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)

Surgical oncologist

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 33

The kind of 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 and 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.

Targeted therapies: Drugs that target cancer cells in different ways to stop or slow down their growth.

Palliative care: This treatment will focus on controlling symptoms rather than curing the cancer.

Will I be OK? Page 31

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 49

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 65

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you. You can also see a list of current cancer trials at **www.cancertrials.ie**

We're here for you Page 106

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 into a Daffodil Centre.
  Email **daffodilcentreinfo@irishcancer.ie** to find your local Daffodil Centre.
- Email us: supportline@irishcancer.ie

See page 106 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.

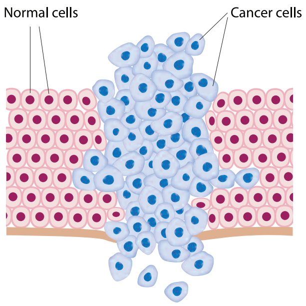
Email: supportline@irishcancer.ie

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).

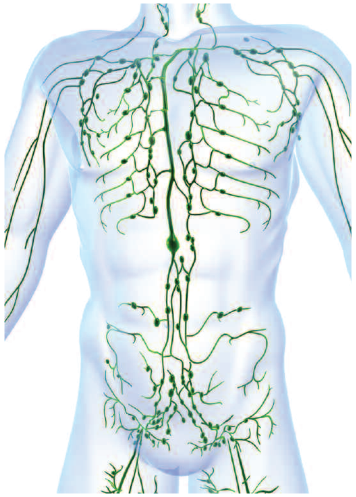
- **Cancers are named after the organ or cell where the cancer starts**
  Liver cancer starts in cells in the liver.



- **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.

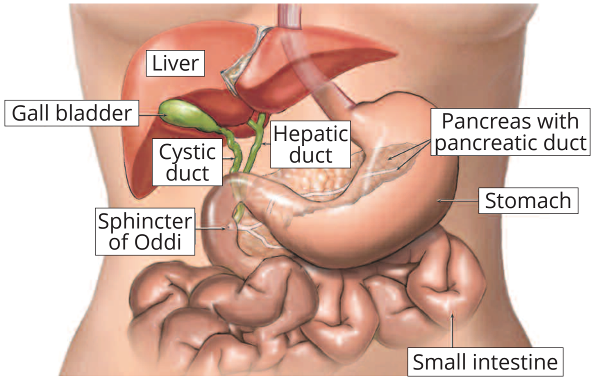
What is the lymphatic system?

- 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 cancer starts in the lymph nodes they can become swollen.



What is the liver?

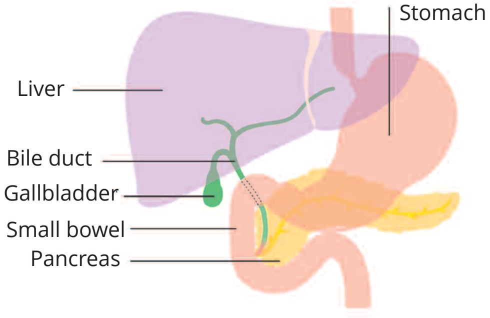
The liver is the largest solid organ inside the body. It has two lobes: a right and left lobe. It is found on the upper right side of the abdomen, under your rib cage.



What does the liver do?

The liver is a very important organ and 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. The 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 on our website, **www.cancer.ie** about bile duct cancer.
- **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.

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

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.

How common is liver cancer?

About 370 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

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 all the information they need – and plan the next steps in your care accordingly.

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).
- **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 as it makes it easier for the nurse or doctor to find a vein. If you are told to fast, you may only drink water.
- **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 medication. 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 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**
- **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

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

Note

If you have to cancel your appointment...

If you are unable to attend your appointment, contact the hospital in advance and they will try to arrange a new appointment for you. If you don't go to your appointment or contact the hospital, you may have to return to your GP and go back on the waiting list for a new appointment.

Diagnosis and further tests

Being diagnosed with liver cancer

Hearing that you have liver 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 (oncology) liaison nurse 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 cancer diagnosis and really knows what you are going through. Our cancer nurses can put you in touch with a volunteer.
- **Talk to other people affected by cancer.** Join our online community at **www.cancer.ie/community**
- **Go to your local cancer support centre.** For more information, see page 112.

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 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 claustrophobic inside the tunnel. Tell the radiation therapist if you're feeling anxious.

An MRI can also be noisy, but you will be given earplugs / headphones to help block out the sound. You might get an injection before the scan to show up certain parts of your body. It is important that you keep as still as possible during the scan.

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.

Usually you can go home soon after the scan.

PET CT scan

A PET 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 pregnant women during this time.

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

Liver biopsy

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

However, 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, you may need to have a liver biopsy.

Sometimes a biopsy is needed if you are taking part in a clinical trial.

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 stage 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 is well and 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 your liver is working, in people who have liver cirrhosis. This system considers your blood test results, if 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.

Staging can be hard to understand, and no two patients are the same. These staging systems are used to help your medical team decide on the most appropriate treatment options to discuss with you. 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:

- **Get the information 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 even 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 again after you have thought about everything.
- **Get emotional support if you need it.** 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.

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 the cancer, as well as the level of liver function.

Liver cancer can be treated using surgical and non-surgical treatments. A team of specialist healthcare professionals (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 two main types of surgery:

- Removal of part of the liver – liver resection
- Removal of the whole liver and replacement with a healthy donor liver – liver transplant

See page 51 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.

Thermal ablation

This treatment uses heat to destroy the cancer cells. There are two 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 57 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 58.

Selective internal radiation therapy (SIRT)

This 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. See page 59.

Drug therapy

Targeted therapies and immunotherapy

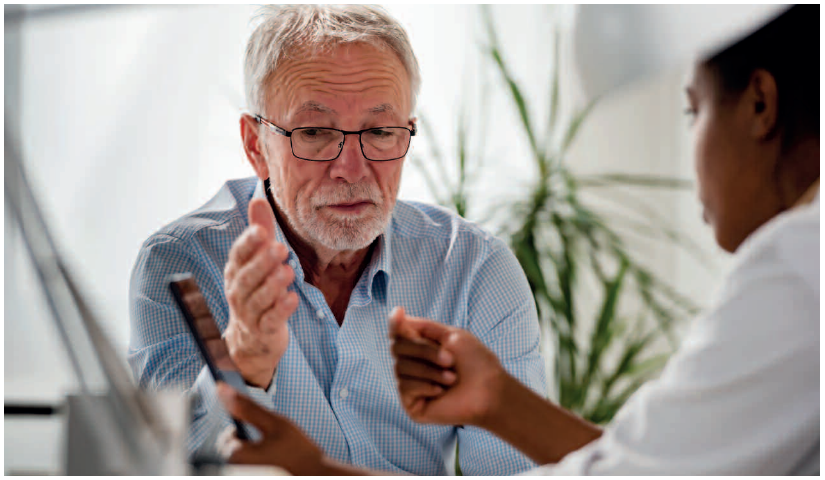
Targeted therapies and immunotherapy can help your body to fight cancer, slow its growth or control side-effects from other cancer treatments. Targeted therapies called tyrosine kinase inhibitors (TKIs) are sometimes used to treat metastatic primary liver cancer. These can help stop the growth of cancer cells.

See treating metastatic (secondary) cancer on page 62 for more on targeted therapies and immunotherapy.

Palliative care

Sometimes treatment for the cancer may be too much for the liver to take. If you have metastatic cancer, or the cancer is advanced, you may be offered palliative treatment to manage symptoms and improve your quality of life. See page 64.

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 main centre in Ireland for treating primary liver cancer and is the only centre that can offer all of 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 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. It is always best to bring a friend or family member along to your consultation. You could write down any questions you have in advance, so you don't forget anything. 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 always 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 treating doctor or your GP can refer you to another specialist for a second opinion if you feel this would be helpful. Getting a second opinion will not affect the care you will receive.

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 (multidisciplinary team) 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 cancer patients using chemotherapy and other drugs.

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 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.

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

Medical social worker A person trained to help you and your family with all your social issues and practical needs. They can give counselling and emotional support. They can also give advice on social welfare benefits, financial matters and practical supports and services available to you from the time of your diagnosis, right through to returning to work.

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.

Pharmacists – in hospital and in your local pharmacy – dispense chemotherapy and other cancer drugs. 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.

Palliative care team This team is specially trained in managing pain and other symptoms. They can also 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.

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

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

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

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

Community health services These include family doctors, public health nurses (who can visit you at home), 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. 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.

You might like to focus on your health and wellbeing while you're waiting for treatment to start. For example, eating well and staying active.

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 can help you feel better. It can also 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 the 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. You can also read our booklet ***Diet and cancer***. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it on our website **www.cancer.ie**

Stay active

If you are able, it can really help to keep 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

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. Be careful not to overdo it at the beginning; it's best to build up gradually.

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 can 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, such as chest infections.
- Smoking can reduce how well some treatments work.
- Quitting can help you to heal better after surgery.
- Quitting reduces your chances of further illness.

If you would like advice or support on quitting, go to www.quit.ie, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. Some hospitals have smoking cessation officers who can help and support you – you can ask your doctor or nurse for a referral to this service.

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. If it makes you anxious, you could ask a friend to do the research for you, and tell you anything important. Make sure you get your information from trustworthy sources such as 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

Therapies 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. Get help if you are finding it hard to cope.

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 two main types of surgery for early liver cancer are:

Surgical resection/lobectomy: Removal of part of the liver; lobectomy is where a lobe is removed

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

Surgical resection/lobectomy

Surgical resection/lobectomy 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.

This surgery is not suitable for everyone, and 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 it spread into the blood vessels?
- Is your liver fairly healthy with little or no cirrhosis? That way the liver can grow back and start working as it did before

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

Alternatively, you may have keyhole (laparoscopic) surgery, where the surgeon makes a series of small cuts. 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, patients may also have an ablation treatment during their surgery (see page 57).

Liver surgery is a major operation and 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 there is the possibility that the cancer may come back despite the operation.

It is important to remember that if the HCC has developed in a liver with cirrhosis, 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 many things to consider:

- Are you well enough for surgery?
- Do you have cirrhosis and how severe is it?
- What is your background liver disease and the 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 in the time 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. It is important that you have a support person to help you during the liver transplant process.

During the assessment phase, you will have a series of tests and investigations.

Tests include: blood tests, chest X-ray, pulmonary (lung) function tests, heart tests – electrocardiograph (ECG) and ECHO – ultrasound scan, CT scan, 24-hour urine collection, dental X-ray.

You will meet some of the members of the MDT team including nursing staff, surgeons, hepatologist, anaesthetist, transplant coordinator, dentist, medical social worker, pharmacist, dietitian, psychiatrist and physiotherapist. (See page 40 for more on who will be involved in your care.)

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 it is decided that a liver transplant is the best treatment option for you, an appointment will be arranged for you to 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 which 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 treatment (bridging treatment) to ensure the cancer stays stable and you keep within the criteria for a transplant. These treatments include thermal ablation (see page 57) or TACE (see page 58). 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 ensure you are healing and recovering well. You will start taking immunosuppressant medications to help 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.

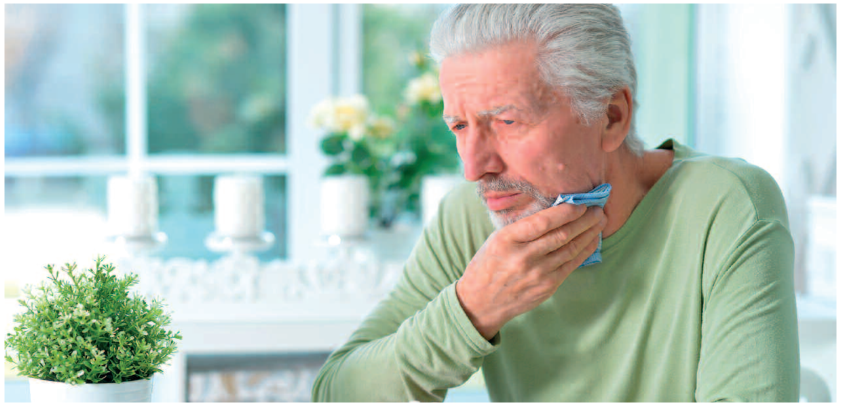
After discharge, you will have regular appointments in the outpatient clinics to ensure you continue to recover well. Once you go home, it will take some time for life to return to normal, but the transplant team will be on hand to support you and answer any questions you may have.

You will need painkillers for a few weeks after your surgery and it may take some months before you start to really recovery. 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 using 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**
- **Microwave ablation**

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 not used so 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.

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, the tube will be guided to your liver and the treatment will take place. You will be given some sedation and a local anaesthetic – it shouldn't hurt. It usually takes about 1-2 hours. It is normal to 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 TACE was.

Radiation therapy

Radiotherapy uses high-energy rays to destroy cancer cells. It is not often used as a treatment for primary liver cancer. You are most likely to have it to control the cancer if it has spread to other parts of the body. The main type of radiation therapy used for this is called selective internal radiation therapy (SIRT).

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. First, you will have a planning angiogram (part 1) to give 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.

Then dye is injected through this tube and a series of X-rays show that the dye is travelling along the blood supply to the liver. If there is no escape of the dye to any other part of your body, you are suitable for SIRT and will progress to part 2.

After 1-2 weeks, you will have SIRT (part 2). This involves another angiogram, but this time tiny radioactive beads 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 as little impact as possible on the surrounding healthy liver tissue. The beads will continue to emit radiation over several weeks after treatment, until the radiation levels decrease. Your team will discuss radiation precautions to take at home.

If, after part 1 of this process, your team finds you are not suitable for SIRT – they will discuss alternative treatment options with you.

Side-effects of radiation therapy

The most common side-effects when the liver is being treated are:

- Diarrhoea
- Tiredness
- Nausea and vomiting
- Loss of appetite
- Temperature
- Pain
- Skin sores or irritations

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.

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.

Treating cancer that has spread

If the cancer spreads to another part of your body, it is called metastatic, secondary or advanced 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. Treatment is usually to try to control the cancer rather than to cure it. Targeted therapies are often used to keep metastatic liver cancer under control (see page 62).

Or you may have one of the treatments listed on pages 57-60.

There may also be treatments that you can have as part of a clinical trial (see page 65). 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 64 for more on palliative care.)

Drug therapy

Your doctor may recommend targeted therapy or immunotherapy drugs for you:

- If the cancer has spread
- If the cancer returns after surgery

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 to feed the cancer cells
- Help your immune system to fight cancer

Sorafenib (Nexavar) and lenvatinib (Lenvima) are medications known as tyrosine kinase inhibitors (TKIs). These are sometimes 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.

The side-effects of sorafenib and lenvatinib may include skin rash, diarrhoea, fatigue and high blood pressure. These side-effects can usually be managed without having to stop treatment.

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 65).

Immunotherapy

Immunotherapy drugs are occasionally prescribed for advanced or metastatic liver cancer. These help the body’s natural defences or immune system to fight cancer cells. Our immune system can often be the most effective weapon to clear cancer cells from our body, but sometimes cancer cells find a way of hiding from the immune system. This allows a tumour to develop or spread. Immunotherapy treatment helps your immune system to work better to destroy cancer cells.

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.

For more information on targeted therapies or immunotherapy, 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 Product 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.

Thanks to recent advances in research and treatments, many people are living longer with metastatic cancer and with a better quality of life.

Palliative care

Depending on the stage of your illness and the severity of your symptoms the 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. You don't need medical insurance.

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 do so.

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. This means that instead of the standard treatment you may get a new trial drug. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using two treatments together.

Because the drugs are still in trial, you'll be very closely monitored for unexpected side-effects and 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 64 for more information on palliative care.

Pain

Your doctor will try to find out what is causing your pain. 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 64 for more on palliative care.)

What you can do

- 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 the 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 your bowels have not opened 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. This causes the whites of your eyes and your skin to become yellow in colour (jaundice). Your skin then can 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 72 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.

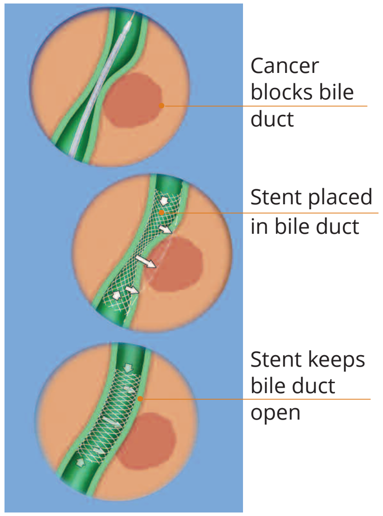
If your skin is very itchy, your doctor may prescribe antihistamines to relieve it.

Hints & 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.

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

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 be inserted by ERCP (see below) or under X-ray guidance by direct puncture of the skin (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. It 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 which 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. Confusion usually resolves with treatment of the underlying problem. Your doctors will prescribe medicines as needed to control hepatic encephalopathy.

Loss of appetite

It is often hard to eat well due to the cancer and 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 & Tips – poor appetite

- **Eat well when you can.** Take small meals and snacks about every 2–3 hours.
- **Take snacks 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.
- **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 taking 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 you.

Tips and hints — 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.
- **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 ***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 (see page 90) may help too.
- **If you are not sleeping well, try to 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, acupuncture or massage, 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 drop into 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 as well 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.

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.

You may find that talking about your feelings eases 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.

There is no set time for you to be ready to have sex again. It varies from person to person. But you may find it will be some weeks before you will feel well enough to have sex again after surgery.

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

Contraception

It is best to use a reliable method of contraception if you are being treated with drug therapy. It is not yet fully known how some treatments might affect a developing baby. You can talk to your doctor or nurse for advice about contraception or if you have any questions about your particular treatment.

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse specialist. 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 a cancer nurse in confidence. Or email the nurses at supportline@irishcancer.ie

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments for cancer and you may not be able to have a child in the future. 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.

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, massage, counselling 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 illness and the side-effects of treatment.

It’s very important to talk to your doctor if you’re thinking of using complementary therapies. 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 at curing cancer and keeping it under control. 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 indefinitely. 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 55.

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 treatment. It's normal 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** and worrying about every small symptom
- **Loneliness** without the company and support of your medical team and fellow patients
- **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**

There is more about how to cope with these feelings and adjusting to life after cancer on our website **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 91 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 finished treatment. 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.

Living a healthy lifestyle

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

- Feel better
- Heal and recover faster
- Keep up your energy and strength
- Reduce your risk of further illness

A healthy lifestyle includes:

- Exercising
- Eating well
- Trying to stay at a healthy weight
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun
- Getting any vaccinations recommended for you

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 pack with different sections and easy-to-read forms. You can fill in 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.

Feelings like sadness, fear, grief, hopelessness, anxiety 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 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.

Counselling

If you're feeling very 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.

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

The Irish Cancer Society funds one-to-one counselling through many local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email our nurses at supportline@irishcancer.ie. A list of counsellors funded by the Irish Cancer Society is available at **www.cancer.ie**.

> 'Counselling has helped me with every part of my life. I feel I have a future now.'

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, and can also give you practical advice and support. See page 112 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 healthcare team 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. Visit www.cancer.ie/community to join the Irish Cancer Society online community.

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 the Irish Cancer Society's one-to-one support programme. You can be put in contact with a trained volunteer who has dealt with a cancer diagnosis. Volunteers give support, practical information and reassurance. Call 1800 200 700 for more information or visit a 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.'

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

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 eemotional 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. The nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet ***Talking to children about cancer***, which has practical advice about how to talk to children of different ages.

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.

Advice for carers

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 them, 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. Free one-to-one counselling is available to friends and family members at many cancer support centres. Talk to your GP or see page 90.

Find out about support for carers

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

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:

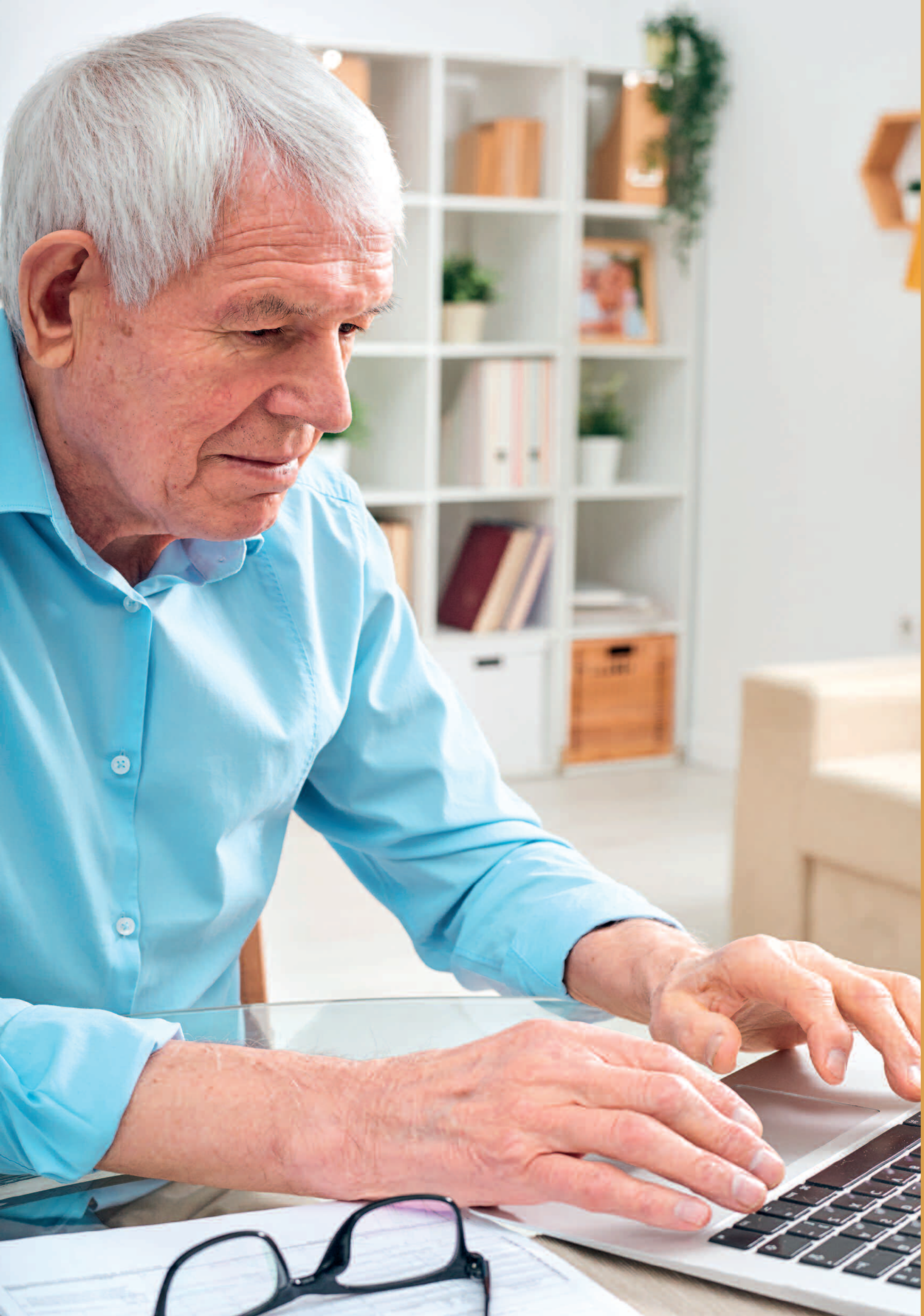
- Getting organised
- Managing and giving medications
- Giving personal care
- Practical and money matters
- Relationships with other people
- Looking after yourself
- Life after caring

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

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.

The booklet ***Caring for someone with cancer*** has a section on how to talk to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can pick up a copy at your local Daffodil Centre.



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, like car parking during hospital visits, 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 cancer if you are worried about money.

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

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, 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 Employment Affairs and Social Protection (DSP)** – 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 photocopy completed forms before posting them.

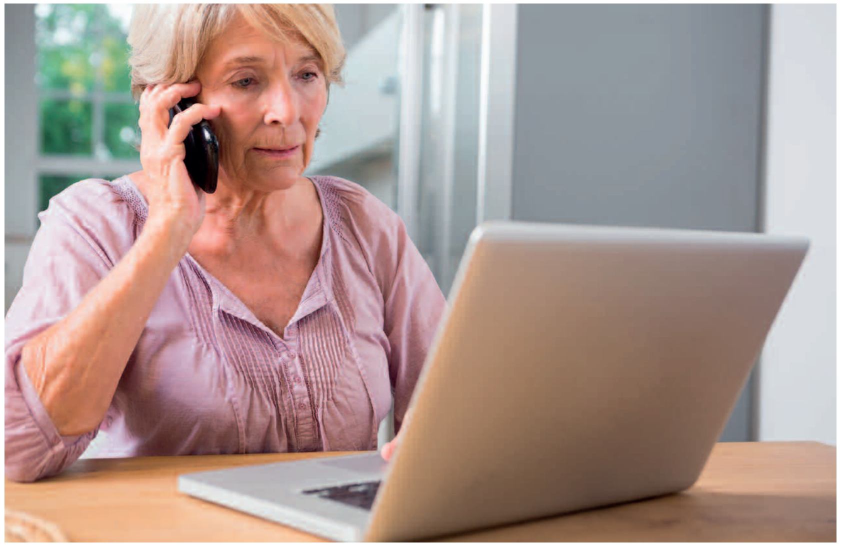
If you have money problems

If you are getting into debt or you are in 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 0818 07 2000 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 109 for more details of our Volunteer Driver Service and the Travel2Care fund.

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



More information

Go to **www.cancer.ie** and see our **Managing money** 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 Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.

Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- Support Line
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support services
- Night nursing
- Publications and website information

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information. The Support Line is open Monday–Friday, 9am to 5pm. You can email us at any time on **supportline@irishcancer.ie** or visit our Online Community at **www.cancer.ie**

For the deaf community, our Support Line is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie

Email: supportline@irishcancer.ie

Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide free confidential advice, support and information to anyone concerned about or affected by cancer.

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Chemotherapy group education sessions
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- End-of-life services
- Lifestyle and cancer prevention
- Local cancer support groups and centres

You can email daffodilcentreinfo@irishcancer.ie or visit **www.cancer.ie** to find your local Daffodil Centre.

Peer Support

Speak to someone who has been through a diagnosis similar to yours. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

Support in your area

We work with cancer support groups and centres and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them. The Society funds professional one-to-one counselling (including telephone and video-call counselling) and group survivorship programmes in communities across the country.

For information about what's available near you, call our Support Line on 1800 200 700 or go to **www.cancer.ie** and search 'Find support'.

Patient travel and financial support services

We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:

- **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are travelling for cancer tests or treatment to one of the national designated cancer centres or their approved satellite centres. Patients must be travelling over 50km one way to access the fund.
- **Irish Cancer Society Volunteer Driver Service** is for patients undergoing chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.

To access either of these services please contact your hospital healthcare professional.

Irish Cancer Society Night Nursing

We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows 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 palliative nursing care at night between 11pm and 7am to cancer patients.

The health professional who is looking after your loved one can request a night nurse for you, so talk to your palliative care team member, GP or public health nurse about this.

Publications and website information

We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website **www.cancer.ie** or call our Support Line for free copies of our publications.

If you would like more information on any of our services, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of one-to-one counselling through many local cancer support centres)

- **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 and reflexology
- **Specialist services** such as prosthesis or wig fitting 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.

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to **www.cancer.ie** and search 'Find support'.

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 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.

Fatigue Ongoing tiredness often not helped by rest.

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 gallbladder.

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.

Radiation oncologist A doctor who specialises in treating cancer patients using radiotherapy.

Staging Tests that measure the size and extent of cancer.

Targeted therapies Drugs or other substances that block the growth and spread of cancer by interfering with specific molecules involved in tumour growth.

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

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?

Your own questions / notes

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.

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

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Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team!

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

Contact our Support Line on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

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

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