

HPB

Hepatic, Pancreatic and Biliary (HPB) Patient Treatment Diary

What's inside the diary?

- An introduction to the diary
- A guide on how to get the most out of your appointments
- An area for you to record your diagnosis
- A brief explanation on what investigations you may undergo
- Who and what is the multi - disciplinary team and contact numbers
- An introduction to the Hepatobiliary Nurse and contact numbers
- Space for you to write your personal thoughts concerns or questions
- Appointment log to enable you to keep track of your appointments
- What to do if you are worried
- List of local and national services

Introduction

This diary is for patients who have been diagnosed with a liver, pancreatic or bile duct lesion, often referred to as HPB

This is your personal diary to help you keep track of your treatment. You may find that you have been given a lot of information which you may find difficult to remember. This diary has been designed for you and your family to use. You can use it to record anything that is important to you about your illness. If you have some questions you want to ask then record them in the diary so that you don't forget to ask when you visit. You may find it helpful to bring the diary with you to all your visits to the hospital or to your GP.



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How to get the most out of your hospital appointments

Patients often find it difficult to take in all the information they are given when they attend the hospital. You may feel that time is limited in a busy clinic so to prevent feeling rushed, go prepared.

Hints and tips

- Bring a friend or relative with you and ask them to come in to see the doctor with you.
- Tell the staff of your wishes or concerns so that these can be taken into account.
- Write down a list of questions that you wish to ask before hand. Think very carefully about the questions you are asking. Frequently asked questions include:
 - What tests and treatment are there?
 - What tests and treatments will I need?
 - Where will I go for treatment?
 - What are the benefits or different options?
 - How will my treatment affect me?
 - How experienced are you and your team?
 - If I have difficulties who can I go to for help?
 - Will I need a special diet?

This is just a sample; further ideas for questions can be found in the Cancer Guide available from the hospital's Macmillan Cancer Information and Support Centre in the main entrance or Macmillan Cancer Support Tel. 0808 808 00 00.

- Ask your friend / relative to write down notes, so that you can concentrate on the consultation
- Do not be frightened if you do not understand what you have been told, ask the question again or tell the doctor that you do not understand.
- If you forget to ask something don't worry, write it down and place in your folder and contact one of the team members.

Patient Information

Your Diagnosis

You have been seen in clinic today by:

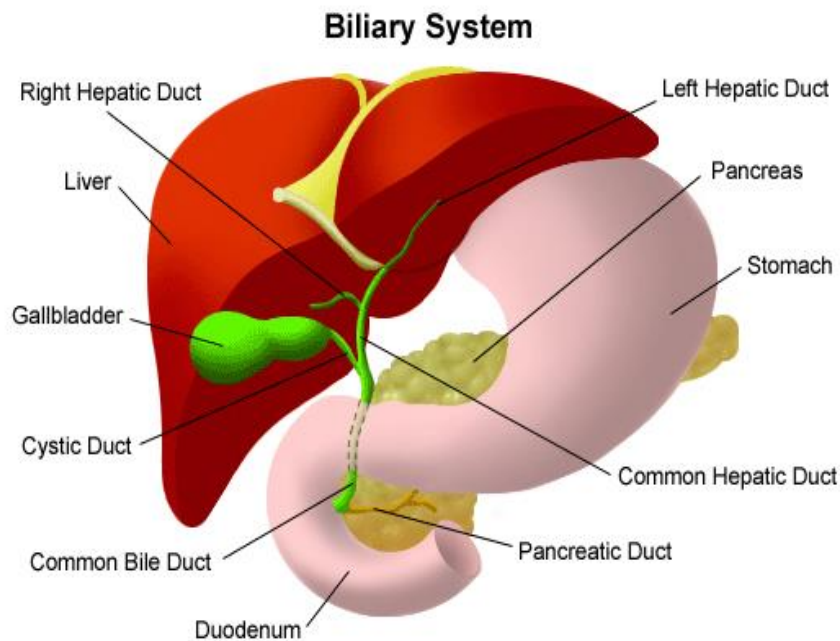
Mr. F.T. Lam

Mr. S. Khan

Mr. G. Marangoni

Mr. J. Ahmad

Other (please state name) _____



You have been diagnosed with:

Your Key Worker, will be a health professional and will be defined as ‘The person who, with the patient’s consent and agreement, takes a key role in coordinating the patient’s care and promoting continuity, ensuring the patient knows who to access for information and advice’ (DH 2004)

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Your Key Worker / Nurse Specialist is: _____

Your proposed treatment is:

.....

Your date to see the Oncologist, if appropriate (Dr. Sothi, Dr Scott Brown or Dr Tween) is:

.....

Before your treatment you may need to have some of the following tests or investigations

Endoscopic Scan <input type="checkbox"/>	Blood Tests <input type="checkbox"/>
Endoscopy (ERCP) <input type="checkbox"/>	MRI Scan <input type="checkbox"/>
CT Scan <input type="checkbox"/>	Biopsy <input type="checkbox"/>
Laparoscopy <input type="checkbox"/>	Heart tracing and scan <input type="checkbox"/>
PET Scan <input type="checkbox"/>	CPET (bike fitness exam) <input type="checkbox"/>

Investigations explanations

Endoscopic retrograde cholangio pancreatography (ERCP)

This investigation is carried out in the Endoscopy Department and will take either a morning or afternoon.

Before the test you will be given an injection to help you relax, it is a diagnostic test and allows your doctor to obtain an X-ray picture of your pancreatic and bile ducts. The bile duct can be unblocked during this procedure if needed. A tube (endoscope) is passed through the mouth,

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stomach and into the small bowel (duodenum). The doctor can look through the tube to find the opening where the bile and pancreatic ducts drain into the duodenum. A dye can then be injected into these ducts which can be seen on X-ray and show up any abnormalities or blockage of the duct.

You will be notified of any special instructions by the Department

Biopsy

This is the removal of a piece of tissue or cells from the body to aid diagnosis. This can be done to determine the extent of the disease in a number of ways, such as by an endoscopy, by ultrasound, with a fine needle or with minor surgery.

CT scan (computerised tomography)

A CT scanner is shaped like a doughnut and you will be required to lie on a couch that will move you through the machine. A number of X-ray pictures are taken of the area from different angles and fed into a computer to form a detailed picture of the inside of the body. Sometimes you will be asked to swallow a dye, to improve the X-ray pictures. CT scans take about half an hour and are painless.

You will be notified of any special instructions by the department

Endoscopic ultrasound (EUS)

Endoscopy and Endoscopic Ultrasound. This procedure allows a specialist to pass a flexible tube through your mouth in order to examine your gullet, stomach and small intestine. This can be carried out using local anaesthetic (throat spray) or light sedation, and allows the specialist to take biopsies if necessary. The specialist may use equipment that produces high frequency sound waves which create pictures of the inside of the body.

Laparoscopy

This is a small operation carried out under a general anaesthetic, to look at the inside of your abdomen. This involves three small incisions being made in your abdomen, and involves an overnight stay in hospital or just as a day case.

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Ultrasound scan (USS)

Ultrasound uses sound waves to build up a picture of the inside of your body. A gel is put on the skin in the area to be scanned and a microphone is passed back and forth over the area. A computer then converts the reflected sound waves into a picture on the screen. This is a painless procedure and will take around 10 - 20 minutes.

You will be notified of any special instructions by the department.

Positron Emission Tomography (CT-PET scan)

This is a new type of scan, which can show if the tissue is active with cancer, or not. Before the scan you will be injected with a tiny amount of dye and then be asked to wait for an hour. The scan can take anything from one hour to three hours.

Magnetic Resonance Imaging (MRI scan)

This is a scan that uses magnetism to build up a picture of the organs inside the body. It is completely painless, rather noisy and takes around half an hour.

Before the scan you will be injected with a dye that helps to make the pictures clearer. You should tell the doctor if you have a pacemaker or any metal parts inside your body such as joint replacements or surgical clips as this may mean you can not have this type of scan.

You will be notified of any special instructions by the department.

Magnetic Resonance Cholangiopancreatography (MRCP)

Similar to **MRI** but assesses the bile and pancreatic ducts.

The Multi Disciplinary Team (MDT)

There will be a number of people involved with planning your care before, during investigations and after your treatment/operation. This is sometimes referred to as the 'patient pathway'. You would normally be under the care of one of the HPB Consultants who may also refer you to the Consultant Oncologist who specializes in treating HPB cancer with chemotherapy and / or radiotherapy.

The multidisciplinary team is a group of consultants, specialist nurses, and dietitians involved with diagnosing, planning and

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carrying out treatment of HPB cancer. The team meets on a Thursday afternoon to discuss each patient's individual 'pathway' of planned treatment. Your 'key worker' will be one of the specialist nurses who attend the meeting and she will be able to keep you informed and up-to-date with regard to decisions made about your treatment.

The members of the team are:

Mr G. Marangoni Lead Clinician

Consultant HPB Surgeon

Secretary 024 7696 5150

Mr S.Khan

Consultant HPB Surgeon

Secretary 024 7696 5277

Mr J. Ahmad

Consultant HPB Surgeon

Secretary 024 7696 5277

Mr F.T.Lam

Consultant HPB Surgeon

Secretary 024 7696 5150

Dr S.Sothi

Consultant Oncologist

Secretary 024 7696 7483

Dr Scott Brown

Consultant Oncologist

Secretary 024 7696 7153

Dr. M. Dhillon / Dr Harding/ Dr L Hon

Consultant Radiologists

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Dr. J. Wong / Dr E Unitt / Dr V Gordon

Consultant Hepatologist

Dr Gopalakrisham

Consultant Histopathologist 024 7696 5433 **Claire Pearce, Michelle**

Faupel and Jamie Bradley

HPB. Specialist Nurse 024 7696 5618

Pamela Semancikova

MDT Facilitator 024 7696 7141

Rosie Hill/Becca Lord

Macmillan Dietitian 024 7696 6137

HPB Specialist Nurses

Who are we?

Claire Pearce, Michelle Faupel and Jamie Bradley

Our aim is to offer support for patients with HPB cancers and endeavour to keep you updated at every stage.

We provide information on your disease, investigations, procedures and treatment options.

Additionally we can offer support and give advice to both you and your family throughout your treatment and answer any questions you may have.

If surgery is indicated we will explain to you what to expect following the operation.

The Clinical Nurse Specialist Team are available between:

8.00am - 4.00pm

Monday to Friday (excluding bank holidays)

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This service provides a direct telephone number and a 24 hour answer phone. For any messages left before 3pm we aim to return the call on the same working day

Telephone 024 7696 5618

In an urgent situation we can be contacted via the hospital switchboard on the following number **Telephone 024 7696 4000**

Other useful information

If you pay for prescriptions please read the information below

Prescriptions (free prescriptions) Patients will be able to apply for medical exemption certificates using application form FP92A (January 2009 revision) which they can get from their GP surgery or oncology centre.

Certificates run for 5 years and can be used until the end date shown. A reminder will be issued automatically to the patient and the certificate may then be renewed if the qualifying conditions still apply. Please speak with your GP or Consultant who will issue you with one.

Holistic Needs Assessment

In accordance with the Department of Health (DH) recommendations in 2007, we offer all patients diagnosed with cancer, an assessment to discuss their physical, psychological, social, spiritual and financial needs that they may encounter at key points on their pathway. If you feel that you would benefit from an assessment, please contact your key worker, Claire, Michelle or Jamie, and they will make an appointment to see you.

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Personal Diary

These sheets are for you and your family to record any symptoms, problems, thoughts and feelings or simply to write down any questions you have so that you don't forget to ask anything important. It may be very useful to discuss this information with your doctor or specialist nurse, when you next see them, if you wish. The diary is for your benefit, so don't be afraid to ask the team to write in it if you wish.

Date	Comments / questions / thoughts

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What should I do if I am worried?

If there is something that you are worried about or require any additional information on, you should contact the specialist nurses that are looking after you. Don't be embarrassed; you are not causing us extra work. We would much rather speak to you and reassure you than leave you to worry.

All the telephone numbers for the nurses can be found on page 8 in this diary.

The University Hospitals Coventry and Warwickshire NHS Trust welcome the views of users on the service that it provides. If you would like to be involved in helping the Trust to improve the services that it provides please contact the department where you are being treated.

Local services

Macmillan Cancer Information Centre.....	024 7696 6052
Coventry Macmillan Care Team (Hospital)	024 7696 5498
(Community)	024 7653 8949
Rugby Macmillan Care Team.....	01788 555119
Gut (Digestive Tract Cancer Support Group for Coventry & Warwickshire)	024 7696 5618
Hospital Chaplaincy	024 7696 7515
Clinical Trials Nurses.....	024 7696 7151
Dietitian.....	024 7696 6161
PALS (Patient Advice and Liaison Service).....	0800 028 4203
Citizens Advice Bureau (appointment only).....	024 7625 2050

Also available at University Hospital:

Physiotherapy, Occupational Therapy, Social Services: Access to these services is by referral from the healthcare team looking after you.

Patient Information

National Contact Numbers

Age UK	0800 169 65 65
Cancer Net	www.cancernet.nci.nih.gov
Macmillan Cancer Support	0808 808 00 00 www.macmillan.org.uk
Marie Curie Cancer Care	0800 716 146
Neuro Endocrine Tumours	www.netpatientfoundation.org 0800 434 6476

The Trust has access to interpreting and translation services. If you need this information in another language or format please contact **024 7696 5618** and we will do our best to meet your needs.

The Trust operates a smoke free policy

To give feedback on this leaflet please email feedback@uhcw.nhs.uk

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