6-8 hours following which you will wake up in the recovery/critical care area. There will be a nurse in attendance who will be monitoring you very closely. Occasionally it may be necessary to spend some time in the High dependency unit or intensive care. When the doctors are satisfied with your recovery you will be moved to the ward, where nurses will continue to monitor you closely.

Breathing

While you are still sleepy you will be given some oxygen to breath. It is important that you take deep breaths and cough. This will help to keep your lungs free from infection.

Tubes/drains

When you come round after your operation you will have some tubes attached to you. These will have been placed whilst you were asleep under anaesthetic. The type and number will vary depending on your operation, but will include:

- ❖ A tube in the vein in your neck to give you fluid and certain medications.
- ❖ A tube in your vein in your arm to give additional fluids and medication.
- ❖ A tube that passes through your nose and into your stomach. This allows us to drain off digestive juices in your stomach that might make you feel uncomfortable, and are likely to make you feel sick.
- ❖ Near to the site of the operation (your wound), you may find one or two drainage tubes (drains) that go

under the skin. These drain off fluid to prevent swelling.

- ❖ A catheter, a fine tube will have been placed into your bladder to collect your urine into a bag. This means you do not have to worry about getting out of bed initially and we are able to monitor what you are producing.

As you recover your drains and tubes will be removed as directed by your doctor.

Will it be painful?

The amount of pain you will experience is variable and individual, but we will work with you to ensure that pain is kept to the minimum. It is important you tell the nursing staff if you have pain, discomfort, or if there is any change in the amount of pain felt.

There are several ways of reducing pain including:

- ❖ Epidurals (the same as for pregnant women in labour) which may not be removed for 5 or 6 days
- ❖ Patient controlled analgesia (this will be explained before your surgery)
- ❖ Pain killing injections, which can be given regularly around every 3-4 hours.
- ❖ Some painkillers can be given in suppository form. Once you are able to drink, your painkillers will be gradually changed to soluble tablets. It is advisable to take these regularly to prevent the pain coming back. You will also be shown how to support your wound when you cough.

Personal Hygiene

Initially you will require help with your personal hygiene, however in a few days you will regain your independence. Once your drains have been removed and you are feeling well enough, a nurse will help you have a bath.

Mobilisation

Initially you will be encouraged to get out of bed and sit in the chair, with short walks at frequent intervals. This will help prevent stiffness, bed sores and constipation and help keep your chest clear. You will be given a pair of elastic stockings to wear, to help the blood flow in your legs. You will also be given a small injection of clexane (anti-coagulant) into your abdomen. This will help the blood flow freely around your body and help prevent clots forming.

Wound

Your stitches resemble 'staples' and are called clips. They will be removed (around day 10) after your surgery. Dressings around your drains will be renewed daily or when required. It is important to report if there is any discharge from your wounds so that it may be treated appropriately.

When can I eat after the operation?

Immediately after the operation you will not be allowed to eat or drink in order to allow your intestinal tract to heal. The doctors will assess this on a daily basis, introducing sips of fluids gradually. By around 7 days you should be eating and drinking. This is very individual and so just a guide.

Depending on the nature of the surgery you have had, you may need ongoing advice on your dietary requirements following your operation. If you do have concerns or would like to have further information please contact your Nurse Specialist or Dietitian.

AT HOME

The following information has been designed to assist you following discharge from hospital after bile duct surgery. It covers the main areas commonly asked by patients, but please ask a member of staff if there is any information you require has not been included.

Rest and Activity

It is quite normal to feel very tired after discharge from the hospital.

Most people benefit from having a planned “rest time” during the day and actually resting on your bed is more relaxing than using a chair.

Moving and Exercise

Gradually increase the amount of exercise you take. Short walks everyday, gradually increasing in distance over a period of weeks is very beneficial.

Movement such as gentle bending and stretching are good but pushing or pulling can cause discomfort, as does standing for long periods of time. Try to avoid these for the first few weeks.

Housework

Light work (e.g. dusting or drying up) can be introduced into your routine when you feel fit and able for it, usually within the first 1-2 weeks you are at home. Avoid any heavy lifting, pushing or pulling for the first 6-8 weeks.

Light gardening such as weeding may be done 2 weeks after discharge. Mowing the lawn and heavy digging should not be done for 8 weeks

Alcohol

There should be no reason why alcohol cannot be taken but the effect may be felt a little earlier than before - so be careful - always consult with your own doctor first.

Remember that certain medications can react with alcohol
- always read the label.

Driving

As a general rule, if you feel safe to do an emergency stop you should be able to drive. This is usually 6 weeks after discharge.

Eating and Drinking

Slight loss of appetite following an operation is not uncommon and this usually corrects itself as you progress back to full fitness. Small but appetising meals are recommended and a well balanced diet of high protein and high calorie foods aids recovery. Please ask staff for advice if you need it.

Sleeping

Sleep patterns are often disturbed after operation. Changes in routine and restricted movements can disturb sleep. This will gradually improve over the weeks.

Bowel Action

You may experience some changes in bowel habit. Diarrhoea or constipation is not uncommon following surgery and are usually due to changes in diet, activity and the use of some drugs.

If you have severe diarrhoea or constipation, it can be treated so be sure to tell your nurse or GP.

Showering and Bathing

It is sensible to have someone else in the house when you take your first shower/bath, even if no help is required. Bathing is not harmful to your wound.

Wound Healing

Healing of your wound will take place over a period of time as all wounds progress through stages of natural healing.

- DO NOT pull off scabs as these protect new tissue underneath.
- SEEK ADVICE if the wound becomes very painful, if it starts to discharge or becomes red or inflamed.
- IT IS NORMAL for the wound to tingle, itch or feel slight numb.
- IT IS NORMAL for the wound to feel slightly hard and lumpy.
- IT IS NORMAL to experience a slight pulling around the wound.

Sexual Activity

Resume sexual intercourse once you feel confident. If you remain relaxed and possibly adopt a more passive role, you may return more easily to your normal routine.

Fatigue (Feeling exhausted most of the time), emotional impact

Everyone has good days and bad days, but due to this operation and any treatment you may have undertaken after the surgery, fatigue is a very common experience. This can last for several weeks or months after treatment has completed. There are many ways of combating fatigue and many strategies which can help you manage your everyday activities. For more information contact Oncology specialist nurses Marilyn Bolter or Claire Downing (See numbers on the last page of this booklet).

Similarly, fear, anxiety, depression, changes in mood is all possible for patients undergoing this operation. Your life may feel like it has been turned upside down, and that all

your future plans are on hold. Everyone needs support through difficult periods in their life. See below for information on who to contact for advice.

Back to Work

This depends on your job and on your recovery. Returning to work can be discussed at your clinic appointment. A time frame of 3 to 4 months after you have returned home is reasonable, but remember it is individual.

If you require advice regarding work and benefits whilst in hospital, ask your nurse who can arrange for you to see a social worker.

Will I need any further treatment?

The surgeon will be able to tell you immediately after the operation some details about what was found and what he did, but it can take two weeks for the laboratories to study the samples sent to them and to interpret the findings. This will give a clearer picture and may enable the surgeon to tell you more clearly about the stage and success of the operation. A few patients may need further treatments such as chemotherapy. More information about this is available from your Upper Gastrointestinal Cancer Nurse Specialist, Claire Downing.

Who can I contact if I have any questions

It is common to have feelings of insecurity after leaving the hospital environment. The whole team are always willing to answer any questions you have, in an open and honest manner. The team includes your Surgeon, Liver Nurse Practitioner, Upper Gastrointestinal Cancer Nurse Specialist, Stonehouse ward nursing staff, physiotherapist, occupational therapist and dietician.

This whole team can be contacted via your **Upper Gastrointestinal Cancer Nurse Specialist, Claire Downing**. She is your key worker and will coordinate your surgical journey. She is available to you, your relatives and close friends for any questions, concerns or worries throughout the whole of your treatment and after your treatment has ended. She can be contacted on **01752 517905** Monday to Friday 9 – 5pm.

An answer phone is available for messages. Outside of these times, urgent matters should be dealt with by your GP, or by contacting Stonehouse ward direct.

The Mustard Tree - Cancer Support Centre

If you would value the opportunity to talk to someone about how you feel or just want need a break from the usual routine we invite you to visit the mustard tree. The centre is available to anyone affected by cancer at any stage of the illness and offers a comfortable space where you can share your concerns, ask questions and receive support. It is staffed by professionals and trained volunteers many of whom have a personal experience of cancer. The centre is open Monday –Friday 09.30 – 4.30pm

Mustard Tree: Cancer Support centre-----(01752) 763672

Web pages/telephone numbers

Cancerbacup----- www.cancerbacup.org.uk
(0808 800 1234)

Cancer care society-----www.cancercaresoc.demon.co.uk
(01794 830300)

Cancerlink-----www.cancerlink.org
(0808 808 0000)

Macmillan Cancer Relief-----www.Macmillan.org.uk
(0845601 6161)

This booklet and other local information can be found on---

www.plymouthhospitals.nhs.uk

Contact details

Stonehouse Ward----- (01752) 431488

Mr Stell's secretary----- (01752) 439288

Girlye Garcia
Liver Nurse Practitioner----- 01752 517886

Claire Downing
UGI Cancer Nurse Specialist----- 01752 517905

Marilyn Bolter
UGI Cancer Nurse Specialist----- 01752 517905

Lucy Pritchard
Dietitian----- 01752 792266

Derriford switchboard----- 08451558155

