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

1. Introduction
This booklet is for patients who use the pancreatobiliary cancer service at University College Hospital and Royal Free Hospital.

The service provides expert, specialised and holistic care for people with liver, pancreatic and biliary disorders. You may have been referred by your GP or your local hospital consultant to have diagnostic tests or surgery. Some of the tests and treatments you require will only be available at specific hospital sites. We are dedicated to providing the best care and information available.

2. About us
The pancreatobiliary team comprises doctors, nurses, dietitians, occupational therapists, administrators and physiotherapists. There are also a number of specialist doctors and nurses in the department, including gastroenterologists, oncologists, surgeons, radiologists, clinical nurse specialists 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 overleaf.
This leaflet outlines some of the tests and treatments you may be offered. Your doctor will discuss any tests or treatments with you, including the risks and benefits, with written information to support this.

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 have the opportunity to discuss anything that you do not understand, or any anxieties 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 do not proceed with the treatment.

### 3. Key worker

You will be allocated a Clinical Nurse Specialist (CNS) as a **key worker**. Your designated key worker will be your main point of contact for any questions or concerns you may have about your tests or treatment. They will be familiar with your case and will coordinate your care.
4. What tests might I have?
We will carry out various tests and scans to assess your illness and assist us in deciding which treatment options are most appropriate for you.

This section provides a brief description of some of the common tests. You may not require all the tests listed in this section and your doctor will advise which are the most appropriate for you. We will provide you with more information and instructions 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 (radiographer or sonographer). Each test has risks, benefits and alternatives - we will discuss these with you in more detail.

We strive to provide you with the very best treatment and support and understand that this can be a difficult and uncertain time for you. If you have any concerns, do not hesitate to speak to one of the team.

5. Computerised Tomography (CT scan)
A CT scan is a special X-ray examination. It produces detailed images of the structures in the body.

The radiology department will give you specific instructions and information before your scan. You will need to stop eating and drinking four hours before your CT scan. You will be asked to change into a hospital gown and to drink some fluid (called a ‘contrast agent’) beforehand. The fluid helps to show the chest, pelvis and abdomen on the scan. We will also give you an injection into a vein in your arm to improve the quality of the scan.
You will be asked to lie on a table and keep very still while you pass through the scanner. The scan takes about 15 minutes and is painless. You should expect to be in the department for around one hour overall.

6. Ultrasound scan
With this test sound waves are used to provide a 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.
7. 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 and 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 which produces 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 cholangiopancreatography (ERCP)**

An ERCP is used to diagnose and treat disorders of the pancreas, bile duct, liver and gallbladder. The doctor will insert an endoscope through your mouth. It is moved down the throat, through the stomach and into the small intestine. The doctor will then inject a dye into the bile duct and the pancreas to enhance the X-ray images.

8. 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 also be taken during an ERCP. The doctor may also be able to remove cells through the endoscope,
using a special type of brush.

9. 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 ‘key-hole surgery’ and involve a small cut in the skin, through which special instruments are inserted. A laparoscopy test is usually done as a day admission and you will be asked to stop eating and drinking up to six hours beforehand.

10. Factors that can affect the treatment options offered
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. Blood vessels run through and around the liver and the pancreas. The cancer may be located near one of these vessels, making surgery either impossible or very risky.

- **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 will 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. They can also make treatment and diagnosis more difficult. However, many medical conditions will have no significant effect on cancer. Please discuss any concerns with the team caring for you.
11. The difference between radical and palliative treatment

Radical treatment is intended 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 listed above, will be considered when planning your treatment.

We understand that it can be very difficult coming to terms with having cancer. The uncertainty of what the future holds is particularly hard to cope with. It is also very distressing to find out that it may not be possible to cure your cancer. 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 offer you in-depth information sheets about individual treatments and tests.

12. Surgery

You may be offered an operation if tests show that your cancer has not spread to other organs. The extent of major blood vessel involvement will affect whether the tumour can be safely removed. The only possible cure we know for pancreatic and bile duct cancer is surgery.

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 because of the location of the tumour. This is a major surgical procedure which will be discussed fully with you if it is suitable for you. Other operations on the pancreas may be undertaken depending on where tumour lies within the pancreas.

For small bile duct cancers, removal of part of the bile duct may be possible. For more advanced bile duct cancers, it may be necessary
to move part of the liver tissue and nearby lymph nodes. In some cases the extent of the cancer may warrant more extensive surgery, such as a Whipples operation.

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.

Even though the tumour may have been successfully removed, this does not unfortunately guarantee that the cancer will not return at some stage in the future; either in a similar area or a more distant part of the body.

13. **Stenting**

Stenting involves the insertion of 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 yellow jaundice and itching. Stents are inserted via an ERCP procedure or a percutaneous transhepatic cholangio-pancreatogram (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.

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.

14. **Chemotherapy**

Chemotherapy is medical (drug) treatment, using anti-cancer medicines (cytotoxic drugs). Chemotherapy (often called ‘chemo’) 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 supporting written information.

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

15. Radiotherapy
Some patients may be eligible for radiotherapy, which is a painless, high energy x-ray treatment. Your doctor will discuss this with you if it is indicated.

16. Clinical trials and medical research
New and better ways to treat cancer are continually being sought. 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. Feel free to ask a member of the team if there are any trials that may be suitable for you.

All of the relevant trial details will be given to you at the time it is being considered. You are not obliged to join any clinical trials or research projects and your care will not be affected if you decide not to participate.
17. Contact details

University College Hospital
Pancreatobiliary Clinical Nurse Specialist (Monday-Friday, 09:00 til 17:00):
Direct line: 020 3447 4791
Mobile: 0794 4139 704
Address: University College Hospital, 235 Euston Road, London NW1 2BU

Royal Free Hospital
Hepato-pancreatobiliary Clinical Nurse Specialist (Monday-Friday, 09:00 til 17:00):
Switchboard: 020 7794 0500
Extension: 31405
Bleep: 1066
Address: Royal Free Hospital, Pond Street, Hampstead, London NW3 2QG

Out of hours contact
If you have a problem outside of these hours, please contact your GP. In an emergency always go to the Accident and Emergency department.
18. Further sources of information

Macmillan Cancer Support
Support Line: **0808 808 0000**
Website: www.macmillan.org.uk **NHS telephone advice service**
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