Irish Cancer Society

Understanding

Primary liver cancer

Caring for people with cancer

Understanding

Primary liver cancer

This booklet has information on:

- Treatment for liver cancer
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Practical and financial matters

Useful numbers

Specialist Nurse

Consultant Hepatologist

Consultant Gastroenterologist

Family doctor (GP)

Surgeon

Medical Oncologist

Radiation Oncologist

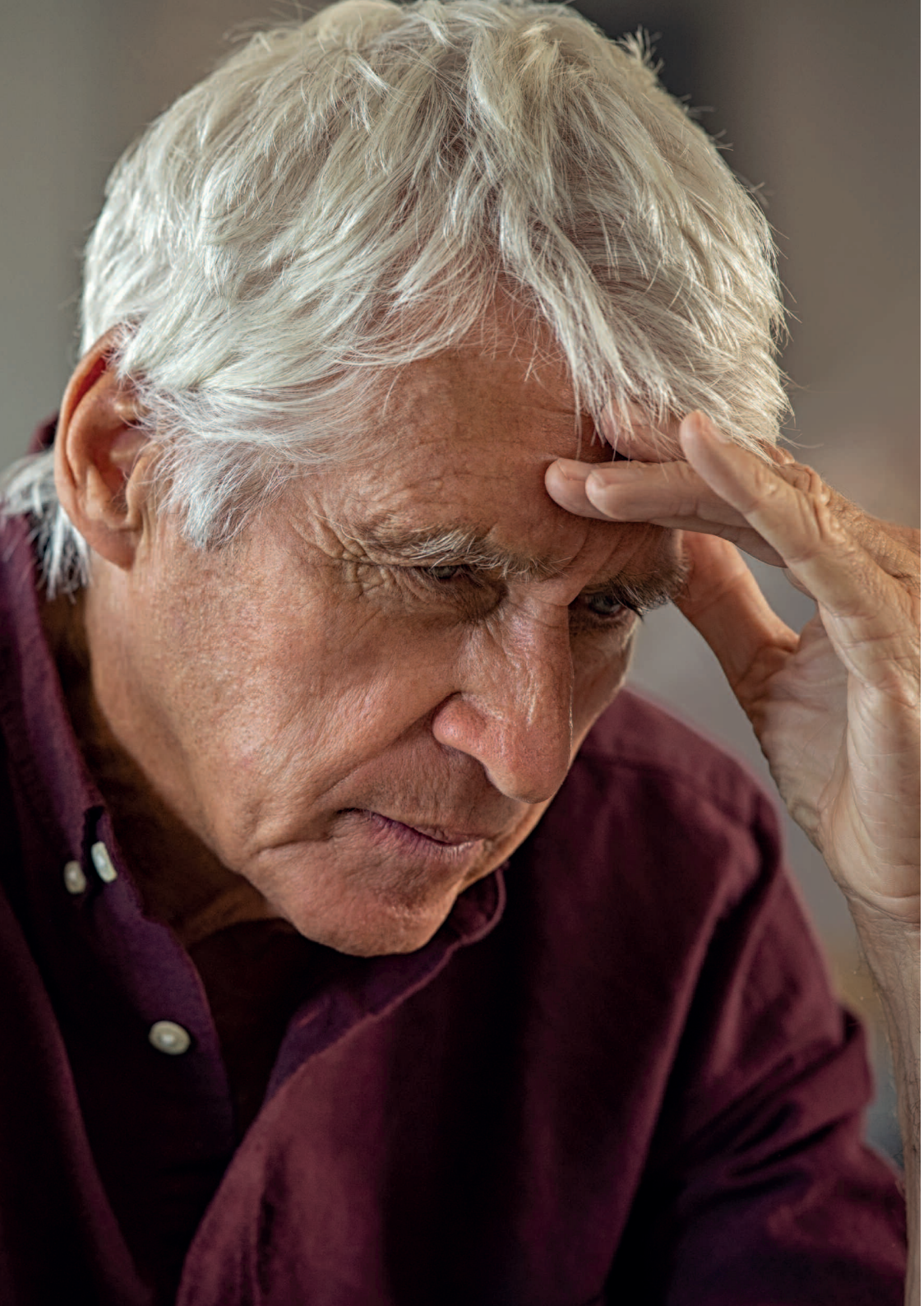
Dietitian

Medical Social Worker

Clinic Secretary

Emergency number

Hospital records number (MRN)



Contents

Fast facts

What kind of treatment might I have? Page 35

Your treatment will depend on the size and number of tumours, how well your liver is working and the exact location of the cancer. Options include:

Surgery: This can be an option for early-stage liver cancer.

Thermal ablation: Using a needle-type instrument to deliver heat to the tumour to destroy it.

Transarterial chemoembolisation: High doses of chemotherapy are given directly to the tumour in the liver while blocking off the blood supply to the tumour.

Radiotherapy: Radiation is used to destroy the cancer cells. It is often used to ease symptoms.

Systemic therapy: Medications used to treat the cancer – immunotherapy and tyrosine kinase inhibitors (TKIs). These can be given directly into your veins (IV), in an injection under the skin or in tablet form.

Palliative care: Treatment that focuses on controlling symptoms rather than curing the cancer.

Will I be OK? Page 32

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things and everyone's prognosis is different. The best thing to do is to talk to your consultant about your own situation.

Will I get side-effects? Page 81

Most treatments cause some side-effects, but these usually get better after treatment has ended. You can read about the different treatments to learn more about any possible side-effects.

There are treatments to help with most side-effects, so tell your doctor if you have any. Don't suffer in silence!

Clinical trials Page 79

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects.

Ask your doctor if there are any trials suitable for you.

We're here for you Page 125

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our Cancer Nurses.

Ways to get in touch

- Call our Support Line on 1800 200 700
- Drop in to a Daffodil Centre.
  Email **daffodilcentreinfo@irishcancer.ie** to find your local Daffodil Centre.
- Email us: **supportline@irishcancer.ie**

See page 125 for more about our services.

Reading this booklet

This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference.

If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

- Call our Support Line on **Freephone 1800 200 700**
- Visit a **Daffodil Centre**
- Email the nurses at **supportline@irishcancer.ie**

About our information

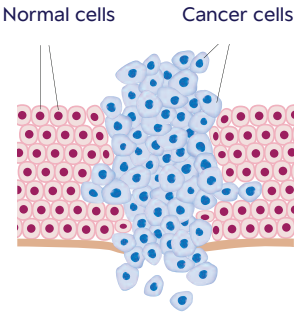
While we make every effort to ensure the information in this booklet is correct and up to date, treatments and procedures in hospitals can vary.

You should always talk to your own team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

About liver cancer

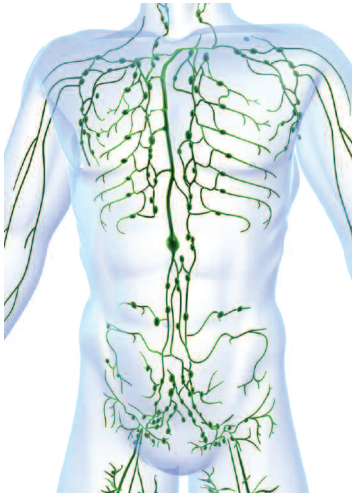
What is cancer?

- **Cancer is a disease of the body's cells**
  Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).
- **Cancers are named after the organ or cell where the cancer starts**
  Liver cancer starts in cells in the liver.
- **Cancers sometimes spread**
  If a tumour is cancerous (malignant), a cell or group of cells can be carried by your blood or lymph fluid to another part of your body, where it can form a new tumour. This is called metastasis. Sometimes cancer cells spread into nearby lymph nodes, which are part of the lymphatic system.



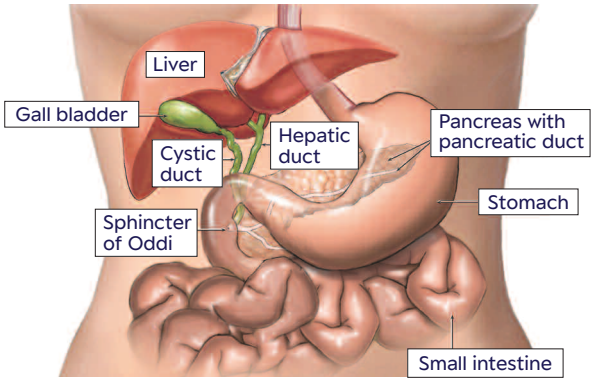
What is the lymphatic system?

- The lymphatic system is part of our immune system. It protects us from infection and disease and removes extra fluid and waste from the body's tissues.
- It is made up of lymph nodes connected by tiny tubes called lymph vessels.
- Lymph nodes are found mainly in the neck, armpit, groin and tummy.
- If cancer cells spread into lymph nodes or if cancer starts in the lymph node, they can become swollen.



What is the liver?

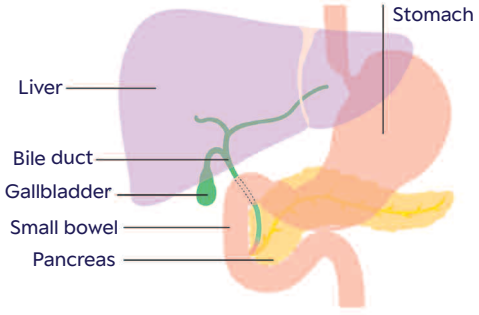
The liver is the largest solid organ inside the body. It has 2 lobes: a right and left lobe. It is found on the upper right side of the abdomen (tummy), under your rib cage.



What does the liver do?

The liver is a very important organ. It has many roles:

- It makes proteins that help blood to clot, preventing bleeding.
- It makes other proteins (albumin) needed for fluid balance in your body.
- It plays an important role in the body's ability to fight infection.
- It makes cholesterol, needed for every cell in your body to grow.
- It stores and converts carbohydrates and fats into energy.



Picture courtesy of Cancer Research UK/Wikimedia Commons

- It makes bile that breaks down fats and absorbs them into the body.
- It stores glucose and nutrients until the body needs them.
- It filters and cleans the blood by getting rid of substances and toxins not needed by your body. These include alcohol, drugs and other waste products.

What is primary liver cancer?

There are 2 broad categories of liver cancer: primary liver cancer and metastatic (secondary) liver cancer. The information in this booklet is mainly about primary liver cancer.

Primary liver cancer is a cancer of the cells that make up your liver. The cancer develops when the liver cells change and grow in an abnormal way to form a group of cells called a tumour.

What is metastatic (secondary) cancer in the liver?

Metastatic (secondary) cancer in the liver is a cancer that started somewhere else in the body and spread to the liver. For example, bowel (colorectal) cancer cells can spread to the liver. These cancer cells are not liver cancer cells. They are bowel cancer cells and are treated with bowel cancer treatments, even though they are in the liver. Metastatic cancer in the liver is a lot more common than primary liver cancer.

To find out more about metastatic (secondary) cancer, talk to a Cancer Nurse on our Support Line 1800 200 700 or at a Daffodil Centre. There is also more information about metastatic cancer on our website **www.cancer.ie**

What are the types of primary liver cancer?

The most common type of primary liver cancer is:

- **Hepatocellular carcinoma (HCC)**. It develops in the main liver cells called hepatocytes. About 8 in 10 patients diagnosed with primary liver cancer have HCC.

Less common types of primary liver cancer include:

- **Cholangiocarcinoma (CCA) or bile duct cancer** – this accounts for about 1 in 10 liver cancers. It occurs in the bile ducts (within the liver) that carry bile to the gallbladder. We have more information about bile duct cancer on our website, **www.cancer.ie**
- **Fibrolamellar hepatocellular carcinoma** is a rare type of primary liver cancer that usually affects younger people.
- **Angiosarcoma** is a type of cancer called a soft tissue sarcoma.
- **Hepatoblastoma** is a very rare type of primary liver cancer that usually affects young children.

For more information about the rarer types of liver cancer and children's cancer, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

What caused my cancer?

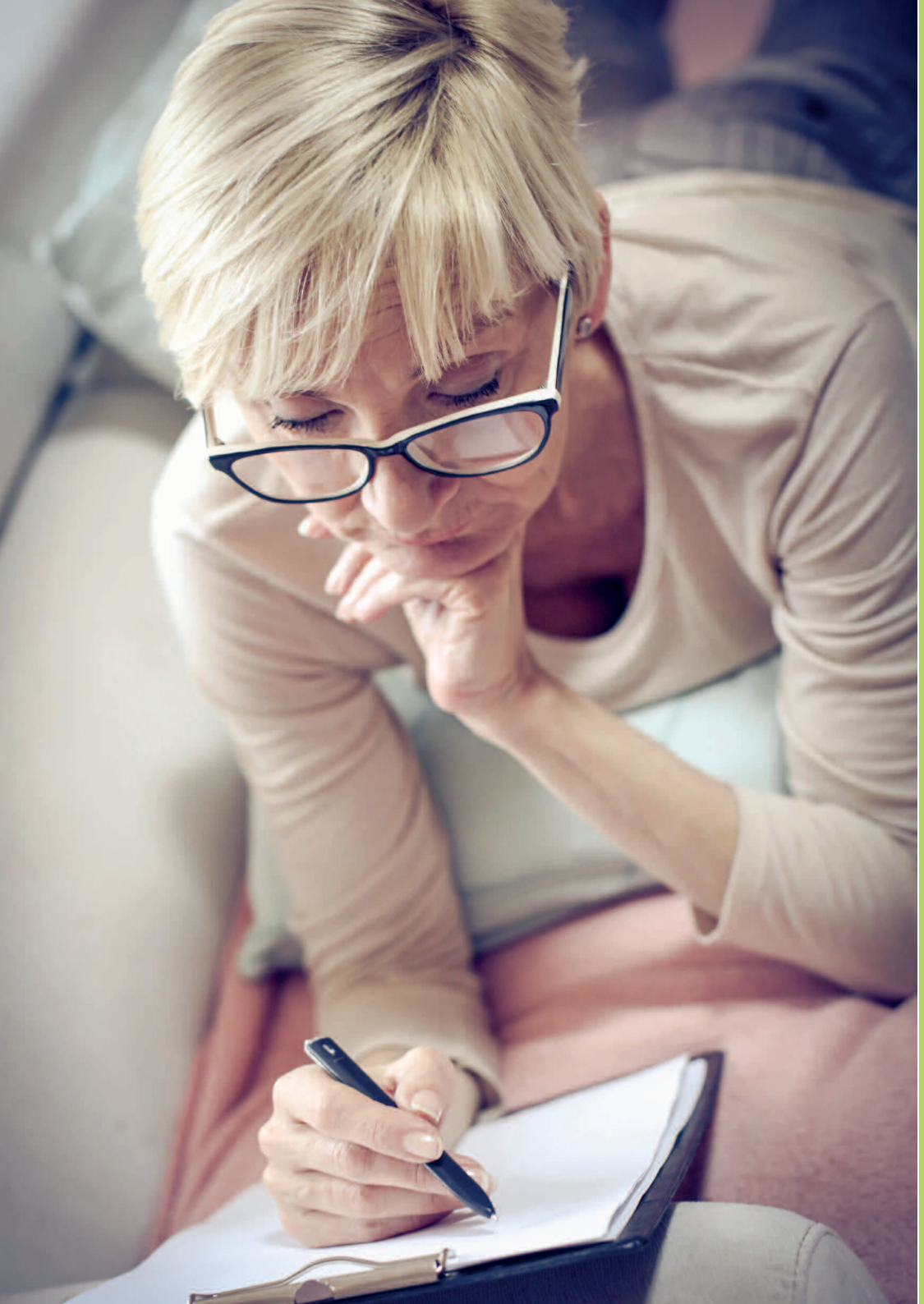
We don't know exactly what causes many cancers, but there are things that can increase your risk of getting cancer. People with a history of liver disease can develop cirrhosis (scarring of the liver). If you have cirrhosis, you are more at risk of developing HCC. Certain types of liver disease causing cirrhosis are strongly linked with this primary liver cancer.

If you want to know more about why cancer happens or to learn about the risk factors for liver cancer, see our website **www.cancer.ie** or talk to a Cancer Nurse – call our Support Line or visit a Daffodil Centre.

This booklet is mainly about **primary liver cancer.** When we refer to primary liver cancer, we are talking about hepatocellular carcinoma (HCC).

How common is liver cancer?

About 300 people are diagnosed with primary liver cancer each year in Ireland. It is twice as common in men than it is in women.



Preparing for your hospital appointments

Preparation is key to getting the most out of your hospital appointments. Being prepared also helps the doctors and nurses get the information they need to plan your care.

Before your appointment

- Write down a list of questions and things you would like to discuss.
- Know where you are going and plan your journey (build in extra time for unexpected delays, such as parking).
- Dress in warm comfortable clothes and shoes – sometimes you can be waiting around for a while. Layers are best, as the temperatures in hospitals can vary a lot. Loose-fitting clothing will be easier to manage if you are having your blood pressure taken, blood tests or a physical examination.
- Try to drink clear fluids (water or juice without pulp) if you are having a blood test and you aren't fasting. This can make it easier for the nurse or doctor to find a vein.
- Check with the hospital if it is okay to bring someone with you. Ask a friend or family member to go along for extra support.

What to take to your appointment

Put together a list of things you might need to bring for your visit, including:

- Your medical card, if you have one
- Your private health insurance details, if you have insurance
- The appointment letter from the hospital, if you got one
- A referral letter or GP letter, if you got one
- Your GP's name and contact details
- Your medical history – remember, your doctor will likely ask you lots of questions so it's a good idea to have everything written down beforehand
- Your list of questions
- A notebook and pen to take notes. (Some healthcare professionals/nurses may be happy for you to record the meeting, but make sure you ask for their permission before doing so)
- A list of your medications or the medication itself – ask your pharmacist to print off a list of your medications. Hand-written lists can be hard to read or inaccurate
- Be aware of when your prescription is due, so you can ask for a prescription before you leave, if needed
- Medications and any medical supplies you may need that day, in case you are delayed
- A light snack and drink if you are likely to have to wait for some time. (Make sure you are not meant to be fasting – check with the hospital beforehand if you are not sure)
- Your phone and your phone number
- Contact details of the person to call in an emergency
- Your glasses and hearing aid, if you use them
- A book or something to listen to (including headphones) to pass the time while you wait

Before leaving the appointment

- Make sure you feel satisfied that your questions were answered and that you have written down what you need to know
- Make sure you know what will happen next
- Ask for the name or number of someone you can contact in case you have further questions
- Ensure you are booked in for your follow-up appointment before you leave, if required

After the appointment

- Arrange any tests in advance of your next appointment as soon as you can, for example, a blood test – if your healthcare professional has asked for it

It's important to go to your appointments

If you can't go to your appointment, contact the hospital as soon as possible and ask them for a new appointment. Contact your GP if you have any trouble getting an appointment.

Questions to ask your doctor

Here is a list of questions that you might like to ask. Never be shy about asking questions. It is always better to ask than to worry.

How long will it take to get the test results?

What type of liver cancer do I have?

What stage is the cancer at?

What treatment will I need?

Will surgery cure the cancer?

Are there other treatment options? Why is this one best for me?

Would I be suitable for a clinical trial?

How long will my treatment take?

Do I have to stay in hospital for my treatment?

What side-effects will I get?

Is there anything I can do to help myself during treatment?

How often will I need check-ups?

What if the cancer comes back?

Does my liver disease have an impact on me receiving treatment for my liver cancer?

Diagnosis and further tests

Being diagnosed with liver cancer

Hearing that you have cancer can be a huge shock. You may be feeling:

- **Upset** and **overwhelmed** by your emotions
- **Confused** by all the information being given to you
- **Worried** about what will happen next
- **Angry** that this is happening to you

However you feel, you are not alone.

If you need to talk to someone or if you want support or advice:

- Ask to speak to the cancer clinical nurse specialist (CNS) or the medical social worker at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters.
- Talk to one of our Cancer Nurses in confidence – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- Speak to an Irish Cancer Society Peer Support volunteer who has had a similar cancer experience and is fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. Our Cancer Nurses can put you in touch with a volunteer.
- Go to your local cancer support centre. For more information, see page 134.

Telling people about your diagnosis

Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straight away. You may be unsure of how to break the news or need a little time to adjust. You may also worry about how other people will react. For example, they may fuss over you or be upset.

If you would like to talk things over with a cancer nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of our booklet ***Understanding the emotional effects of cancer.*** It can help you find ways to talk about your cancer and to ask for the help and support you need.

Tests after diagnosis

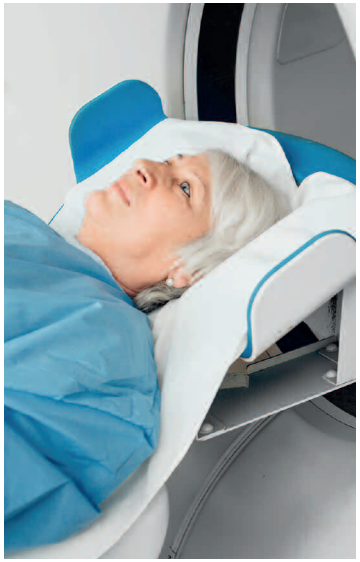
- After being diagnosed with cancer, you may have more tests to find out about the cancer and your general health.
- Tests you may have include scans such as a CT, MRI or PET scan.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

Tests you may have include:

CT scan

This is a type of X-ray that gives a detailed 3D picture of the tissues inside your body. You might be asked to fast (not eat) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. The injection may make you feel hot all over for a few minutes. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.

MRI scan



This is a scan that uses magnetic energy to create a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine. Some people are afraid they will feel anxious or claustrophobic inside the tunnel. Tell the radiographer if you're feeling anxious.

You might get an injection before the scan to show up certain parts of your body. During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test.

An MRI can be noisy, but you will be given earplugs or headphones to help block out the sound. It is important that you keep as still as possible during the scan.

Usually you can go home soon after the scan.

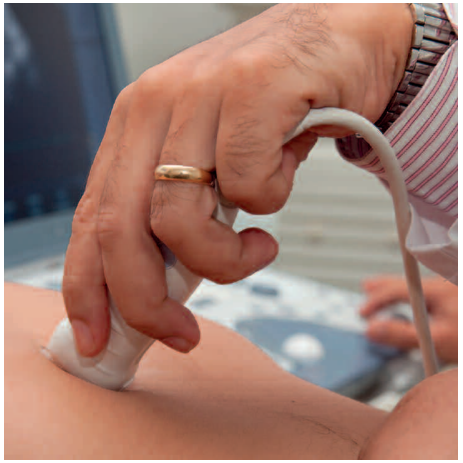
PET CT scan

A PET CT scan can show if the cancer has spread to other tissues and organs. A low dose of radioactive sugar is injected into your arm. An hour or so later you will have a scan. The radioactivity can highlight cancer cells in your body.

During the scan, you will lie on a table which moves through a scanning ring. The scan can last up to an hour. Before the scan, you may have to fast (not eat) for a few hours.

You will be slightly radioactive for about 6 hours after the scan. You should avoid contact with young children and anyone who is pregnant during this time.

Ultrasound scan



This is a scan that uses sound waves to look at your liver and surrounding organs. It may be used to monitor patients, as part of their follow-up care. The scan is painless and only takes a few minutes. Some gel is first put on your tummy and then a small hand-held device is passed over the area being scanned.

For most scans you will be alone in the treatment room, but the medical staff can still see you, hear you and speak to you. If you need anything, just speak or raise your hand.

Liver biopsy

A liver biopsy may be required for 3 possible reasons:

1. To help with the diagnosis of primary liver cancer, if scans are not enough to diagnose the cancer
2. To determine how well the background liver tissue (separate to the cancer) is functioning
3. As a requirement if you are taking part in a clinical trial

A liver biopsy is not always needed for diagnosing primary liver cancer as it may be diagnosed from scans alone.

In some circumstances, your team may need more information about how well your liver is working. If they can't get this information through scans and blood tests alone, you may need to have a liver biopsy.

If a liver biopsy is required, you will have to fast (not eat) for a few hours before this test. Your doctors will insert a long thin needle into your liver either through your skin (percutaneous) or into a vein, guided by ultrasound (transjugular). Alternatively, they may take the sample using keyhole surgery (laparoscopic) under general anaesthetic.

After a liver biopsy you will need to stay in hospital for a few hours, or sometimes overnight. This is so you can recover from any sedation or anaesthetic you may have been given. The team will also want to monitor you, as there is a small risk of bleeding after this procedure. Your doctor will talk to you about any risks involved.

Waiting for test results

It usually takes up to 2 weeks for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a Cancer Nurse. Once all the tests have been completed, the multidisciplinary team will meet to decide on how to manage your cancer.

Staging liver cancer

- Staging cancer means finding out its size and location.
- Staging helps your doctor to decide the best treatment for you.
- Your prognosis is what your doctor expects to happen with your cancer.

The tests you have after diagnosis help the doctor to give your cancer a stage. Staging describes:

- The cancer itself
- The condition of the liver and how well it's working (its function)
- How well you are

This will help your medical team decide what treatment might be of most benefit to you.

How is liver cancer staged?

Many liver cancer specialists use a combination of staging systems, which include:

TNM staging system

This refers to the size of the tumour (T), if the cancer has spread to your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis).

Your doctor often uses the TNM information to give your cancer a number stage – from 0 to 4.

A higher number, such as stage 4, means a more advanced cancer. In general, the lower the number, the less the cancer has spread. Some stages are further divided into stages A and B.

Barcelona Clinic Liver Cancer (BCLC) staging system

Another type of staging used specifically for HCC is the BCLC staging system. It looks at liver function as well as the size and number of tumours. It has 5 stages:

- **Stage 0:** One small tumour less than 2cm. The person is well and has normal liver function.
- **Stage A:** One tumour less than 5cm, or 2-3 smaller tumours – none bigger than 3cm. The person is well and has normal liver function.
- **Stage B:** There are many tumours in the liver. The person is well and has normal liver function.
- **Stage C:** The size and number of tumours may vary, but the cancer may have spread to nearby blood vessels and/or lymph nodes. It may also have travelled to other parts of the body. The person has normal liver function.
- **Stage D:** There is severe damage to the liver. The person is not well at all. They can have any number of tumours.

The Child-Pugh system

The Child-Pugh system has 3 classes that describe how well the liver is working, in people who have liver cirrhosis. This system considers your blood test results, whether there is fluid (ascites) in your abdomen, and your brain function (hepatic encephalopathy).

- **Class A:** The liver is working normally
- **Class B:** Mild to moderate liver damage
- **Class C:** Severe liver damage

Performance status (PS) (Based on the Eastern Co-operative Oncology Group (ECOG)/WHO system)

Performance status (PS) is a scale to rate how well and physically fit you are:

- **PS 0:** You are fully active and can do much the same as you did before your diagnosis.
- **PS 1:** You cannot do heavy physical work, but can do everything else.
- **PS 2:** You are up and about more than half the day. You can look after yourself, but you can't work.
- **PS 3:** You are in bed or a chair for more than half the day. You can look after yourself to some extent but need help.
- **PS 4:** You are in bed or a chair all the time and need complete care.

These staging systems are used to help your medical team decide on the most appropriate treatment options to discuss with you. Staging can be hard to understand, and no 2 patients are the same. Make sure to ask your doctor and nurse for more information if you need it.

Asking about your prognosis

Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy. It's not always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.

Should I ask about my prognosis?

If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control by having as much information as possible. Or you may not want to know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.

If you decide you want information on your prognosis:

- Think carefully about how you will cope with the information before asking for your prognosis.
- Get information on your prognosis from your doctor. They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- Ask a friend or family member to go with you, if you would like some support.
- Be careful with online information. It may be hard to understand or it may be incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- Accept that you will need some time to think about what you have been told. You may forget some things or there may be things you didn't understand. You may need to talk to your doctor or nurse again after you have thought about everything.

If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our Cancer Nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Support Line Freephone 1800 200 700

Treatment overview

How is liver cancer treated?

- A team of healthcare professionals will be looking after you (multidisciplinary team – MDT).
- The type of treatment will depend on factors such as the size and stage of your cancer, as well as your level of liver function.

Liver cancer can be treated using surgical and non-surgical treatments. A team of specialist healthcare professionals called the multidisciplinary team (MDT) will meet to discuss your situation and recommend a treatment plan specific to you.

The type of treatment they recommend will depend on factors including:

- The stage of the cancer
- The size of the tumour or tumours
- The exact location of the cancer
- If the cancer has spread
- How well your liver is working (liver function)
- Your age and general health

Surgical treatments

For early-stage primary liver cancer, surgery is the most common and effective treatment. However, this will depend on where the tumour is and how well your liver is working. There are 2 main types of surgery:

- Liver resection: Removal of part of the liver
- Liver transplant: Removal of the whole liver and replacement with a healthy donor liver. If you are recommended for a liver transplant you may have some other treatments while you are waiting for a donor liver. This is called 'bridging therapy'.

See page 57 for more about surgery.

Non-surgical treatments

Non-surgical treatments are used to reduce the growth of the cancer if surgery is not an option. A combination of non-surgical treatments can be used along with, or after, other treatments.

Thermal ablation

This treatment uses heat to destroy the cancer cells. There are 2 main types of ablation – radiofrequency ablation (RFA) and microwave ablation (MWA).

Percutaneous ethanol injection can also be used if thermal ablation therapies are not recommended due to the risk of damage to other organs near the cancer.

See page 65 for more on these treatments.

Embolisation

Embolisation involves blocking the blood supply to the tumour, which will kill the cancerous cells. Transarterial embolisation (TAE) and transarterial chemoembolisation (TACE) are both examples of embolisation techniques. These procedures may help to control the cancer and relieve symptoms. See page 66.

Radiotherapy

High-dose radiotherapy may be used to target tumours in the liver. There are 2 main types of radiotherapy – selective internal radiation therapy (SIRT) and stereotactic body radiation therapy (SBRT). SIRT delivers tiny radioactive beads (microspheres) directly to the tumour through your blood vessels. SBRT is a type of external radiotherapy, where a machine outside your body directs highly focused and accurate X-ray beams at the area to be treated. SIRT and SBRT are used to try to control areas of cancer in the liver and relieve symptoms. See page 67 for more on these treatments.

Systemic therapy

There are 2 main types of systemic therapy:

- **Immunotherapy (IO) combinations.** For example, atezolizumab with bevacizumab and durvalumab with tremelimumab.
- **Targeted therapy drugs**, mainly tyrosine kinase inhibitors (TKIs). For example, lenvatinib and sorafenib.

These regimens are generally used to treat advanced liver cancer, especially if it has spread to another part of the body (metastatic cancer). These treatments can help to stop the growth of cancer cells.

See page 73 for more on targeted therapies and page 75 for more on immunotherapy.

Palliative care

Sometimes treatment for the cancer may be too much for the liver to take. For example, if there is a lot of cancer in the liver or the cancer has spread to other parts of your body (metastatic cancer). In this case you may be offered palliative treatment to manage symptoms and improve your quality of life. See page 77.

Your doctor will discuss your treatment options with you.

Specialist cancer centres

Liver cancer is treated in specialist centres in Ireland. The staff at these centres have a lot of experience in managing patients with liver cancer. As a result, you may be transferred to another hospital from the one where you received your diagnosis, depending on your diagnosis and treatment plan. St Vincent's University Hospital is the National Liver Cancer Centre and is the only centre that can offer all the treatments for primary liver cancer.

Deciding on treatment

Multidisciplinary team

A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, a hepatologist (specialist in diseases of the liver), specialist nurse, liver surgeon, radiologist and oncologist (cancer doctor). The team will meet to discuss your test results and treatment plan.

Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance, so you don't forget anything. You could use the fill-in pages at the back of this booklet for your questions and answers.

If you do forget something or need more explanations, ask your specialist nurse or talk to one of our Cancer Nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Time to think

It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can ask for more time to decide about the treatment, if you are unsure when it's first explained to you.

Second opinion

You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your doctor can refer you to another specialist for a second opinion if you feel this would be helpful.

Accepting treatment

You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse a particular treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.

Who will be involved in my care?

Usually, a team of health professionals will be involved in your treatment and care.

Consultant: An expert doctor. They are in charge of your treatment. They have a team of doctors working with them.

Hepatologist: A doctor who specialises in diseases of the liver, bile ducts and gastrointestinal tract.

Gastroenterologist: A doctor who specialises in diseases of the digestive system.

Liver (hepatobiliary) surgeon: A surgeon who specialises in surgery to the liver, pancreas, gall bladder and bile ducts.

Medical oncologist: A doctor who specialises in treating patients with cancer using chemotherapy and other anti-cancer drugs.

Radiation oncologist: A doctor who specialises in treating patients with cancer using radiation.

Advanced nurse practitioner (ANP): An ANP gives expert information and support and is specially trained to carry out tests and help to review your treatment.

Oncology liaison nurse/clinical nurse specialist (CNS): A specially trained nurse who works in a cancer care unit. They give information and reassurance to you and your family from diagnosis and throughout your treatment.

Interventional radiologist: A specialist who performs minimally invasive procedures, such as imaging, to help give treatments such as ablation or embolisation.

Radiologist: A doctor who specialises in interpreting X-rays and scans such as CT, MRI and PET.

Histopathologist: A doctor who examines tissues and cells, usually under a microscope, to help give a diagnosis.

Pharmacists: A healthcare professional who dispenses chemotherapy and other cancer drugs. Some pharmacists are based in hospitals and others are in local pharmacies. They can give advice on cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

Dietitian: An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms.

Physiotherapist: A therapist who treats injury or illness with exercises and other physical treatments.

Occupational therapist: A therapist who specialises in helping people who are ill, recovering from an illness, or disabled learn to manage their daily activities.

Medical social worker: A person trained to help you and your family with your social issues and emotional and practical needs. They can also give advice on social welfare benefits, financial matters and practical supports and services available to you.

Psycho-oncology team: These are specialists in psychological care and support for patients with cancer. Usually the team includes psychiatrists, clinical psychologists and nurses.

Psychologist: A specialist who can talk to you and your family about emotional and personal matters and can help you make decisions.

Palliative care team: This team is experienced in managing pain and other physical symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the symptom management team. A specialist palliative care service is available in most hospitals. Palliative care teams also work in the community.

GP (family doctor): While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you. You can contact your GP about any worries you have or if you are finding it hard to cope.

Community health services: These include family doctors, public health nurses (who can visit you at home), community welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

Individual treatment

You may notice that other people with liver cancer are not getting the same treatment as you. Their cancer may not be the same type or at the same stage as yours. Everyone's treatment needs will be different. Don't be afraid to ask your doctor about your treatment.

Giving consent for treatment

Before you start any treatment, you should be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- Possible side-effects from treatment
- Any other treatments that may be available

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

Waiting for treatment to start

Planning cancer treatment takes time. Most people want to start treatment right away. You may worry that the cancer will spread during this time.

Cancer treatment should start soon after diagnosis. But for most cancers, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works.

If you are worried, talk to your doctor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a Cancer Nurse.

While you're waiting for treatment, you might like to focus on your own health. This can help you prepare for your treatment and feel more in control. For more information, see the next page.

Pre-treatment education workshops

Ask your specialist nurse or visit a Daffodil Centre for information on our pre-treatment education workshops. The workshops give information on certain treatments, including what to expect and how to manage side-effects. You can also learn about different treatments by watching our patient education videos at **www.cancer.ie/video-library/patient-education-videos**

How can I help myself?

It can be very difficult to cope with a cancer diagnosis and all the changes that this can bring. Your healthcare team can offer you different types of support, but there are also things you can do yourself to prepare for treatment and feel as well as possible.

Eat well

Eating well when you have cancer can help you feel better. It can help you to:

- Keep up your energy and strength
- Keep your weight stable and avoid muscle loss
- Tolerate your treatment better, so you can finish your course of treatment
- Cope better with side-effects of treatment
- Reduce your risk of infection and other complications
- Recover faster

Ask to talk to the dietitian at the hospital for advice on the best diet for you. We provide group online information sessions with an

Oncology Dietitian, to support you to eat well during cancer treatment and beyond. You can also read our booklet ***Understanding diet and cancer***. For more information call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Stay active

If you are able, it can really help to be active before, during and after your treatment. Keeping up or increasing your activity levels can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Strengthen your muscles, joints and bones
- Reduce the risk of other health issues
- Reduce the risk of some cancers coming back

Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you and they may have information on exercise programmes and classes. Call our Support Line or visit a Daffodil Centre for information and support on how you can make exercise part of your everyday life. Ask about our free exercise classes, to build strength and fitness in a supportive environment.

Give up alcohol

If you are diagnosed with cirrhosis (scarring of the liver), it is important that you give up (if possible) or cut down on drinking alcohol. Cancer treatment may not be possible if your liver is in failure. If you stop drinking, your liver function may improve.

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking. However, research tells us that:

- Non-smokers are likely to have fewer or less severe side-effects during cancer treatment. For example, chest infections.
- Smoking can reduce how well radiotherapy and some other anti-cancer treatments work
- Not smoking can help you to heal better after surgery
- Quitting reduces your chance of further illness

If you would like advice or support on quitting, call the HSE Quit Team on Freephone 1800 201 203, visit **www.QUIT.ie** or Freetext QUIT to 50100. Some hospitals have a stop-smoking service, with advisors who can help and support you.

Other ways to help yourself

Get information about your cancer and treatment

Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. Make sure you get your information from trustworthy sources like your medical team, the Irish Cancer Society and the HSE.

Involve your family and close friends

Don't keep any worries or physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.

Use your support network

Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example, lifts to the hospital, practical help at home, child-minding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Try relaxation and stress management techniques

Activities like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups to help you learn these techniques.

Accept change in your life

Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

Know that there will be ups and downs

Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. There is help and support available if you are finding it hard to cope. Call into your nearest Daffodil Centre or call our Support Line on 1800 200 700.

Try to cope day by day

Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

Types of treatment

Surgical treatments

- The aim of surgery is to completely remove the tumour and the tissue close to it.
- Surgery can cure early-stage liver cancer.
- You may have part of your liver removed or have a full liver transplant.

Your multidisciplinary team will decide if you are suitable for surgery. This decision is usually based on the size and location of the tumour or tumours, how healthy the rest of your liver is and your general health.

Types of surgery

The 2 main types of surgery for early liver cancer are:

Surgical resection: Part of your liver is removed.

Liver transplant: Your liver is removed and replaced with a healthy donor's liver.

Surgical resection

Surgical resection is an operation to remove part of your liver. How much is removed depends on the size of the tumour, where exactly it is in the liver and how well the rest of your liver is working. The removal of a whole lobe is called a lobectomy or hemi-hepatectomy. Other types of resection include segmentectomy and sectionectomy. Your surgical team will explain the type of surgery you are having.

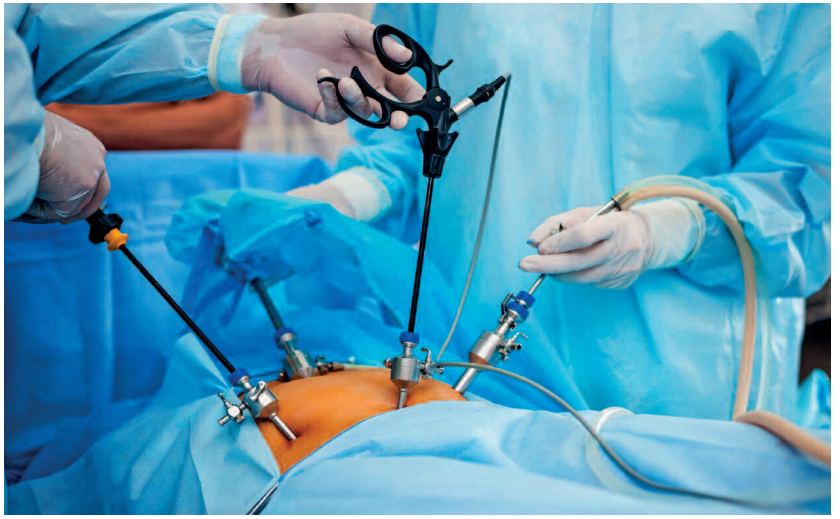
This surgery is not suitable for everyone. Your team will take many factors into consideration including:

- Are you fit for surgery?
- What size is the tumour? (If it's small, there's less chance it has spread.)
- Has the cancer spread into the blood vessels?
- Is your liver fairly healthy with little or no cirrhosis? In that case, the liver can grow back and start working as it did before.

Before surgery, you will be referred to the pre-operative assessment unit where you will be reviewed by an anaesthetist. The anaesthetist will look at your heart, lung and kidney function, as well as your blood tests, to see if it is safe for you to be put under general anaesthetic. If the anaesthetist is satisfied with the assessment, you will be cleared to have surgery.

The operation may be done through open surgery (laparotomy). This is where the surgeon operates through one long cut in the abdomen (tummy).

Alternatively, you may have keyhole (laparoscopic) surgery, where the surgeon makes a series of small cuts in the abdomen.



Sometimes, they will do robotic surgery. This is where the surgeon uses a robotic device and computer to help perform minimally invasive surgery.

In some cases, you may also have an ablation treatment during your surgery (see page 65).

Liver surgery is a major operation. Risks associated with it include infection, bleeding and bile leak. There is also a risk that some of the cancer cells have escaped undetected before the surgery. This means it's possible that the cancer may come back despite the operation.

It is important to remember that if the primary cancer has developed in a liver with cirrhosis (scarring of the liver), there is a risk of a new, separate liver cancer developing in the remaining liver tissue.

Liver transplant

A liver transplant means removing your liver and replacing it with a healthy donor liver. This operation is used for some primary liver cancers, but it is not suitable for everyone. There are strict criteria that guide whether your cancer is treatable with a transplant. For example:

- Are you well enough for surgery?
- Do you have cirrhosis and how severe is it?
- What is your background liver disease and does that type of liver disease have specific criteria for a transplant (for example, no alcohol intake for at least 6 months)?
- What size is the tumour or tumours?
- Has it grown into blood vessels or spread outside the liver?
- Has the tumour progressed while waiting for a transplant?

If you are being considered for a liver transplant, you will be referred to the National Liver Transplant Unit in St Vincent's University Hospital (SVUH) in Dublin for review by the multidisciplinary team (MDT). Your case will be discussed at the weekly MDT meeting, and you will be brought to the clinic there for review. If you are being considered for a transplant, you will have regular meetings with the liver transplant team and coordinators.

Before transplant surgery

Liver transplant assessment: The liver transplant assessment may be carried out as an inpatient, outpatient or in some cases, as a combination of both. During the assessment phase, you will have a series of tests and investigations. These tests might include: blood tests, chest X-ray, pulmonary (lung) function tests, heart tests – electrocardiograph (ECG) and echocardiogram (echo) – ultrasound scan, CT scan, 24-hour urine collection or a dental X-ray.

You will meet some of the members of the MDT including nursing staff, surgeons, hepatologist, anaesthetist, transplant coordinator, dentist, medical social worker, pharmacist, dietitian, psychiatrist and physiotherapist. (See page 44 for more on who will be involved in your care.)

It is important that you have a support person to help you during the liver transplant process, as it can be a stressful time. You will need practical and emotional support during hospital visits, and during your recovery if you go on to have a transplant. A support person can also help you to remember information about your treatment and care that you are told during hospital appointments.

Once the assessment phase is complete, the MDT will review the results and discuss liver transplantation with you, if it is the best treatment option for you.

Waiting for a liver transplant

If a liver transplant is the best treatment option for you, you will meet with a liver transplant coordinator for an education session about going on the liver transplant waiting list. A donor liver is matched with a recipient based on blood group, weight and a rating called the model for end-stage liver disease (MELD) score. (This is a score that measures the health of your liver and how urgently you need a liver transplant.)

Waiting for a liver transplant can be a difficult time for you and your family, as it is the time of least activity. The waiting times can range from weeks and months to years.

While you are waiting for your transplant, you may have bridging treatment to make sure the cancer stays stable and that you remain within the strict criteria for a transplant. These treatments include thermal ablation (see page 65), TACE (see page 66), SIRT (see page 67) and SBRT (see page 68). The liver transplant team will explain this to you.

Liver transplant operation

When a donor liver becomes available, the transplant coordinator will contact you with clear instructions for coming to the hospital. You will meet some members of the MDT again. They will explain everything to you as you prepare for your operation.

After a liver transplant

After the operation, you will probably stay in hospital for 1-2 weeks. During this time, you will be looked after in the intensive care unit, the high dependency unit and then on the ward. Your medical and surgical transplant teams will see you regularly to make sure you are healing and recovering well.

You will start taking immunosuppressant medications to help keep your body from rejecting the new liver. The nurses on the ward will teach you about your new medications, including when and how to take them.

After discharge, you will have regular appointments in the outpatient clinics to make sure you continue to recover well. Once you go home, it will take some time for life to return to normal, but the transplant team will be on hand to support you and answer any questions.

You will need painkillers for a few weeks after your surgery and it may take some months before you start to really recover. To help your wound to heal, avoid lifting anything heavy or doing strenuous housework or gardening.

Your doctor or specialist nurse will tell you more about what to expect after your transplant.

Immunosuppressants and infection

If you have a liver transplant, you will be taking medication (immunosuppressants) to help keep your body from rejecting the new liver. One of the side-effects of this medication is that it weakens your immune system and leaves you less able to fight infections. It's important to wash your hands regularly and stay away from anyone who has a cold or flu. Your nurses will tell you how to watch out for signs of infection – which include a high temperature, sore throat or just generally feeling unwell. They will tell you who to contact if you feel you have an infection.

Help at home

If you live alone or have problems getting around the house, talk to your nurse or the medical social worker on your ward as soon as you are admitted to the hospital. That way, they can organise community services you may need after you leave hospital.
For example, organising a public health nurse to visit and give you support at home with wound dressings. The medical social worker can also advise you about social welfare benefits or entitlements you can apply for. It's best to have this sorted out before your surgery.

Non-surgical treatments

Thermal ablation

Thermal ablation is a treatment that uses heat to destroy the cancer cells. It can be used if surgery isn't suitable or if the tumour is very small. There are 2 main types of thermal ablation:

- **Radiofrequency ablation (RFA)**
- **Microwave ablation (MWA)**

Both types of ablation use an electric current to destroy the cancer cells in the liver. A needle-type probe is guided into the tumour using an ultrasound scan or CT scan. This probe heats the tumour and destroys (ablates) it.

This procedure takes about 30 minutes and is usually done under general anaesthetic. You will probably be kept in hospital overnight.

You will have either a CT or MRI scan 8-12 weeks after the procedure to see how effective the thermal ablation was.

There are other types of ablation that are not used as often. These include:

- **Percutaneous ethanol injection** – ethanol is injected directly into the tumour to kill the cancer cells
- **Cryoablation** – uses extremely cold temperatures to destroy the cancer cells
- **Laser ablation** – uses a narrow, thin beam of light to destroy cancerous cells

Your doctor or nurse will explain these treatments to you in detail if they feel they are an option for you.

Embolisation

Embolisation involves blocking the hepatic artery blood supply to the tumour, killing the cancerous cells. Transarterial embolisation (TAE) and transarterial chemoembolisation (TACE) are both examples of embolisation techniques.

Transarterial embolisation (TAE)

TAE involves injecting the hepatic artery with tiny beads. This stops the cancer from growing by blocking off its blood supply.

Transarterial chemoembolisation (TACE)

TACE is very similar to TAE, except chemotherapy drugs are injected directly into the liver. The blood flow is also blocked (embolisation) so that the chemotherapy can stay longer in the liver and kill the cancer cells.

For both TAE and TACE you will need to fast (not eat) from the night before the procedure.

On the day of the procedure, you will have a drip for fluids and antibiotics to prevent infection.

The procedure will be done in the radiology department. The radiologist will put a fine tube through a cut (incision) made in your wrist or groin. With the help of an X-ray, they will guide the tube to your liver and the treatment will take place. You will be given some sedation and a local anaesthetic – it shouldn't hurt, but you may feel some discomfort. It usually takes about 1-2 hours. Usually you will stay in hospital overnight after this procedure.

You will have either a CT or MRI scan 8-12 weeks after the treatment to see how effective the treatment was.

Radiation therapy

Radiotherapy uses high-energy rays to destroy cancer cells. The aim of the treatment is to control the cancer in the liver and also if it has spread to other parts of the body. There are 2 main types of radiation therapy used for primary liver cancer: selective internal radiation therapy (SIRT) and stereotactic body radiation therapy (SBRT).

Selective internal radiation therapy (SIRT)

Selective internal radiation therapy (SIRT) is a type of internal radiotherapy. It is usually used to control cancer in the liver that cannot be removed by surgery. SIRT is sometimes called radioembolisation or transarterial radioembolisation (TARE). SIRT is completed in 2 parts:

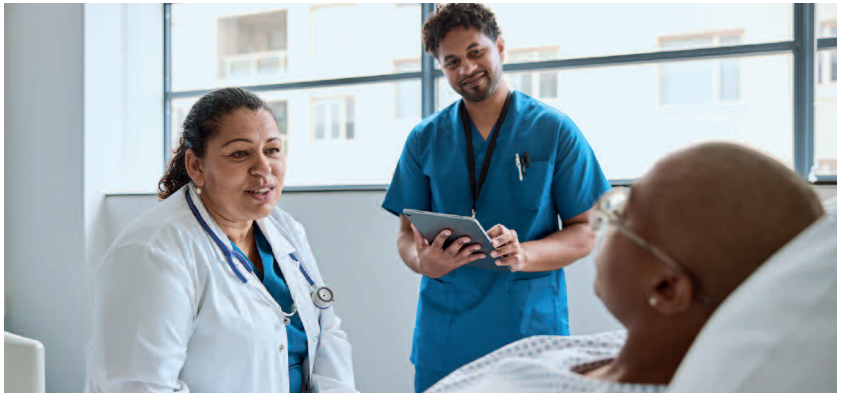
Part 1 – Planning angiogram

This gives your doctor more information about your liver and to see if you are suitable for internal radiotherapy. The angiogram is done by guiding a thin tube to your liver through a blood vessel in your wrist or groin. Dye is injected through this tube and a series of X-rays show how the dye is travelling along the blood supply to the liver. If the dye does not escape to any other part of your body, you are suitable for SIRT and will move on to part 2. However, if the dye does travel to other parts of the body, you may not be suitable for SIRT and you may need to have a new treatment plan.

Part 2 – SIRT

After 2-3 weeks, you will have SIRT. This involves another angiogram, but this time tiny radioactive beads (microspheres) will be injected into the liver, guided by the dye showing the blood supply to the tumour in the liver. These radioactive beads give off radiation and damage the cancer cells with little impact to the surrounding healthy liver tissue. The beads will continue to give off radiation over several weeks after treatment, until the radiation levels decrease.

Your team will tell you what steps you should take at home to keep yourself and others safe after radiation.



Stereotactic body radiation therapy (SBRT)

SBRT may also be referred to as stereotactic ablative radiotherapy (SABR). This involves the precise delivery of high-dose radiotherapy to liver cancer tumours, over a number of treatments. When you have SBRT you do not feel anything and it does not make you radioactive.

At your first appointment, the treatment will be explained to you and you will be asked to sign a consent form. You will have a planning CT scan and possibly also an MRI scan to plan your treatment accurately. During your planning scan, you will be asked to hold your breath if possible for short periods of time.

The team will also decide on the best position for you to be in to have your treatment accurately. You'll need to be able to stay comfortably in this position for up to an hour. Usually, patients lie on their back, with arms above their head, in a custom-made support. If you think you may have difficulty keeping your arms above your head, please discuss this with your radiation oncologist.

When you have treatment, the radiation therapist will help you get into the approved position. The treatment couch and the machine will be moved to direct the radiation at the cancer. Scans will be taken in the treatment room to check you're in the correct position and that the area for treatment matches your most recent treatment plan. The machine will rotate around you but it will never touch you.

It is important that you stay as still as possible throughout treatment. You will be in the room on your own once treatment starts, but the radiation therapist will be monitoring you the whole time and can talk to you on an intercom system.

You will need to attend for a course of treatments, usually 3–5 sessions, over 1–2 weeks. You may need to fast (not eat) for 2 hours before each treatment. The team will monitor you for side-effects throughout the treatment course and review you weekly during it.

It is very important you do not miss any treatment days as it may make your treatment less effective. If you feel you are unable to attend a session for any reason, please telephone your radiotherapy department to discuss this.

Side-effects of radiation therapy

Possible short-term side-effects when the liver is being treated are:

- Tiredness
- Loss of appetite
- Change in bowel habits
- Nausea or vomiting
- Skin reaction

These side-effects can affect 1 in every 5 people who are treated and usually settle within 6 to 8 weeks following treatment.

How severe these side-effects are will vary from person to person. Most side-effects develop during or shortly after your treatment and can usually be managed with simple medications. However, some side-effects are longer term. They are usually rare but may be permanent. Your radiation oncologist will go through all of the risks of treatment with you before you consent to treatment.

For more information on the side-effects of radiotherapy or a copy of our booklet ***Understanding radiotherapy***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also look at our website **www.cancer.ie** for tips on coping with side-effects.

Bridging therapy before liver transplant

The aim of bridging therapy is to keep the cancer under control while you wait for a new liver, to make sure that you stay within the strict criteria required to be suitable for a transplant.

The non-surgical treatments mentioned above – thermal ablation (RFA and MWA), embolisation (TACE and TAE) and radiation therapy (SIRT and SBRT) – can all be used as bridging therapy while a person with primary liver cancer is waiting for a liver transplant.

Treating cancer that has spread

If the cancer spreads to another part of your body, it is called metastatic cancer. The cancer may be in more than one part of your body when it is first diagnosed.

If the cancer has spread, it can still be treated. The aim of treatment is to try to control the cancer rather than to cure it. Systemic therapies are often used to keep metastatic liver cancer under control (see opposite page). Or you may have one of the treatments listed on pages 65–71.

There may also be treatments that you can have as part of a clinical trial (see page 79). Your doctor will tell you if there are any clinical trials that might be helpful for you.

You can also have treatment to help with any symptoms. You may be referred to the palliative care team, who are experienced in managing the symptoms of metastatic cancer. Palliative care makes sure you have the best quality of life. (See page 77 for more on palliative care.)

Systemic therapy

Your doctor may recommend you have immunotherapy drugs or targeted therapy drugs, such as tyrosine kinase inhibitors (TKIs) if:

- The cancer has spread.
- The cancer returns after surgery.
- You are not suitable for other treatments, for any reason. For example, if you have other health issues that make other treatments unsuitable.

Immunotherapy

Immunotherapy has become an important treatment option for advanced hepatocellular cancer (HCC). For example, immune checkpoint inhibitor drugs, which help the immune system to recognise and attack tumour cells. They do this by blocking proteins that stop the immune system from attacking the cancer cells.

Examples of checkpoint inhibitor drugs are atezolizumab and durvalumab. These are called PD-L1 inhibitors because they block a protein called PD-L1, which helps cancer cells 'hide' from the immune system. PD-L1 inhibitors can be used in combination with other drugs. For example:

- Atezolizumab given with bevacizumab, which targets the growth of new blood vessels that cancer cells need to survive and may improve immune response.
- Durvalumab given with tremelimumab (which blocks a protein called CTLA-4). Giving 2 checkpoint inhibitors together can produce a stronger anti-tumour immune response.

These treatments are delivered by infusion into a vein and are typically given in an oncology day ward or infusion unit. If you are having these treatments, you will need regular monitoring of your blood tests and vital signs.

Your medical oncologist will decide which drug or combination of drugs is best for you depending on your health history. These treatments can improve survival and produce good responses in some patients.

Liver function plays an important role in deciding if you are suitable for immunotherapy. You may need some additional tests to assess your level of liver disease before you can start immunotherapy drugs. You might have a camera test called an oesophagogastroduodenoscopy (OGD) to check if there are varices (small veins) in the food pipe and stomach before you have bevacizumab. If varices are present, they will need treatment before starting the medication due to a risk of bleeding. Your oncologist and hepatologist will discuss this with you.

If immunotherapy is a treatment option for you, your doctor and nurse will explain it to you in more detail and tell you about any likely side-effects. Always tell your doctor or nurse straight away if you don't feel well or if you are having any symptoms that are troubling you.

Targeted therapies

Targeted therapies are drugs that work by 'targeting' certain parts of cancer cells that make them different from other cells. In other words, they take advantage of differences between normal cells and cancer cells.

Different drugs work in different ways. For example, they can:

- Block or turn off chemical signals that tell cancer cells to divide and grow
- Change proteins in the cancer cells so the cells die
- Stop making new blood vessels that feed the cancer cells
- Help your immune system to fight cancer

Tyrosine kinase inhibitors (TKIs)

Tyrosine kinase inhibitors (TKIs) are medications used to treat metastatic hepatocellular cancer (HCC). TKIs help stop the growth of cancer cells by blocking the enzyme tyrosine kinase, which helps cells to grow and divide. TKIs are usually given as tablets. Lenvatinib (Lenvima) and sorafenib (Nexavar) are first-line TKIs used for liver cancer. If the first (first-line) treatment option doesn't work for you, your medical oncologist may recommend another option.
For example, regorafenib (Stivarga) and cabozantinib (Cabometyx).

The side-effects of TKIs may include skin rash, diarrhoea, fatigue and high blood pressure. These side-effects can usually be managed without having to stop treatment. You should report any side-effects to your treating team. This doesn't mean your treatment will be stopped, but they can help you with managing the side-effects.

New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a targeted therapy as part of a clinical trial (see page 79).

For more information on immunotherapy or targeted therapies or to ask for a copy of the booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Understanding your drug treatment

It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you. If you know the name of a drug prescribed for you, visit the Health Products Regulatory Authority's website at **www.hpra.ie** for more information about the drug and possible side-effects.

If you have any questions or need any more information, you can speak to our Cancer Nurses by calling our Support Line on 1800 200 700 or visiting a Daffodil Centre.

Email: supportline@irishcancer.ie

Palliative care

Depending on the stage of your illness and the severity of your symptoms, your doctor may discuss palliative care with you. The palliative care team are experts in managing the symptoms of advanced liver disease and metastatic cancer. These symptoms may include pain, breathlessness, nausea, fatigue, build-up of fluid in the abdomen (ascites) or brain fog (hepatic encephalopathy).

Palliative care also offers emotional support and comfort to patients and their families. Palliative care includes end-of-life care, but your doctor may also recommend palliative care earlier in your illness, to help to relieve symptoms and improve your quality of life.

The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors. Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with advanced cancer.

Palliative care can be given in a hospice or community hospital or in your own home. You may go to a hospice for a day or two to get treatment for your symptoms or you may stay at the hospice in the later stages of your illness.

For more information, including the booklet ***Palliative care – Asking the questions that matter to me***, visit the Palliative Hub at **www.adultpalliativehub.com** Talk to your doctor and nurse for more advice. If you do not feel well enough, your family can talk to them for you.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Patients with cancer are sometimes asked to consider taking part in a clinical trial. Clinical trials investigate new treatments and/or using existing treatments in different ways. For example, giving a different dose of a drug or using 2 treatments together.

If treatment is given as part of a clinical trial, you will be closely monitored and you may have extra tests and appointments.

Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial.

For more information, you can read our factsheet ***Cancer and clinical trials***. It's available to read or download on our website, **www.cancer.ie** You can also get a free copy by calling our Support Line on 1800 200 700 or by dropping into a Daffodil Centre. You can see a list of current cancer trials at **www.cancertrials.ie**

Managing side-effects and symptoms

How can my symptoms be relieved?

The most common symptoms of liver cancer are pain, jaundice, eating difficulties and fatigue. Other symptoms such as fluid that collects in your tummy area (ascites) and brain fog or confusion (hepatic encephalopathy) can also cause problems. Some symptoms can be helped by surgery, radiotherapy and targeted therapies. The palliative care team can also help with any symptoms that are causing you problems. See page 77 for more information on palliative care.

Pain

If you have pain, your doctor will try to find out what is causing it. For example, a blockage or pressure on the nerves. Surgery, radiotherapy or targeted therapies can all help to ease pain. There are also a lot of good painkillers (analgesia) available today. Your doctor will decide which painkiller is best suited to the type of pain you have.

If the medication does not help the pain, tell your doctor or nurse. They may need to try you on different painkillers to find one that suits you best.

Sometimes your cancer doctor will ask the palliative care team to help to manage your pain even while you are on treatment. (See page 77 for more on palliative care.)

Hints and tips: Pain

- **If you are in pain tell your doctor or nurse about it straight away.** Be honest about the level of pain that you are in. There is no need to suffer in silence or play down the amount of pain that you have.
- **Taking care of pain is important.** Make sure to take the painkillers as prescribed.
- **Some painkillers have side-effects, especially opioid-based ones.** These can include constipation, feeling sick (nausea) and drowsiness.
- **If you have constipation, it's a good idea to take a laxative every day.** Drinking plenty of fluids such as water and fruit juice between meals will also help keep your bowel habits regular. Your doctor or nurse will give you a different laxative if you have not pooed for 2 or 3 days.
- **Tell your doctor if you are if you are feeling sick (nausea).** They may give you anti-sickness tablets. Take them as instructed. This nausea often improves as you get used to your medication. Some painkillers can cause drowsiness, but this usually wears off after a few days. Do not drive or work machinery if you feel drowsy.

Jaundice

Jaundice is caused by a build-up of bilirubin in your blood. Bilirubin is a waste product that forms when old red blood cells break down. Jaundice causes the whites of your eyes and your skin to become yellow in colour (jaundice). Your skin can then become dry and itchy, your urine becomes dark in colour and your stools pale. You may feel sick, weak and tired, and have windy pains.

Jaundice can be a sign of liver failure. It could also be a sign of a blocked bile duct. The doctor will work out which is causing your jaundice. If it is due to a blockage, this can be helped by putting in a small tube (stent). See page 86 for more about stents. A special tube to drain the bile can also be put in through your skin if needed. The bile flows into a drainage bag outside your body that can be emptied each day. If your skin is very itchy, your doctor may prescribe antihistamines to relieve it.

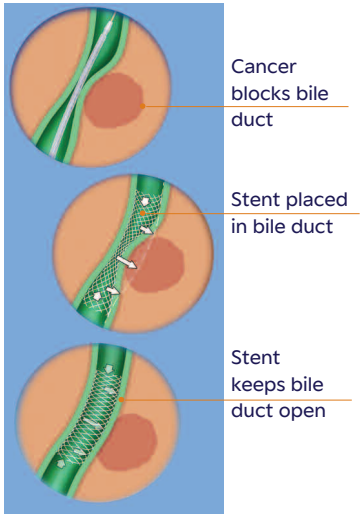
For more information on how to manage the itch, ask your doctor or nurse or call our Support Line on 1800 200 700.

Hints and tips: Itchy skin

- **Rub calamine lotion or splash cool water on the itchy areas** to help ease the itch.
- **Add a half cup of baking soda to a bath of warm water and soak in it.** Baking soda can help to soothe and soften your skin.
- **Use a mild soap when washing.**
- **Moisturise your skin using soothing lotions** such as cocoa butter.

Stents

If you have a blocked bile duct, this may cause yellow discolouration of the skin (jaundice) and you may have severe itching. In this case you might have a stent put into the bile duct. This is a small metal or plastic tube, which can hold the bile duct open. A stent can be inserted by ERCP (see opposite page) or by puncturing the skin and using X-rays to guide the stent into position (percutaneous transhepatic cholangiogram – PTC). Your doctors and nurses will tell you more about having a stent put in and any risks it may involve.



ERCP

ERCP stands for endoscopic retrograde cholangiopancreatography. The doctor passes a long thin tube called an endoscope through your mouth and down to your tummy. The tube has a light and camera on one end so your doctor can see the inside of your stomach and duodenum and can inject dye into the bile duct. These can then be seen on X-rays and will show up any signs of blockage that may be caused by the cancer. It may be possible to unblock the duct with a stent, allowing the bile to drain.

Ascites

Ascites is a build-up of fluid in the tummy area (abdomen) due to low protein levels. This fluid causes the abdomen to become swollen and bloated. This can cause pain or other symptoms as pressure increases in the area and on the organs in your tummy. You may feel breathless, have a poor appetite or have indigestion as a result.

Fluid can build up over a few weeks or more suddenly over a few days.

What you can do

Tell your doctor if you have symptoms of ascites. They can do tests to find out the cause – for example, an ultrasound scan, blood test or taking a sample of fluid from your tummy using a needle.

How is it treated?

Treatment of ascites includes being prescribed a water tablet (diuretic) and a low-salt diet. In some cases, the doctor can remove the fluid with a long, fine tube called a drain (large volume paracentesis or LVP). They will use a local anaesthetic to numb the skin before inserting the tube. The fluid will drain through the tube over a few hours or days, depending on the amount of fluid.

Confusion

Confusion can be caused by a build-up of toxic substances in the blood which the liver is no longer able to break down. This is called hepatic encephalopathy. It occurs mainly due to constipation, infection, bleeding or electrolyte imbalance/dehydration. It can develop quickly, causing disorientation and, in severe cases, coma.

If you notice symptoms of confusion at home, it is important to contact your team to let them know. Confusion usually resolves with treatment of the underlying problem. Your doctors may prescribe medicines as needed to control hepatic encephalopathy.

Loss of appetite

It is often hard to eat well due to cancer and the effects of treatment. But do try to eat as well as you can to keep your strength up. Eat smaller amounts more often. Getting some fresh air and exercise may help to boost your appetite.

Hints and tips: Poor appetite

- **Eat well when you can.** Take small meals and snacks about every 2–3 hours.
- **Have snacks that are high in calories and protein.**
- **Use a smaller plate for your meals.** Large portions can be off-putting if your appetite is small.
- **Eat slowly and chew your food well.**
- **Choose drinks that give some nutrition,** such as milk and yoghurt drinks.
- **Do not fill up on food and drinks that are not high in energy.** For example, tea, coffee, water, thin soups and diet drinks. These may stop you from having more nutritious foods.
- **Try nutritional supplements as recommended by your dietitian or doctor.** Special high-calorie drinks can help to keep your strength up too. Your dietitian will let you know if these are suitable for you. Your doctor can then give you a prescription for these drinks.
- **Take only small sips of fluid while eating,** as drinking might make you full.

Fatigue

It's common to feel exhausted when you have cancer. This extreme tiredness (fatigue) can be caused by many things, including:

- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well

Usually fatigue starts to improve once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you. Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count, a transfusion can make you feel better. If you are not eating well, a dietitian may be able to give you some advice to help.

Hints and tips: Fatigue

- **Ask your doctor about exercising.** Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you. You can ask our Cancer Nurses about free exercise classes. Call our Support Line or visit a Daffodil Centre to talk to a nurse.
- **Plan your days.** Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- **Ask for help at work or at home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor. Our booklet ***Understanding diet and cancer*** has tips to help.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling may help too (see page 108).
- **If you are not sleeping well, have a good bedtime routine and try relaxation techniques.** Avoid stimulants like caffeine and alcohol in the evening and try not to use electronic devices for an hour before bedtime.
- **Short naps (less than an hour) and rest periods can be helpful,** as long as they don't stop you from sleeping at night.
- **Try complementary therapies like meditation or acupuncture,** if your doctor says they're safe for you.

Our booklet ***Coping with fatigue*** has more advice. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy. It's also on our website **www.cancer.ie**

Will treatment affect my sex life?

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take quite a while. It can be hard to relax when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment and lose interest in sex as a result. Or you may be coming to terms with changes in your appearance after treatment.

There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. Touching and holding each other can help you to stay physically close.

There is no set time for you to be ready to have sex again. It varies from person to person.

You may find that talking about your feelings may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse.

Our Support Line 1800 200 700 and our Daffodil Centres can help you to find supportive information and accredited therapists if you would like to talk to someone. Therapy can help you and your partner deal with a change in your sexual relationship and find ways of being close again. You can also ask for a copy of our booklet, ***Understanding sex, sexuality and cancer,*** or download it from **www.cancer.ie**

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

Contraception

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment. Some anti-cancer cancer drugs may harm a developing baby, so it's important to avoid pregnancy during and for some time after treatment. Many specialists recommend that you wait for up to 2 years after treatment before trying to start a family or having more children. This time gives your body a chance to recover from the effects of the cancer and its treatment.

Ask your doctor for advice about contraception or if you are thinking about having children after treatment.

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor and nurse are well used to talking about these matters, so try not to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with our Cancer Nurses in confidence. Or email the nurses at supportline@irishcancer.ie

Support Line Freephone 1800 200 700

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. This may be temporary or permanent. It depends on the type and amount of treatment you have.

Discuss any worries you have about infertility with your doctor before treatment starts. They can tell you if there are any options open to you. For example, it may be possible to freeze your eggs or sperm before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this is an option for you.

Dealing with infertility can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener or with a professional counsellor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from our Cancer Nurses.

Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, mindfulness, reflexology and aromatherapy. Complementary therapies can't treat or cure cancer, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their cancer and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Tell them also if you're using or considering using over-the-counter or herbal medications. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

Integrative care

Integrative care means combining (integrating) your standard cancer treatment with complementary therapies to try to feel as well as possible and to cope better with your cancer.

What's the difference between complementary and alternative therapies?

Complementary therapies are used **together with** standard medical treatment.

Alternative therapies are used **instead of** standard medical care.

Modern medical treatments are very effective in treating cancer. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

More information

To find out more about complementary therapies, you can talk to one of our Cancer Nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet ***Understanding cancer and complementary therapies***, or download it from our website **www.cancer.ie**

After treatment

What follow-up will I need?

After your cancer treatment has ended you will still need regular check-ups. This is called follow-up. Your level of follow-up will depend on what type of treatment you have. All follow-up will involve regular visits to your consultant. At first you will see them quite often, sometimes every 3 to 6 months, especially for the first 2 years. The visits are likely to continue for the rest of your life. Your follow-up may involve having blood tests and scans, such as MRI or CT scans.

The purpose of follow-up is to:

- Help with any side-effects that you may have
- Check for signs of new side-effects that may develop after you have finished treatment
- Check for signs of the cancer coming back (recurrence)

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope. It can help to write down what you want to say before you see the doctor, so you don't forget anything.

Liver transplant follow-up

If you had a liver transplant, your recovery will be closely monitored. You will have tests to make sure your body is not rejecting the new liver. See 'After a liver transplant' on page 62.

It is important to go to all your follow-up appointments. If you're between check-ups and have a symptom or problem that's worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment, if necessary. Go to your GP or the hospital emergency department if you're unwell and you can't contact the hospital team.

What if the cancer comes back?

If cancer does come back, it can often be treated again. Your cancer doctor will advise you on your treatment options.

Life after treatment

It can take some time to adjust to life after cancer diagnosis and treatment. It isn't unusual to feel quite low and lost after your treatment has ended, especially during the first few months. Feelings you may have include:

- Fear of cancer coming back, worrying about every small symptom
- Loneliness without the company of fellow patients and fewer visits to your medical team at the hospital
- Stress at having to deal with things that may have been on hold during your treatment, such as your finances, going back to work and family issues
- Isolation or guilt if your family and friends expect you to get back to normal before you are ready
- Anxiety and self-doubt about sexual and romantic relationships
- Anger at what has happened and the effect on you and your loved ones
- Depression or sadness

For more about how to cope with these feelings go to **www.cancer.ie**

You can also call our Support Line or visit a Daffodil Centre to talk to a Cancer Nurse in confidence. See page 109 for other ways to get emotional support.

After-treatment workshops

You might like to join our **Life and Cancer – Enhancing Survivorship (LACES)** programme when you have completed treatment or have started maintenance therapy. This workshop covers topics such as diet, exercise, wellbeing, finance and self-management and gives information on support and services to help you. Call our Support Line or visit a Daffodil Centre for details or ask your specialist nurse or doctor to refer you to a LACES workshop.

Living a healthy lifestyle

Having a healthy lifestyle is important as it can help you to:

- Feel better
- Heal and recover faster
- Cope better with any side-effects
- Keep up your energy and strength
- Reduce your risk of further illness

A healthy lifestyle includes:

- Exercising
- Eating well
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun

It's also important to have any vaccines recommended for you. For example, flu and pneumonia. Some vaccinations may not be suitable if you've had cancer treatment, so check with your doctor which you should have and make sure you get them.

If you want more information or advice, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also go to our website **www.cancer.ie** for tips and publications on healthy living.

Planning ahead

Many people find it puts their mind at rest to have medical plans in place and sort out legal and practical matters, even though they still hope to live for a long time. Planning ahead is useful for everyone, whether they have an illness or not.

Planning ahead might include:

- Thinking about how you feel about different types of medical treatment, including if you want to stop treatment at any stage or carry on for as long as possible.
- Writing an advance care directive. This is where you can write down your wishes about your medical care. Doctors can use this if you are not well enough to say what you want.
- Picking someone to make medical decisions for you if you are not well enough
- Making a will
- Talking about what you want to your family, friends, carers and healthcare providers
- Sorting financial affairs

Who can help me plan?

Think Ahead is a planning booklet with easy-to-read forms to fill in to record your personal, medical, financial and legal information and preferences. It's available from the Irish Hospice Foundation at **www.hospicefoundation.ie**

Coping and emotions

How can I cope with my feelings?

Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer.

You may find it hard to come to terms with your diagnosis. You may blame yourself, resent other people who are healthy or feel very anxious or depressed.

Emotions like sadness, fear, grief, hopelessness and anger can happen at different times, sometimes months or years after treatment.

> A cancer diagnosis can be hard on you – mentally and emotionally. Give yourself time and space to deal with your emotions and get help if you need it.

A helpful booklet that discusses in detail how you may be feeling is called ***Understanding the emotional effects of cancer***. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy.

Anxiety and depression

If you feel that anxiety or low moods are getting the better of you, or if you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family.

Your doctor may also suggest medication to help with anxiety or depression. Often a short course of medication can work well. Professional counselling can also be very helpful.

It's not a sign of failure to ask for help or to feel unable to cope on your own.

Counselling

If you're feeling distressed or finding it hard to cope, a trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them.

Counselling can also give you emotional support, help you to make decisions and learn ways to cope better. The Irish Cancer Society funds professional one-to-one counselling, remotely and through some local cancer support centres. To find out more about counselling, call our Support Line on Freephone 1800 200 700, visit a Daffodil Centre or email the nurses at supportline@irishcancer.ie

> "Talking about cancer made it feel less awful and helped ease my fears. I learned to cope and understand myself better."

Ways to get emotional support

Find out about cancer support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 134 for more about cancer support services.

Join a support or educational group: You might find it reassuring to talk to other people who are in a similar situation and facing similar challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services if they are available at your hospital.

Get online support: Special websites called online communities let you write questions, share stories, and give and receive advice and support.

Talk things through: It can be a great weight off your mind to share your feelings and worries. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to one of our cancer nurses.

Seek spiritual support: For some people, spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life.

If you need more information or help with finding support, call our Support Line on 1800 200 700 or drop into a Daffodil Centre.

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. To be referred to a Peer Support volunteer, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Positive feelings

In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships. Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

> "I am very happy and content... even though I have to live with this."

You and your family

Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet ***Understanding the emotional effects of cancer*** can help you to find ways to talk about your cancer and to ask for the help and support you need.

Further information and support

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our Cancer Nurses. Call us on 1800 200 700 or visit a Daffodil Centre.

Changing relationships

You may feel that people are treating you differently. Some people may withdraw and not contact you as much because they are afraid of doing or saying the wrong thing. Others may not understand that you feel too unwell to go out. Try to talk openly to your friends and family if there are any misunderstandings or problems. Tell them how you feel. If you find it hard, ask another family member or friend to talk to them.

Talking to children and teenagers

Saying nothing

If you have children, you may feel it's best not to tell them anything. You may be worried about what to say or how they will react. But children and teenagers can often sense that there is a problem. If no one explains to them why things have changed, they may imagine something worse or blame themselves. By talking openly you can answer their questions and help them to cope with their emotions.

How to tell your children

It's best that you or your partner tell your children about your cancer diagnosis. How you discuss your cancer and treatment with them will depend on their age and character. A useful booklet called ***Talking to children about cancer: a guide for parents*** gives practical advice for talking to children about cancer, with specific advice for different age groups. It also has information on supporting children and teenagers and helping them to deal with their emotions.

Our Cancer Nurses can also support you if you have children and aren't sure what to say to them.

Supporting someone with cancer

Supporting someone with cancer

Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support the person with cancer, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

Here are some things that can help to make life a little easier:

Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one's illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Visit our website **www.cancer.ie** or call our Support Line for free copies of our cancer information booklets.

Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a Cancer Nurse in confidence.

Be kind to yourself

Your health and happiness matter too. Make some time for yourself, stay in touch with your friends and don't be afraid to let other people help out with the caring.

Try counselling

You might find it helpful to talk to a counsellor. The Irish Cancer Society funds one-to-one counselling for friends and family members, remotely and through many local cancer support centres. Talk to your GP or see page 108.

Find out about support for carers

Find out about groups and organisations especially for carers of people with cancer. Many local cancer support centres have services for carers too.

How to talk to someone with cancer

When someone close to you has cancer, it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of saying the wrong thing. Often what people with cancer want most is someone to listen to them.

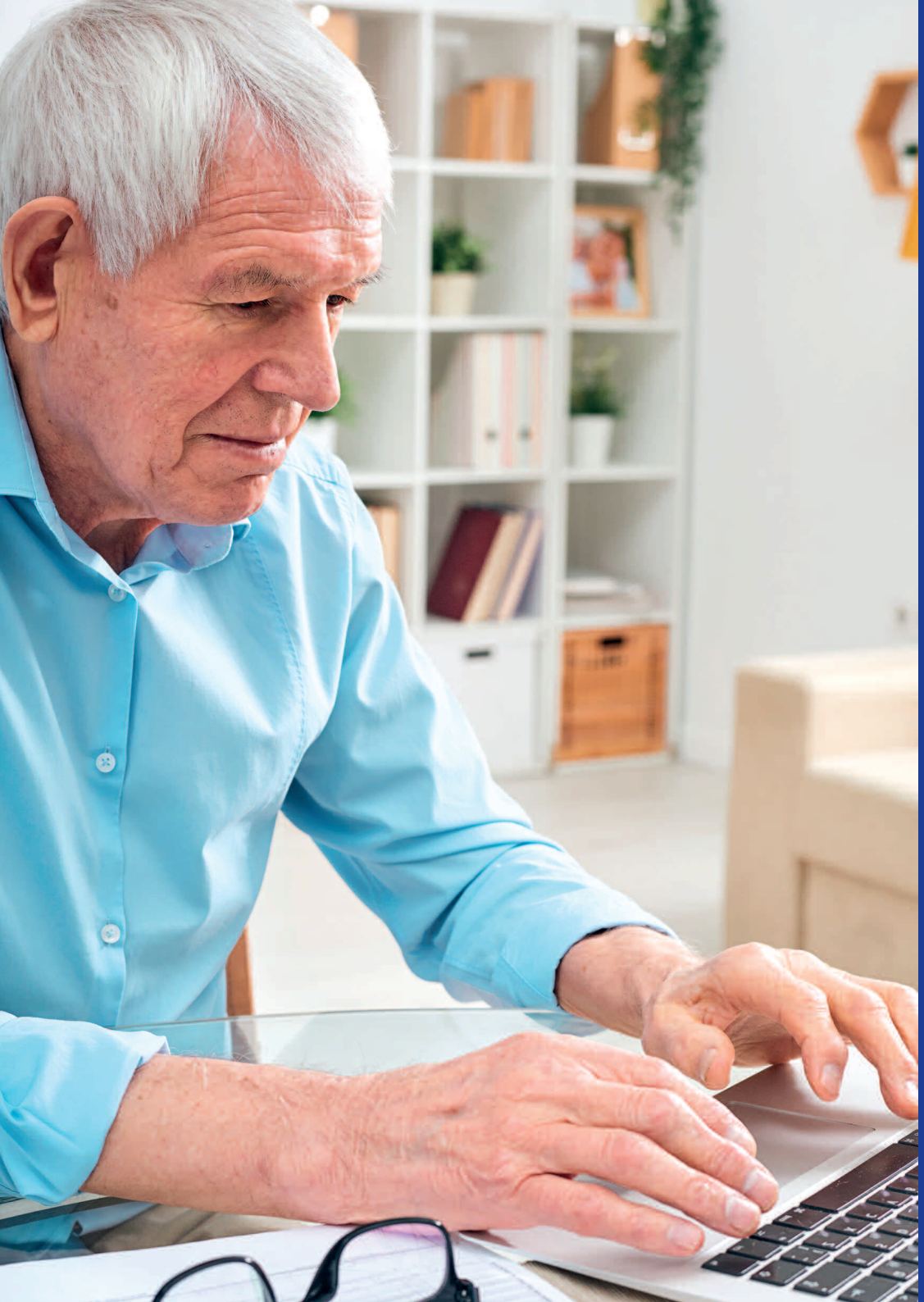
If you want advice on how to support a friend or loved one with cancer, call our Support Line on 1800 200 700. Ask for a copy of our booklet ***Caring for someone with cancer***. The booklet gives advice on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can also pick up a copy of the booklet at any Daffodil Centre or download it at **www.cancer.ie**

Support for you

Our Cancer Nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information. Our booklet, ***Caring for someone with cancer***, has lots of information on:

- **Getting organised**
- **Managing and giving medications**
- **Giving personal care**
- **Practical and money matters**
- **Relationships with other people**
- **Looking after yourself**
- **Life after caring**

Free copies are available from our Daffodil Centres and our Support Line, or download it from our website **www.cancer.ie**



Support resources

Money matters

- If you have cancer, you may not be able to work for a time. You may also have extra expenses.
- You may have to pay for some of your cancer treatment.
- You might be entitled to certain social welfare payments.
- There are services to help you if you're finding it hard to manage.

A diagnosis of cancer often means that you will have extra expenses, such as medication, travel, heating and childcare costs.

If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with your illness if you are worried about money.

Our Welfare and Supports Service

Cancer can create additional challenges. Our Welfare and Supports team can help. We can advise on benefits, social welfare entitlements, public services, medical card applications, community support, legal entitlements, housing and mortgages, childcare or talking to your workplace about your diagnosis.

For more information or to be referred to our Welfare and Supports Service, visit **www.cancer.ie/welfare-and-supports**, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Medical aids and equipment (appliances), like wigs and incontinence products

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. If you are over 70, you can get a free GP visit card.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

If you don't have a medical card, you will have to pay some of the cost of your care and medication.

If you have health insurance, the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It's important to contact your insurance company before starting treatment to check you're covered.

Benefits and allowances

There are benefits that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit and Carer's Leave.

If you want more information on benefits and allowances, contact:

- **The medical social worker** in the hospital you are attending
- **Citizens Information** – Tel: 0818 074 000
- **Department of Social Protection** – Tel: 0818 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to keep a copy of completed forms, so take a photo or photocopy them before posting them.

If you have money problems

If you are in debt or worried about getting into debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline on 0818 072 000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 131 for more details of our Transport Service and the Travel2Care fund.

You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

Money and finances

Go to **www.cancer.ie** and see our **Welfare and support** page for information on:

- Medical costs and help available
- Benefits and allowances that you or your family may qualify for
- Travel services
- Ways to cope with the cost of cancer

Our website has lots of information on government supports for people who are unwell and their carers. Our Welfare and Supports Service may also be able to help (see page 122).

Irish Cancer Society services

We provide a range of cancer support services for people with cancer, at home and in hospital, including:

- **Support Line**
- **Daffodil Centres**
- **Telephone Interpreting Service**
- **Patient Education**
- **Peer Support**
- **Eating well information sessions**
- **Exercise information and support**
- **Counselling**
- **Transport Service**
- **Welfare and Supports Service** (see page 122)
- **Publications and online information**
- **Night Nursing**

Support Line Freephone 1800 200 700

Our Cancer Nurses offer confidential advice, support and information for anyone affected by cancer. Our Support Line is open Mon to Fri 9am – 5pm. Email us on supportline@irishcancer.ie

The Support Line also offers video calls. From the comfort of your own home, you can meet a Cancer Nurse virtually. To avail of this service, offered on the Microsoft Teams platform, visit **www.cancer.ie/Support-Line-Video-Calls** One of our nursing team will email you with the time for your video call and instructions on how to access Microsoft Teams on your phone, tablet or computer.

Daffodil Centres

Our Daffodil Centres, located in 13 hospitals nationwide, are staffed by Cancer Nurses and trained volunteers who provide face-to-face advice, support and information for anyone affected by cancer. This service is free and confidential. This is a walk-in service; you do not need an appointment.

To see your nearest Daffodil Centre, contact details and opening hours visit **www.cancer.ie/daffodil-centres**

What information is available?

Our Cancer Nurses provide free and easy-to-understand information on:

- Screening, cancer prevention and early detection
- Cancer types
- Tests and investigations used to diagnose cancer
- Cancer treatments and side-effects
- Local cancer support services
- Life after cancer treatment
- Financial and practical supports
- End-of-life services

Our Cancer Nurses can also give you more information or refer you to any of our supports and services.

Telephone Interpreting Service

We make every effort to ensure that you can speak to our Cancer Nurses in your own language through our Telephone Interpreting Service. To use the service:

- Tell us in English the language you would like.
- You will be put on hold while we connect with an interpreter. You may be on hold for a few minutes. Don't worry, we will come back to you.
- We will connect you to an interpreter.
- The interpreter will help you to speak to us in your own language.

For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit **www.cancer.ie/our-services**

Patient Education

We offer free group sessions (online and in person) and video resources that provide information to guide you through and beyond cancer treatment.

Chemotherapy Education is for cancer patients who are due to have chemotherapy. The aim of the session is to guide the patient through the treatment from beginning to end: what chemotherapy is, how it is given, managing side-effects and available supports.

Our after-treatment education workshop is called **Life and Cancer – Enhancing Survivorship (LACES).** It was developed in partnership with the National Cancer Control Programme. LACES aims to improve the quality of patients' lives after active treatment has ended.

Patient education sessions are led by our Cancer Nurses. Sessions take place online or in person in our 13 Daffodil Centres nationwide.

We also have pre-treatment video resources that you can watch in your own time. For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre, visit **www.cancer.ie/our-services** or email patienteducation@irishcancer.ie

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. If you have a cancer diagnosis, you can be connected with a Peer Support volunteer who has had a similar cancer experience. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

More information on Peer Support is available at **www.cancer.ie/our-services** To be connected to a Peer Support volunteer, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Eating well information sessions

We provide group online information sessions with an Oncology Dietitian on the important role nutrition has for people with cancer. Using evidence-based specialist advice, we can support you to eat well during cancer treatments and beyond.

For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit **www.cancer.ie/our-services**

Exercise information and support

Exercise before, during and after treatment can improve quality of life. We provide information and support on how you can make exercise part of your everyday life. We also offer free exercise classes to help people with cancer to improve fatigue, quality of life, reduce anxiety and build strength and fitness in a fun and supportive environment.

For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit **www.cancer.ie/our-services**

Counselling

We fund professional one-to-one counselling for anyone affected by cancer – the person diagnosed with cancer, family members and close friends. Counselling sessions are available remotely (over the telephone/online) or in person in certain cancer support centres around the country.

For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit **www.cancer.ie/our-services**

Transport Service

We provide transport and limited financial grants for patients in need who are in cancer treatment.

Transport is available to patients having chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments. We have recently opened a pilot service for patients having radiotherapy treatment at University Hospital Cork and Bons Secours Hospital, Cork.

Travel2Care is a fund for patients who are having difficulty getting to and from their appointments for diagnostic tests or cancer treatment. Patients can apply for this fund if they travel over 50 kilometres one way to a national designated cancer centre or satellite centre. Travel2Care is made available by the National Cancer Control Programme (NCCP).

To access this support, please contact your hospital healthcare professional. For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit **www.cancer.ie/our-services**

Publications and online information

We provide information on a range of topics, including early detection of cancer, cancer types, treatments, side-effects and coping with cancer. Visit our website **www.cancer.ie** to see our full range of information and download copies. You can also call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre for free copies of any of our publications.

Night Nursing

We provide end-of-life care for cancer patients in their own homes. We offer up to 10 nights of care free of charge for each patient. Our service supports patients to remain at home for the last days of their lives, surrounded by their families and loved ones. This is a unique service in Ireland, providing night-time palliative nursing care to cancer patients, mostly between 11pm and 7am.

To access this service please contact the healthcare professional looking after your loved one. For more information visit **www.cancer.ie/our-services**

> We were really lost when we brought Mammy home from the hospital and the night nurse's support was invaluable. She provided such practical and emotional support.

> Our night nurse was so caring and yet totally professional. We are so grateful to her for being there for Dad and for us.

To find out more about the Irish Cancer Society's services and programmes:

Visit us at www.cancer.ie

Speak with one of our Cancer Nurses:

- **Call our Support Line on Freephone 1800 200 700**
- **Visit one of our 13 Daffodil Centres in hospitals nationwide**

Email the nurses at supportline@irishcancer.ie

Follow us on:

- **Facebook @IrishCancerSociety**
- **X @IrishCancerSoc**
- **Instagram @irishcancersociety**
- **LinkedIn @irish-cancer-society**

Local cancer support centres

Local cancer support centres have a range of services for cancer patients, their partners, families and carers, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds one-to-one counselling through many local support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists or cancer nurses
- **Special exercise programmes**
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting, and lymphoedema services, such as education, exercise, self-management and manual lymph drainage
- **Mind and body sessions,** for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

Visit **www.hse.ie** to find a cancer support centre in your area or visit **www.cancer.ie** and search '**local cancer support centres**'.
Our Cancer Nurses can also help you to find support and services. Call our Support Line or visit a Daffodil Centre to talk to a nurse.

Email: supportline@irishcancer.ie

What does that word mean?

Ablation: The complete or partial removal of cancer cells.

Anti-emetic: A tablet, injection or suppository to stop you feeling sick or vomiting.

Ascites ("ah-site-ease"): The name for a build-up of fluid in the abdomen due to liver disease or cancer.

Benign: Not cancer. A tumour that does not spread.

Biopsy: Removing a small amount of tissue to find out if cancer cells are present.

Cells: The building blocks that make up your body. They are tiny and can only be seen under a microscope.

Cholangiocarcinoma: A rare cancer that forms in the bile ducts.

Excision: Removal by surgery.

Hepatic encephalopathy: The name for confusion (brain fog) from a build-up of toxins in the bloodstream.

Hepatobiliary: To do with the liver, bile ducts, and/or gall bladder.

Jaundice: A yellow appearance to the skin.

Liver function test: Blood tests that check how well the liver is working.

Medical oncologist: A doctor who specialises in treating cancer patients using chemotherapy and other drugs.

Metastasis: The spread of cancer from one part of your body to other tissues and organs.

Oncology: The study of cancer.

Palliative care team: A team of doctors and nurses who are trained in managing pain and other symptoms caused by cancer. They can also help you cope with any emotional distress.

Prognosis: The expected outcome of a disease.

Pruritis: The medical term for itchy skin.

Staging: Tests that measure the size and extent of cancer.

Variceal bleeding: Bleeding caused by a build-up of pressure in the blood vessels along the digestive tract.

Notes/Questions

Notes/Questions

Acknowledgments

This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave their time and expertise to contribute to previous editions of this booklet.

LIVER CANCER ADVISERS

Michèle Bourke, Hepatocellular Carcinoma (HCC) Advanced Nurse Practitioner
Prof Emir Hoti, Liver Transplant and HPB Surgeon
Dr Fergus Keane, Medical Oncologist
Dr Maeve Keys, Radiation Oncologist

CONTRIBUTOR

Laura Dennehy, Daffodil Centre Nurse

EDITOR

Sarah Lane

The following sources were used in the publication of this booklet:

- *Cancer Nursing: Principles and Practice,* CH Yarbro, MH Frogge, M Goodman & SL Groenwald. Jones and Bartlett, 7th Ed (2011).
- *The Chemotherapy Source Book,* M Perry. Lippincott Williams and Wilkins, 5th Ed (2012).
- *National Cancer Strategy 2017-2026,* National Cancer Control Programme
- *National Cancer Registry Ireland (2024) Cancer in Ireland 1994-2022:* Annual statistical report of the National Cancer Registry. NCRI, Cork, Ireland.

Published in Ireland by the Irish Cancer Society.

Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team! Visit **www.cancer.ie** if you want to get involved.

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Peer Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Did you like this booklet?

We would love to hear your comments or suggestions.
Please email reviewers@irishcancer.ie

Irish Cancer Society

Our cancer nurses are here for you:

- Support Line Freephone **1800 200 700**
- Email **supportline@irishcancer.ie**
- Contact your nearest Daffodil Centre

Irish Cancer Society

www.cancer.ie