If you need a large print, audio, braille, easy read, age-friendly or translated copy of this leaflet, please contact us on 020 3447 9229. We will do our best to meet your needs.

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About this booklet
This booklet provides information about the Pancreatobiliary Cancer Service and outlines some of the tests and treatments you may be offered. Your doctor will discuss any tests or treatments with you in detail, including the risks and benefits, and offer you written information to support this. If you have any questions about the service or the information in this booklet, please talk to the team looking after you.

What is the Pancreatobiliary Cancer Service?
The Pancreatobiliary Cancer Service provides expert, specialised and holistic care for people with liver, pancreatic and biliary disorders.

The pancreatobiliary team consists of doctors, nurses, dietitians, occupational therapists, administrators and physiotherapists. There are also a number of specialist doctors and nurses in the service, including gastroenterologists, oncologists, surgeons, radiologists, clinical nurse specialists (CNSs) and the palliative care team.

The pancreatobiliary team meets regularly to plan your care. As you will meet a number of different people, you may wish to write down their details in the table below.

<table>
<thead>
<tr>
<th>Job title</th>
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<td>Surgeon</td>
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<td>Oncologist</td>
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<td>Radiologist</td>
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<td>Clinical nurse specialist (CNS)/Key worker</td>
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<td>Palliative care</td>
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<td>Occupational therapist (OT)</td>
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<td>Other</td>
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You may have been referred to our service by your GP or your local hospital consultant to have diagnostic tests or treatment. This is because some of the tests and treatments you need are only available at specific hospitals, including UCLH.

When you and your doctor have agreed on a treatment option, you will need to sign a consent form. At any time before you start your treatment you will have the opportunity to discuss anything that you don’t understand, or any worries you may have. If you decide not to have a test or treatment, your doctor will discuss with you any alternatives and what may happen if you don’t proceed with the treatment.

**Key worker**

One of the pancreatobiliary CNSs will be your **key worker**. This means that they will be your main point of contact for any questions or concerns you may have about your tests or treatment. They will also coordinate your care between the different healthcare professionals.

**What tests might I have?**

We will carry out various tests and scans to assess your illness and to help us decide on the best treatment options for you.

We have explained some of the common tests in this section. You may not need all of them and your doctor will advise which are the most appropriate for you. We will provide you with more information and instructions about the tests you will need in your appointment letter and before each test.

If you have any questions, please speak with your CNS, doctor or the person performing the test. Each test has risks, benefits and alternatives – we will discuss these with you in more detail.

We will make every effort to provide you with the best treatment and support, and understand that this can be a difficult and uncertain time for you. If you have any worries, please speak to one of the team.
Computerised tomography (CT scan)

A CT scan is a special x-ray examination. It produces detailed images of the structures in the body and is carried out in the x-ray department.

You will need to stop eating and drinking four hours before your CT scan. When you arrive at the x-ray department, you will be asked to change into a hospital gown and drink special fluid called a ‘contrast agent’. This fluid helps to show the chest, pelvis and abdomen on the scan. We may also give you an injection of contrast agent into a vein in your arm to improve the quality of the scan.

You will need to lie on a table and keep very still while you pass through the scanner. The scan will take about 15 minutes and is painless. You should expect to be in the department for around one hour in total.

The radiology department will give you detailed instructions and information before your scan.
Ultrasound scan
Ultrasound scan uses sound waves to provide a detailed picture of the pancreas, bile ducts and other organs. Ultrasound scans are performed in the x-ray department.

You will be asked to change into a hospital gown and lie on your back. Some gel will be applied to your abdomen to enhance the images. The sonographer will then move a small probe shaped like a microphone over your abdomen. The probe emits sound waves and a computer converts these into a picture. The test is painless and takes about 10 to 15 minutes to complete.

Endoscopic examination
An endoscope is a thin, flexible tube with a camera at the end of it, which is inserted through the mouth. An endoscopy provides valuable information about a number of gastrointestinal tract disorders. Medical instruments can be attached to an endoscope to allow the doctor to collect samples or to treat specific problems. There are many different types of endoscopy – some of those performed within the Pancreatobiliary Cancer Service are listed below:

- **Endoscopic ultrasound (EUS)**
  An EUS involves obtaining an ultrasound image during an endoscopy. An ultrasound probe is built into the end of the endoscope to produce ultrasound images alongside the camera image.

  Small samples of tissue can be collected during an EUS and sent to a laboratory for detailed examination. This is called a biopsy.

- **Endoscopic retrograde cholangio-pancreatography (ERCP)**
  An ERCP is used to diagnose and treat disorders of the pancreas, bile duct, liver and gallbladder. The endoscope is moved down the throat, through the stomach and into the small intestine. The doctor then injects a dye (special fluid) into the bile duct and the pancreas to enhance the x-ray images. They sometimes take samples of tissue to be tested in the laboratory.
**Biopsy**
If your doctor thinks that you might have cancer of the pancreas or liver, they may advise that some cells or small pieces of tissue be removed from the tumour and examined under a microscope.

A biopsy can be taken in a number of ways:

- It may be possible to insert a needle through the skin of the stomach using ultrasound or CT scan for guidance.
- Cells can be taken during an ERCP and EUS.
- The doctor may also be able to remove cells through the endoscope, using a special type of brush.

**Laparoscopy**
This test allows us to look at the pancreas, liver and surrounding organs to see if an operation is possible and likely to be beneficial to you. Laparoscopic procedures are known as ‘keyhole’ procedures and involve a small cut in the skin, through which special instruments are inserted. A laparoscopy test is usually done as a day procedure, which means you will be admitted to hospital to have the test and discharged home on the same day. You will need to stop eating and drinking up to six hours before the test.

**Factors that can affect your treatment options**
Everyone is different so the treatments and therapies offered will differ from person to person. Some of the factors we consider when planning treatment are:

- **Location of the cancer**
Pancreatic cancers can occur anywhere in the pancreas. Biliary cancers can occur within the bile ducts and the liver. As blood vessels run through and around the liver and the pancreas, it may make surgery either impossible or very risky if the cancer is located near one of these vessels.
• **Size of the tumour**
Pancreatobiliary cancers can grow to a relatively large size before they cause any symptoms. Some may be too small to identify on scans and other tests.

• **Spread of the cancer**
Scans can help identify if the cancer has spread to other parts of the body, such as the lymph glands or other organs.

If the cancer has spread to the lymph glands, there is a bigger risk of it spreading further (this process is called metastasis).

• **Your age**
Age can affect how well your body works and responds to treatment. People are living longer and many people are healthier for longer. We assess every patient based on their individual health status, not the expected status of someone their age.
• **Other medical problems**

Other medical problems can affect how well your body copes with cancer, or make treatment and diagnosis more difficult. However, many medical conditions will not have a big effect on cancer. Please discuss any concerns with the team caring for you.

**The difference between radical and palliative treatment**

Radical treatment aims to cure the cancer, while palliative treatment is used to reduce symptoms and improve quality of life when a cure is not possible. A range of factors, including those in the previous section, will be considered when planning your treatment.

We understand that it can be very difficult to come to terms with having cancer. The uncertainty of what the future holds, or finding out that it may not be possible to cure your cancer, can be very distressing. We will do everything we can to help you and can refer you to a specialist psychologist and other support services if needed.

You will have the opportunity to discuss the treatments offered to you and we will support you in the choices you make. We will also give you detailed information sheets about individual treatments and tests.

**Surgery**

The only possible cure we know for pancreatic and bile duct cancer is surgery. You may be offered an operation if tests show that your cancer:

- has not spread to other organs
- is not located near the major blood vessels.

The most common surgical procedure for pancreatic cancer is called a ‘Whipples operation’. During this operation, the head of pancreas, gallbladder and part of the small bowel is removed. This is a major surgery that you medical team will discuss with you if you are suitable.
There are other types of operations that can be carried out on the pancreas depending on where the tumour is within it.

For small bile duct cancers, it may be possible to remove part of the bile duct. For more advanced bile duct cancers, it may be necessary to remove part of the liver tissue and nearby lymph nodes. Sometimes, depending on the extent of the cancer, a Whipples operation may be recommended. If this operation is not possible, palliative surgery may be an option. This may include surgery to bypass an obstruction caused by the cancer causing symptoms such as vomiting and pain.

Unfortunately, even if the tumour has been successfully removed, this does not guarantee that the cancer will not return at some stage in the future. This can be either in a similar area or a more distant part of the body.

**Stenting**

Stenting involves inserting a fine plastic tube or metal mesh-type instrument into the narrowed bile duct. The stent keeps the duct open, allowing bile to pass through to reduce the symptoms of jaundice (yellowing of the skin and whites of the eyes) and itching. Stents are inserted via an ERCP or a percutaneous transhepatic cholangiogram (PTC).

A PTC is a type of x-ray of the bile duct, the liver and the pancreas via a tube inserted into the liver.

During a PTC, fluid is injected through the tube to improve the images. Pictures are then taken to investigate any defects or blockages in the bile ducts, liver and pancreas.

Your doctor will advise which of these procedures is best for you.
Chemotherapy
Chemotherapy (often called ‘chemo’) uses anti-cancer medicines (cytotoxic drugs) to treat cancer. It can be used as palliative treatment where surgery is not possible, or in addition to radical surgical treatment.

Chemotherapy can shrink or slow down the progress of the cancer. It can also reduce the symptoms of your cancer and may increase life expectancy. For some people, chemotherapy can cause unpleasant side effects – we will discuss these with you and offer you written information.

If you have had surgery with the intent to cure your cancer, you may be advised to have chemotherapy after your operation.

Radiotherapy
Radiotherapy is a painless, high energy x-ray treatment. If your doctor thinks you may benefit from it, they will discuss this with you in detail.

Clinical trials and medical research
Clinical trials are a way of assessing or comparing treatments and combinations of treatments. We run many clinical trials and may offer you the option of joining a trial that is suitable for you. You can also ask a member of the team if there are any potential trials you could join.

You will receive the relevant trial details when you are considering it. Please note that you don’t have to take part in a trial and your care will not be affected if you decide not to participate.
**Contact details**

Pancreatobiliary clinical nurse specialist (CNS)
(Monday – Friday, 9am to 5pm):

Direct line: **020 3447 4791**
Mobile: **0794 4139 704**

**Out-of-hours contact**
If you have a problem outside of these hours, please contact your GP.

In an emergency, go to your local Emergency Department (A&E) or call our **24-hour emergency number on 07947 959020**.

**Further information**

**Macmillan Cancer Support**
Support Line: **0808 808 0000**
Website: www.macmillan.org.uk

**NHS 111**
Call **111** when you need medical help fast but it’s not a 999 emergency (available 24 hours a day, 365 days a year).

**Pancreatic cancer UK**
Speak to a specialist nurse: **020 3535 7099**
Website: www.pancreaticcancer.org.uk

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We are committed to delivering top-quality patient care, excellent education and world class research.