Irish Cancer Society

Understanding

# Cancer of the pancreas

Caring for people with cancer

Understanding

# Cancer of the pancreas

This booklet has information on:

- Treatment for pancreatic cancer
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

## Useful numbers

Specialist nurse

Family doctor (GP)

Surgeon

Medical oncologist

Radiation oncologist

Psycho-oncology team

Dietitian

Medical social worker

Emergency

Medical records number (MRN)

# Contents

# Fast facts

## What kind of treatment might I have? Page 39

Pancreatic cancer is mainly treated with surgery, chemotherapy and radiotherapy, depending on the stage of the cancer.

## Will I have surgery? Page 57

Surgery is the main treatment for early-stage pancreatic cancer. Most patients will also have chemotherapy before and/or after surgery to improve their chance of cure. When the cancer cannot be removed, endoscopic or X-ray-guided procedures are most often used to relieve symptoms, such as jaundice or vomiting. Your doctor will discuss all the options with you.

## Are there side-effects from treatment? Page 55

Most treatments cause some side-effects, but these usually get better after treatment has ended.

Read about the different treatments to learn more about their side-effects.

There are treatments to help with most side-effects, so tell your doctor or nurse. Don't suffer in silence.

## Will I be OK? Page 34

What is likely to happen to you (your prognosis) is hard to predict. The best thing to do is to ask your consultant about your situation.

## Clinical trials Page 84

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.

## We're here for you Page 131

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

### Ways to get in touch

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

See page 131 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.

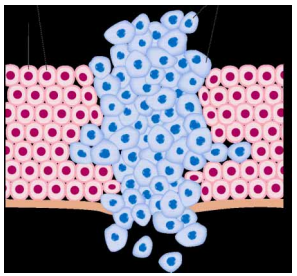
You should always talk to your own medical team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.



# About pancreatic cancer

## What is cancer?

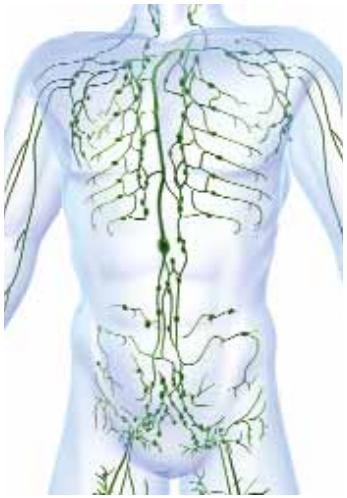
- **Cancer is a disease of the body's cells.** Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).
- **Cancers are named after the organ or cell where the cancer starts.** Pancreatic cancer starts in cells in the pancreas.




- **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 (secondary) tumour. This is called metastasis.

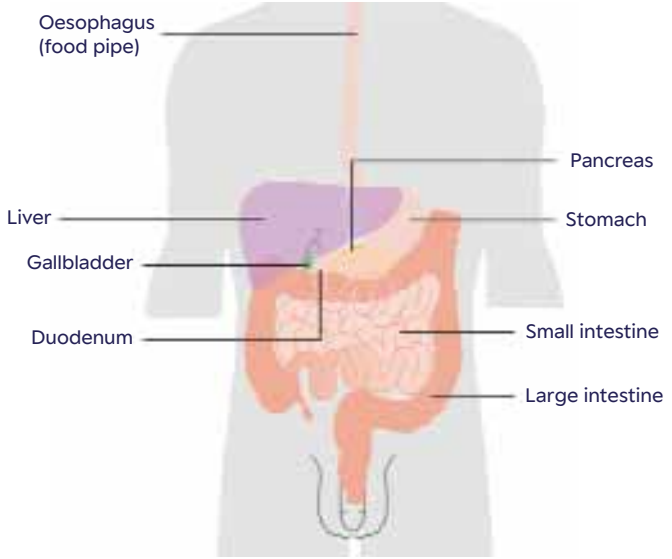
## What is the lymphatic system?

- The lymphatic system is part of our immune system, which 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, chest, armpit, groin and tummy.
- If cancer cells spread into lymph nodes or if cancer starts in the lymph nodes, they can become swollen.



## What is the pancreas?

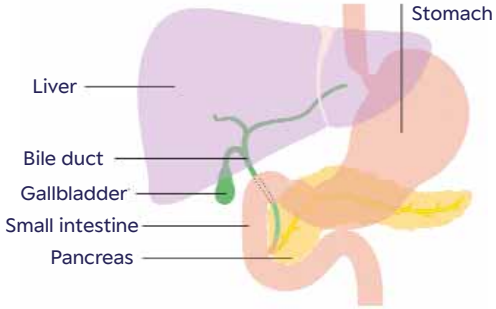
The pancreas is a gland that is part of your digestive system. It is about 15 cm (6 inches) long and lies deep inside your tummy (abdomen), behind your stomach and in front of your spine.




Pictures courtesy of Cancer Research UK/Wikimedia Commons

It has 3 main parts: the head, the body and the tail. The head is the broad rounded part of your pancreas. It is connected to the first part of the small intestine (duodenum). The body of the pancreas lies in the middle and the tail is the thin end below your left ribcage.

The pancreas is surrounded by important structures and blood vessels. The pancreas makes digestive juices (enzymes) and hormones (insulin and glucagon).






Digestive juices are chemicals that help to break down food so it can be absorbed into the lymph system and bloodstream. Once food reaches the small intestine (duodenum), the digestive juices flow through the pancreatic duct (tube). Then they mix with the food to break it down into very small parts. Another tube called the bile duct also joins the duodenum at the same place as the pancreatic duct. The bile duct drains bile, which is another type of digestive juice, from the liver and gallbladder.

Insulin and glucagon are hormones that are released into the blood from the pancreas. They control blood sugar and have opposite effects. Insulin lowers blood sugar. If the pancreas is unable to make enough insulin, this causes diabetes. Glucagon increases blood sugar if your blood sugar levels are low.

## What is pancreatic cancer?

Most pancreatic cancers start in the cells that line the ducts in the pancreas. These cancer cells may cause very few symptoms in the beginning. But as they grow they may cause discomfort or pain in your tummy area. Cells may break away from the pancreas and spread to lymph nodes, to nearby tissues or other parts of your body. It is common for the bile duct to be blocked due to cancer cells. This causes bile to back up into the bloodstream and cause jaundice (yellowing of skin and eyes). See page 89 for more about jaundice.

## What causes cancer?

We don't know exactly what causes many cancers but there are things that can increase your risk of getting cancer. If you want to know more about why cancer happens or to learn about risk factors for pancreatic cancer, see our website **www.cancer.ie** or talk to one of our Cancer Nurses – call our Support Line or visit a Daffodil Centre.

## Family history and inherited conditions

Your family may be at increased risk of pancreatic cancer if there is a family history of the disease or of certain other medical conditions including:

- Hereditary pancreatitis
- An altered BRCA2 (or possibly BRCA1) gene
- Bowel conditions such as familial adenomatous polyposis (FAP), Lynch Syndrome (hereditary nonpolyposis colorectal cancer – HNPCC) and Peutz-Jeghers syndrome
- Mole skin conditions like familial atypical multiple mole melanoma (FAMMM) syndrome

If a family member is concerned about their risk, they should talk to their doctor, who can advise them if they might benefit from monitoring or screening.



# What are the types of pancreatic cancer?

The most common type of pancreatic cancer is adenocarcinoma. Adenocarcinoma starts in the glandular and ductal tissue in the pancreas that makes and drains pancreatic juice. Adenocarcinomas can occur anywhere in the pancreas. About 9 in 10 people diagnosed with pancreatic cancer will have adenocarcinoma. The information in this booklet mainly deals with pancreatic adenocarcinoma.

Some less common types of pancreatic cancer or tumour are:

- Neuroendocrine tumours (NETs), some of which make hormones
- Cystic tumours – these may be benign (not cancer), pre-malignant (at risk of becoming cancer) or malignant (cancer)
- Lymphoma of the pancreas (affects the lymphatic tissue in the pancreas)

Around 1 in 4 pancreatic surgeries are performed for less aggressive or pre-malignant conditions, such as NETs and cystic tumours.

Lymphoma of the pancreas is treated with chemotherapy rather than surgery.

Your doctor will discuss the treatment that is right for you.

For more information about the rarer types of pancreatic cancer, call our Support Line on 1800 200 700 or visit a Daffodil Centre. If you have a pancreatic NET, ask for a copy of our booklet, ***Understanding neuroendocrine tumours (NETs)***.

# How common is pancreatic cancer?

About 600 people – mostly over the age of 60 – are diagnosed with pancreatic cancer in Ireland each year.

Email: supportline@irishcancer.ie

# Preparing for your hospital appointments

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

## Before your appointment

- Write down a list of questions and things you would like to discuss.
- Know where you are going and plan your journey (build in extra time for unexpected delays, such as parking).
- Dress in warm comfortable clothes and shoes – sometimes you can be waiting around for a while. Layers are best, as the temperatures in hospitals can vary a lot. Loose-fitting clothing will be easier to manage if you are having your blood pressure taken, blood tests or a physical examination.
- Try to drink clear fluids (water or juice without pulp) if you are having a blood test and you aren't fasting. This can make it easier for the nurse or doctor to find a vein.
- Check with the hospital if it is OK 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 may be happy for you to record the meeting, but make sure you ask for their permission first)
- 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 any medical supplies you may need that day, in case you are delayed
- A light snack and drink if you are likely to have to wait for some time. (Make sure you are not meant to be fasting – check with the hospital beforehand if you are not sure)
- Your phone and your phone number
- Contact details of the person to call in an emergency
- Your glasses and hearing aid, if you use them
- A book or something to listen to (including headphones) to pass the time while you wait



## Before leaving the appointment

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

## After the appointment

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

### It's important to go to your appointments

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

## Questions to ask your doctor

Here is a list of questions that you may want to ask. Try not to be shy about asking questions. It is always better to ask than to worry.

What tests do I need?

How long will it take to get the test results?

What type of pancreatic cancer do I have?

What stage is my cancer at? Has it spread beyond my pancreas?

What treatment will I need?

Will surgery be successful for my cancer? Can the cancer be removed?

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

Will I be transferred to a centre that specialises in treating pancreatic cancer?

What is my prognosis?



# Diagnosis and tests

# Being diagnosed with pancreatic cancer

Hearing that you have pancreatic 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

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

- Ask to speak to the cancer (oncology) liaison nurse, the medical social worker or the psycho-oncology team at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to one of our Cancer Nurses in confidence – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- Speak to an Irish Cancer Society Peer Support volunteer who has had a similar cancer experience and is fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. Our Cancer Nurses can put you in touch with a volunteer.
- Go to your local cancer support centre. For more information, see page 140.

However you feel, you are not alone.

## Telling people about your diagnosis

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

If you would like to talk things over with one of our Cancer Nurses, 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.



# What tests will I have?

- Tests you may have include an ultrasound, CT scan and MRI scan.
- Staging helps your doctor to decide on the best treatment for you.
- Your prognosis is what your doctor expects to happen with your cancer.

You might need more tests after you have been diagnosed with pancreatic cancer.

The tests give doctors more information about your cancer. Some tests may also be used to see how well you are responding to treatment.

## Blood tests

Blood tests can help to check your general health. They will be done regularly during your treatment. Blood tests can also check the level of substances called tumour markers or biomarkers. For example, CA19-9 and CEA. Sometimes people with pancreatic cancer have higher-than-normal levels of these biomarkers in their blood, but this isn't always the case. Checking biomarker levels may help doctors to see how well you are responding to treatment.

## Ultrasound

This is a scan that uses sound waves to look at your liver, pancreas and bile duct. The scan is painless and only takes a few minutes. Some gel is first put on your tummy area and then a small hand-held device is passed over the area being scanned.

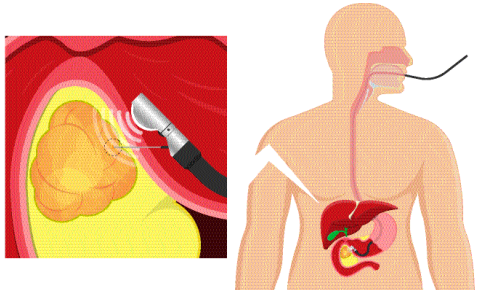
## CT scan (CAT scan)

This is a special type of X-ray that gives a detailed 3D picture of the tissues inside your body. It is the most important test in the diagnosis of pancreatic cancer. It is also important when planning surgery.

For a CT scan of your abdomen (tummy area), you may be asked to fast (not eat) 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 that 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.

## Endoscopic ultrasound (EUS)

An EUS is often used in the diagnosis of pancreatic cancers. This test uses an endoscope, which is a thin tube that the doctor passes down your throat. It has an ultrasound tip. This gives very detailed close-up pictures of the pancreas. A biopsy needle can be passed through the scope so that a sample of the tumour can be taken. This can confirm the diagnosis of cancer.



An EUS and biopsy may be done to complete the staging of your cancer. This test is usually done as a day case, so you won't have to stay overnight in hospital. Before the test, you may be given sedation into a vein (through a drip) to help you relax.



## MRI scan

This is a scan that uses magnetic energy and radio waves to create a picture of the tissues inside your body. MRI scans are sometimes used to clarify any irregularity seen on a CT scan.

You will need to complete a form before the test to ensure that it is safe for you to have an MRI scan. If you have any medical device in your body, like a pacemaker or metal pin, you should let your doctor know, as you may not be suitable for the test. You cannot wear metal jewellery or hairclips during the scan. You might get an injection before the scan to show up certain parts of your body.

During the test you will lie inside a tunnel-like machine for around 40-60 minutes. The length of time depends on the number of images that are needed and the area of the body being scanned.

Some people are afraid they will feel anxious or claustrophobic inside the tunnel. Tell the radiographer if you're feeling anxious.

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

Usually you can go home soon after the scan.

## MRCP scan

MRCP stands for magnetic resonance cholangiopancreatography. It is an MRI scan that shows up the pancreatic duct, bile duct and gallbladder in more detail. It is often helpful in planning the treatment of jaundice that has been caused by a tumour. It takes about 20 minutes.

## PET scan

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

Before the scan, you may have to fast (not eat) and drink only plain unflavoured water for a few hours. You may also be asked to avoid strenuous exercise the day before and the morning of the scan.

During the scan, you will lie on a table that moves through a scanning ring. The scan usually lasts between 20 and 60 minutes. You will be asked to stay still during the scan.

You may have to travel to a specialist centre to have a PET scan, as not every hospital has these scanners.

You will be slightly radioactive after the PET scan, so you should not have close contact with pregnant women, babies or young children for a few hours after the scan.

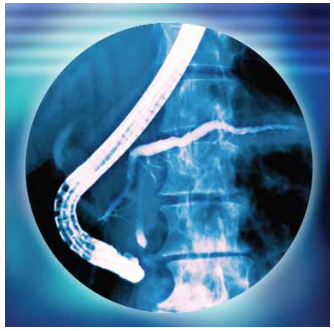
Drink plenty of fluids and empty your bladder regularly after the scan. This can help flush the radiotracer from your body.

PET scans are not routinely used in pancreatic cancer but are sometimes useful in staging the disease.

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



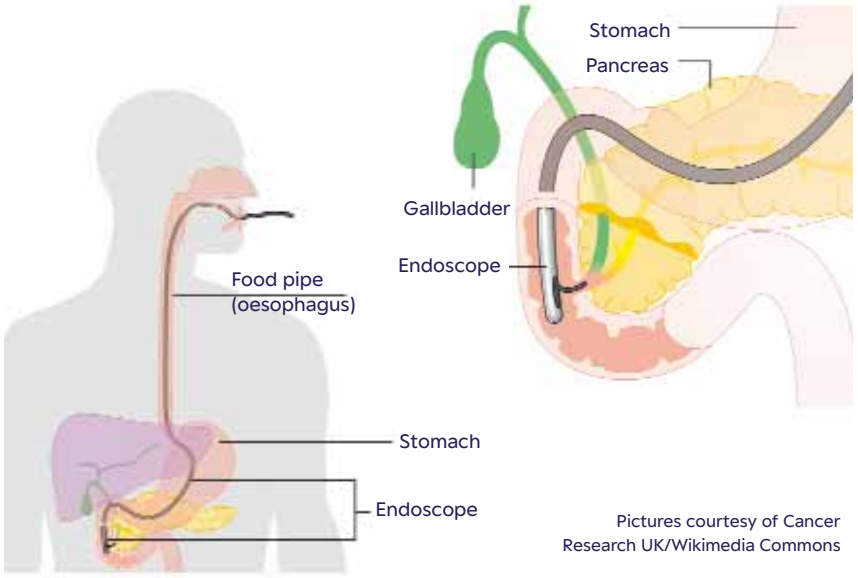
## ERCP



ERCP stands for endoscopic retrograde cholangiopancreatography. Before the ERCP, you will be asked to fast (not eat) for a number of hours. You will then be given sedation to help relax you. An endoscope will be passed through your mouth and down into your stomach. 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. The dye can then be seen on X-rays and will show up any signs of blockage, which may be due to cancer.

Your doctor may also be able to take samples of the cancer (biopsy). These can then be examined in a laboratory.

If the cancer is blocking your bile duct, it may be possible to unblock the duct at this time with a stent. See page 62 for more about stents. An ERCP may be done at the same time as an EUS (see page 26).



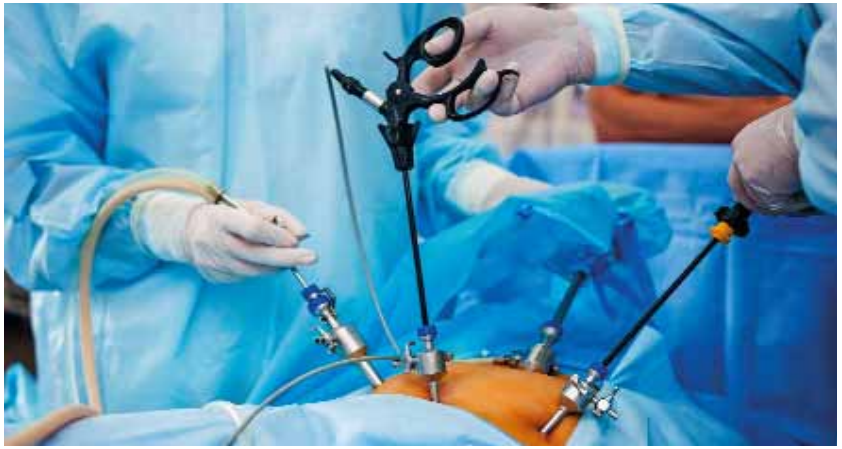

Pictures courtesy of Cancer Research UK/Wikimedia Commons

## Biopsy

A biopsy means removing a small piece of tissue so that it can be examined under a microscope. There are many ways to take a biopsy. Your doctor will consider the best way for you. It may be done during an EUS or ERCP, a laparoscopy or by putting a needle through the skin in your tummy area, guided by an ultrasound or CT scan. A biopsy is not always possible before surgery.

## Laparoscopy

Laparoscopy is sometimes used to diagnose or stage pancreatic cancer. Your doctor will discuss with you whether a laparoscopy will be useful in your case. This test allows your doctor to look inside your abdomen (tummy area). Laparoscopy is done under general anaesthetic, so you will be asleep for the procedure. Just before the test you may be given a sedative. This will help you feel more relaxed before going into the operating theatre. While you are asleep, your doctor will make 1-3 small cuts in your abdomen to place a laparoscope inside. This is a thin, flexible tube with a camera on the tip.



By looking through the laparoscope, your surgeon can see some of your pancreas and nearby organs. A small ultrasound probe can also be put inside your tummy.



During the laparoscopy, your doctor may take a biopsy (tissue sample). This is to confirm a diagnosis of pancreatic cancer.

The result of the laparoscopy will help your doctor to decide what kind of surgery is possible.

During the procedure, carbon dioxide gas is passed into your abdomen. This can cause uncomfortable wind or shoulder pain for 3 or 4 days. Walking about or taking sips of peppermint water often eases the pain. You will have 2-3 stitches at the wound site. In general, these stitches do not need to be removed as they usually dissolve once the wound heals.

# 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 one of our Cancer Nurses.

# How is pancreatic cancer staged?

- Staging cancer means finding out its size and if it has spread.
- For pancreatic cancer, an important part of staging is working out how close the tumour is to the major blood vessels near the pancreas.
- Staging helps your doctor to decide the best treatment for you.
- The stage of your cancer will help your doctors to decide if surgery to remove the cancer is possible.

The tests you have after diagnosis help the doctor to stage your cancer. Staging means finding out the size of the cancer and if it has spread to other parts of your body. Staging is very important, as it helps your doctor to plan the best treatment for you. Sometimes it may only be possible to find out the stage during surgery.

There are different ways to describe the stages of cancer. When speaking to you, your doctor will give your cancer a number stage – from 1 to 4. A higher number, such as stage 4, means the cancer has spread to other parts of the body.

Staging can be hard to understand, so ask your doctor and nurse for more information if you need it.

## What are the stages of pancreatic cancer?

### Stage 1

This means the cancer is at an early stage. The tumour is approximately 2cm in size or less and found within the pancreas. There is no sign that it is in the lymph nodes or that it has spread outside the pancreas.



### Stage 2

The tumour is more than 2cm in size. The cancer is now found outside the pancreas in nearby tissues like the bile duct and/or the small intestine (duodenum). There is no sign of cancer in the nearby lymph nodes.

### Stage 3

The cancer has spread outside the pancreas to nearby tissues. It is also in the lymph nodes and may have spread to other organs through the lymphatic system or bloodstream.

### Stage 4

This is known as metastatic or advanced cancer. This stage can be divided into 4a and 4b. In 4a the cancer has spread to nearby organs and blood vessels. This includes the stomach, spleen, large intestine or large blood vessels. The cancer is also found in lymph nodes. In 4b, the cancer has spread to the liver or the lungs, or both.

## Surgical staging

In practical terms, pancreatic cancers are usually staged according to how likely it is that surgery will remove the tumour:

- **Resectable** – looks like it is removable with a clear margin (no cancer cells remaining). May be treated with surgery first or chemotherapy/radiotherapy first (before your surgery).
- **Borderline resectable** – looks like it is removable but there is a high chance that a microscopic amount of tumour will be left behind. Usually treated with chemotherapy and/or radiotherapy first, followed by surgery.
- **Unresectable** – looks like the tumour is not removable with surgery. Unresectable tumours can be:
  - **Locally advanced unresectable** (the tumour involves essential blood vessels near the pancreas). Usually treated with chemotherapy and radiotherapy. Some people may go on to have surgery if the tumour responds to this treatment.
  - **Metastatic unresectable** (distant secondary tumours are present). Usually treated with chemotherapy.

Your test results are reviewed at a multidisciplinary team meeting to decide on the correct staging. This helps to work out the best treatment plan for you.

# Asking about your prognosis

Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy.

It's not always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.



## Should I ask about my prognosis?

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

If you decide you want information on your prognosis:

- Think carefully about how you will cope with the information before asking for your prognosis.
- Get information on your prognosis from your doctor. They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- Ask a friend or family member to go with you, if you would like some support.

- Be careful with online information. It may be hard to understand or even incorrect. Also, the information may not apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- Accept that you will need some time to think about what you have been told. You may forget some things or there may be things you didn't understand. You may need to talk to your doctor or nurse again after you have thought about everything.

If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Support Line on 1800 200 700, email supportline@irishcancer.ie or visit a Daffodil Centre. 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.



# Treating pancreatic cancer

# How is pancreatic cancer treated?

- There are many ways to treat pancreatic cancer. Once all the test results are ready, your doctor will discuss your treatment options with you.
- Surgery is the main treatment for early-stage pancreatic cancer. Chemotherapy and radiotherapy may be used before or after surgery.
- If surgery is not possible, chemotherapy and/or radiotherapy may be the main forms of treatment you receive.
- A team of healthcare professionals (multidisciplinary team) will be looking after you.

## Surgery to remove pancreatic cancer

The main treatment for early-stage pancreatic cancer is surgery. By looking at your test results, the multidisciplinary team will decide if it can be removed. A cancer that looks like it can be successfully removed by surgery is called resectable cancer. Not everyone can be offered surgery. Sometimes it is not possible to find out how advanced the disease is until surgery has been done.

There are different types of surgery that can be done, depending on where the tumour is found. See page 57 for more about surgery. These are major operations and an assessment of your general fitness for surgery is very important.

## Chemotherapy

Chemotherapy is sometimes given to people with pancreatic cancer. It can be given before or after surgery or on its own. Chemotherapy before surgery is called neoadjuvant chemotherapy.

You may have chemotherapy for 3 months, after which you will have a CT scan. This scan will help your doctors to decide whether the chemotherapy has shrunk the tumour enough to allow you to have surgery.

Chemotherapy is often used to shrink the cancer when surgery is not possible. This helps to relieve symptoms and to improve your quality of life. See page 72 for more about chemotherapy.

## Radiotherapy

Radiotherapy can sometimes be used to treat pancreatic cancer. If your tumour is causing pain, a small dose of radiotherapy may help to relieve it. Sometimes radiotherapy can be used in combination with chemotherapy to shrink the tumour before surgery. See page 78 for more about radiotherapy.

## Targeted therapies

Targeted therapies are also used for pancreatic cancer. These drugs only target the cancer cells. They work by blocking the signals that tell cancer cells to divide and grow. See page 81 for more about targeted therapies.



## Surgery to relieve symptoms (bypass surgery)

Bypass surgery is done to relieve symptoms, such as vomiting, when the tumour cannot be removed. See page 61 for more details.

## Using stents to relieve symptoms

The bile duct can often become blocked if you have pancreatic cancer. If this happens, you may have a small tube (stent) inserted to relieve a build-up of bile. For more information see page 62.

## Supportive or palliative care

This is treatment that is given to help relieve your symptoms, especially if you have advanced (metastatic) cancer. Surgery, chemotherapy or radiotherapy may be needed as part of your palliative care. A special team called the palliative care team may be involved in your care too. They can work alongside other teams to help with symptoms such as pain, bowel problems and nausea. See page 101 for more details.

## Specialist cancer centres

All surgery is carried out in specialist pancreatic cancer centres. The staff at these centres have a lot of experience in managing people with pancreatic cancer who need surgery. In Ireland, surgery for pancreatic cancer is carried out at St Vincent's University Hospital, Dublin and Cork University Hospital.

## Treatment or no treatment

Unfortunately, your doctor may not be able to cure your cancer. But some treatment might prolong your life and give you a good quality of life.

In some cases, you may not benefit from treatment at all. The treatment may not shrink the tumour or improve your quality of life. The side-effects of treatment may be greater than the benefits. Your doctor and nurse will discuss this with you in more detail.

## Why is pancreatic cancer hard to treat?

- It is unusual for it to be diagnosed at an early stage.
- It is close to important organs and vessels, so it is hard to remove.
- It can spread very easily.
- It can make you feel very sick and weak and you can have a lot of weight loss. This can make you less suitable for surgery and other treatments.
- It is less sensitive to treatments than other cancers.

## Your treatment plan

- The treatment plan your doctor recommends for you is based on the latest research and international guidelines about the best ways to treat pancreatic cancer.
- You may notice that other people with pancreatic cancer are not getting the same treatment as you. Their cancer may not be the same type or at the same stage as yours, so your treatment plan may be different.
- Talk to your doctor or nurse if you have any questions about your treatment plan.



# 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 surgeon, oncologist (cancer doctor), specialist nurse, radiologist and pathologist.
The team will meet to discuss your test results and your suggested treatment plan.

## Understanding your treatment

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

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

## Time to think

It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can 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 GP can refer you to another specialist for a second opinion if you feel this would be helpful.

## Accepting treatment

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



# Giving consent for treatment

Before you start any treatment, you will 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.

## Who will be involved in my care?

Usually a team of healthcare professionals will be involved in your treatment and care. These may include:

**Hepato-pancreato-biliary (HPB) surgeon:** A surgeon who specialises in surgery to the pancreas, liver, gall bladder and bile duct.

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

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

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

**Radiation therapist:** A specially trained person who delivers radiotherapy and gives advice to cancer patients about their radiation treatment.



**Advanced nurse practitioner (ANP):** ANPs give expert information and support and are specially trained to carry out tests and help to review your treatment.

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

**Hepato-pancreato-biliary (HPB) surgical clinical nurse specialist (CNS):** A specialist nurse who provides care and support to people with pancreatic and hepatobiliary conditions, including pancreatic cancer.

**Endocrinologist:** A doctor who specialises in diseases of the endocrine system, such as diabetes. Diabetes can be caused by, or be made worse by, pancreatic cancer.

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

**Occupational therapist:** A therapist who specialises in helping people who are ill or have disabilities learn to manage their condition and their daily activities, such as washing, dressing, housework, parenting, work and leisure activities.

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

**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.

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

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

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

**Palliative care team:** This team is experienced in managing pain and other physical symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the symptom management team. A specialist palliative care service is available in most hospitals. Palliative care teams also work in the community. See page 101 for information on palliative care.



## 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 one of our Cancer Nurses.

### Pre-treatment education workshops

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

# How can I help myself?

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

## Eat well

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

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

Ask to talk to the dietitian at the hospital for advice on the best diet for you. We provide group online information sessions with an Oncology Dietitian, to support you to eat well during cancer treatment and beyond. You can also read our booklet ***Understanding diet and cancer***. For more information, call our Support Line on 1800 200 700 or visit a Daffodil Centre.



## Be active

If you are able, it can really help to be active before 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 and may have information on exercise programmes and classes. Call our Support Line or visit a Daffodil Centre for information and support on how you can make exercise part of your everyday life. Ask about our free exercise classes to help build strength and fitness in a supportive environment.

## Quit smoking

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

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

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

## Other ways to help yourself

### Get information about your cancer and treatment

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

### Involve your family and close friends

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

### Use your support network

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



### Try relaxation and stress management techniques

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

### Accept change in your life

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

### Know that there will be ups and downs

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

### Try to cope day by day

Some people find it helpful to concentrate on the present and on getting through each day of tests or treatment. This may help you to cope with your illness, especially if you are worrying a lot about the future.

### Plan ahead

Some people with a cancer diagnosis find it reassuring to organise medical and legal matters. See page 110 for more about planning ahead.

# Types of treatment

# Surgery

- Surgery aims to remove all of a tumour.
- Surgery can also be used to relieve symptoms.
- There are different types of surgery for pancreatic cancer.
- You may have chemotherapy before and/or after surgery.

Surgery is only suitable if you have early-stage pancreatic cancer. This means it suits about 1 in 5 patients at the time of diagnosis.

With modern treatment approaches – in particular, giving chemotherapy (and sometimes radiotherapy) before surgery – some people whose cancer looked like it couldn't be removed at first, may later become suitable for surgery.

The surgery is complex because the pancreas lies deep inside your body and is surrounded by many large organs and blood vessels. Major pancreatic surgery is only offered when the whole tumour can be removed, as incomplete removal doesn't improve how long or how well people live.

If surgery is considered, you will be referred to a specialist centre – either in Dublin or Cork – where surgery is done regularly by an experienced team.

## Types of surgery

There are a number of different types of surgery, depending on where the cancer is found.

These are major operations and you can develop complications after surgery that may prolong your stay in hospital. Your surgeon will discuss these issues with you before your operation. It can take a few weeks or even months to recover fully after surgery.

In the long term, there is a risk of developing diabetes following surgery. You may also need to take enzymes to help digest your food.

Some of these operations are done as keyhole procedures using robotic or laparoscopic surgery. Keyhole (minimally invasive) surgery is now the preferred approach for most operations on the body and tail of the pancreas (distal pancreatectomy). Some minimally invasive Whipple's operations are carried out in specialist centres for suitable patients.

The main advantage of minimally invasive surgery is that it can reduce discomfort after surgery and speed up recovery and discharge from hospital. However, the priority for any pancreas operation is that it is done safely by an experienced team who are experts in carrying out these types of operations.

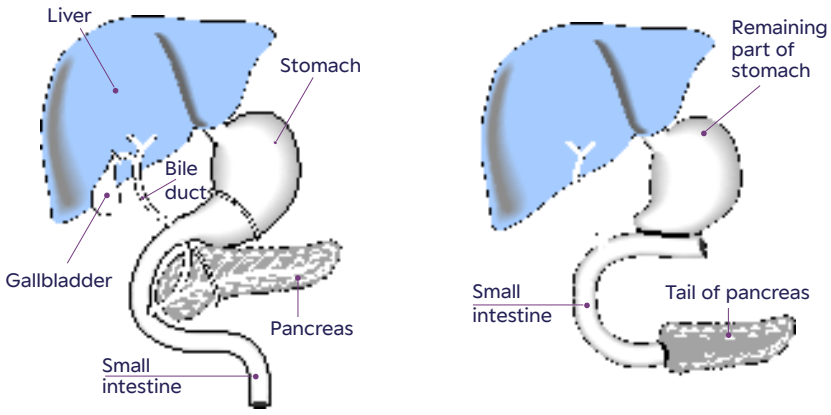


## Whipple's procedure (pancreaticoduodenectomy)

This type of surgery is done if the cancer is in the head of the pancreas. The surgeon will remove the head of the pancreas, the first part of your small intestine (duodenum), part of the bile duct, your gallbladder and surrounding lymph nodes. In the classic Whipple's operation, the lower part of the stomach is also removed. In the pylorus-preserving version (see page 60), all of the stomach is kept.

If the tumour is close to or involves a major vein behind the pancreas, a short segment of the vein is sometimes removed and reconstructed so that all of the cancer can be cleared. This is now a routine part of surgery in borderline resectable disease.

The surgeon will join the remaining pancreas, bile duct and stomach to the small intestine. This allows the pancreatic enzymes, bile and stomach contents to flow into the small intestine for normal digestion.

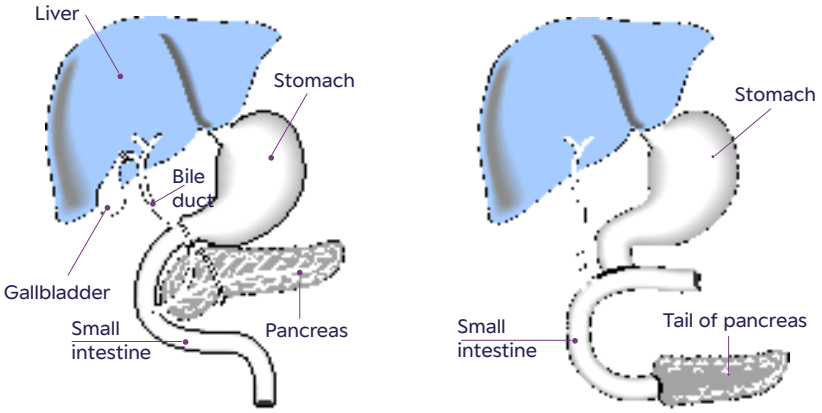



Before surgery

After surgery

## Pylorus preserving pancreaticoduodenectomy (PPPD)

This is very similar to a Whipple's procedure, with the main difference being that none of the stomach is removed.

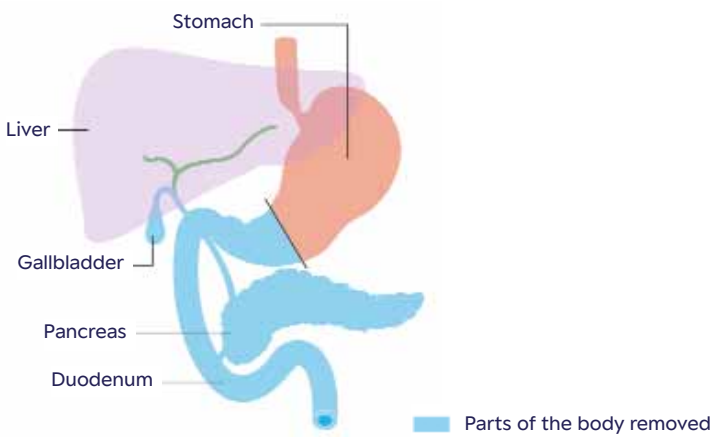



Before surgery

After surgery

## Total pancreatectomy

Total pancreatectomy is where all of your pancreas is removed as well as some of your small intestine, part of your stomach, your gallbladder, part of the bile duct, your spleen and nearby lymph nodes. This kind of surgery is uncommon.




Picture courtesy of Cancer Research UK/Wikimedia Commons



After a total pancreatectomy, you will need insulin and pancreatic enzyme replacements for the rest of your life. If your spleen is removed, you will have an increased risk of developing infections. You will need a course of vaccinations, for example the influenza (flu) vaccine and the pneumococcal vaccine. You may also need to take a low-dose antibiotic every day for the long term to protect you from certain infections.

## Distal pancreatectomy and splenectomy

This kind of surgery is done for cancer in the body and tail of the pancreas. The tail of the pancreas is removed, as well as your spleen.

## Spleen-preserving distal pancreatectomy

With this surgery, the tail of the pancreas is removed but the spleen is left intact.

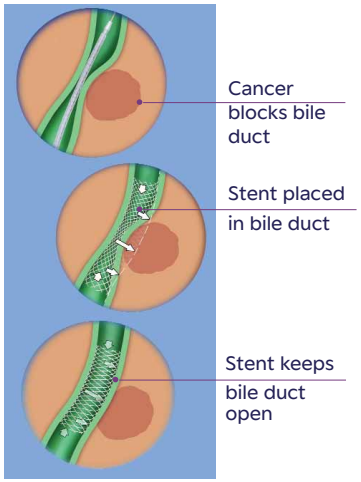
## Bypass surgery

Bypass surgery is done to relieve your symptoms when the cancer cannot be removed. For example, you may be vomiting due to a blockage in your small intestine (duodenum) caused by the cancer. In this case, your surgeon might connect your small intestine to your stomach. This operation is called a gastrojejunostomy.

Some people no longer need surgical bypass because a similar result can usually be achieved by placing a stent (see next page) through an endoscope. This is less invasive and avoids the use of a general anaesthetic, which allows you to go home faster.

### Stents

It is quite common for the bile duct to be blocked by pancreatic cancer. This causes jaundice, symptoms of which can include a yellowing of the skin and whites of the eyes, and severe itching (see page 89). In this case you might have a stent put into your bile duct. This is a small metal or plastic tube, which can be inserted by ERCP (see page 29) or or by puncturing the skin and using X-rays to guide the stent into position (percutaneous transhepatic cholangiogram – PTC).




For people whose cancer cannot be removed, a self-expanding metal stent is usually used because it stays open for longer than a plastic one. If you are going to have surgery, you might have a stent put in. Your medical team will decide on the best approach for you.

Although neither of these procedures needs a surgical incision (cut), they are both invasive procedures. There may be some risks involved, which your doctor and nurse will explain to you. They will also give you more information about stents or bypass surgery if you need it.

## Preparing for surgery

You may have extra tests to make sure you are fit enough for surgery. These may include a chest X-ray, heart test (ECG) and blood tests.

Usually you will meet a dietitian before surgery. You may be advised to take pancreatic enzyme supplements and extra nutritional supplements for some time before surgery.



You will probably have to fast (not eat) from midnight the night before your surgery. Some specialist centres may allow you to drink clear fluids up to 2 hours before the operation and they may give you a special carbohydrate drink the night before and the morning of surgery.

Many centres also now offer a period of 'prehabilitation' in the weeks before your operation, providing you with tailored advice on exercise, nutrition and stopping smoking and alcohol. This has been shown to improve fitness for surgery and speed up recovery.

Before your surgery, you may also get an anti-clotting injection like heparin and elastic stockings may be put on your legs, to prevent blood clots. Before you go to the operating theatre, you may be given medication that will make you feel more relaxed and sleepy. In the operating theatre, you will be given a general anaesthetic so that you will be asleep for your surgery.

## After surgery

You will either stay in an intensive care or high dependency unit (HDU) where the staff will keep you under close observation for a day or 2, or you will go straight to the ward.

## Complications after surgery

About 1 in 3 patients develop some complications that can delay them from going home. The most common complications after a Whipple's operation are:

- Leakage of pancreatic juice from the join between the pancreas and the intestine. This is called a pancreatic fistula
- Delayed emptying of the stomach (delayed gastric emptying or DGE)
- Bleeding

Most of these are managed without further surgery, usually by draining any collection of fluid through the skin, guided by X-rays or ultrasound. In specialist centres, the risk of dying following a Whipple's operation is now less than 3%.

Other general complications include chest and wound infections and leg clots. Dealing with these complications may mean you have to take extra medication or antibiotics. You may also need to spend a bit longer in hospital.

While removing part or all of the pancreas is a major operation, remember that your surgeons are highly skilled. If you have any concerns, you should discuss these with your medical team.



## Drips, drains and tubes

When you wake up, you will have some tubes attached to your body. Don't be alarmed as they are normal after an operation like this.

- You will have a drip in a vein in your arm. You will be given fluids through this until you can drink again. You may also be given antibiotics to prevent infection.
- A thin plastic tube may be up your nose. This is called a nasogastric tube and leads down into your stomach. This tube is usually removed at the end of the operation. If it is kept in place, your nurses can keep your stomach empty by removing the fluid in your stomach through this tube. This will stop you from feeling sick and let your wound heal. The tube is removed once the stomach starts emptying normally.
- One or more thin tubes called drains may be coming out of your tummy (abdomen) near your wound. These help to drain any fluid such as pancreatic juice, blood or bile from the operation site to prevent a build-up of these fluids inside your abdomen.
- A thin tube called a catheter may be put into your bladder to drain any urine. It is usually removed after 48 hours, or once you are able to get out of bed.
- You may have a thin epidural catheter in your back to help with pain relief. You may have a tube called a beeline which delivers pain relief directly into the site of the wound.

Email: supportline@irishcancer.ie

## Pain

You may have some pain after the operation, especially when you cough or move. Your nurse can give you medicine to control the pain and prevent you feeling or getting sick, if you need it. You may have an epidural tube in your back to relieve pain after the surgery. If you have a patient-controlled analgesia pump (PCA), your nurse will show you how to use it. Always ask for help if you have any pain or feel sick.

## Wound site

As well as drains, you will have a dressing over your wound site. This will be checked regularly for any signs of bleeding or leakage.

## Replacing insulin and pancreatic enzymes

If you have had part or all of your pancreas removed, you may develop diabetes and need to take insulin. Insulin is normally made by the pancreas. The diabetes nurse specialist will visit you and give you advice if you develop diabetes due to surgery.

Nearly everyone who has had pancreatic surgery needs to take extra digestive enzymes with every meal and snack. This is known as pancreatic enzyme replacement therapy (PERT). PERT is usually started in hospital and is almost always continued long term, as it helps prevent weight loss, bloating, wind and fatty diarrhoea – improving your quality of life.



If all of your pancreas is removed (total pancreatectomy), you will definitely need both insulin and enzyme replacement for the rest of your life.

After a Whipple's operation, some people develop low vitamin B12 levels. Your medical team will check this with a blood test and replace it if needed, usually by injection.

## Eating and drinking

Pancreatic surgery slows down stomach emptying and the movement of your bowel. As a result, it can take many days before you return to normal eating and drinking. You will start by taking sips of water and then the amount of fluids will be increased. Most people can manage a light meal within 2 or 3 days of surgery. As you begin to drink enough again, the drip giving you fluids will be removed.

With pancreatic cancer, you are likely to lose some weight. Your dietitian will give you advice on suitable foods and meals, as well as nutritional and pancreatic enzyme supplements.

### Bowel function

You may have difficulty passing wind or opening your bowels (pooing) after the surgery. Your nurse can give you medication to help get your bowels back to normal. Things will also improve when you are up and moving about. However, sometimes it can take a few weeks for your bowel habits to return to normal or for you to get used to a new normal.

## Getting up and about

A physiotherapist will visit you regularly after surgery. These visits are to help you with breathing and leg exercises. Even when you are in bed you will be encouraged to move your legs and do deep breathing exercises at least once an hour. On the day after surgery the physio or nurse will help you get out of bed and take you for a short walk. These walks will become more frequent and longer as you get better.



## Going home

You will probably go home about 7-10 days after a Whipple's operation and 3-7 days after a distal pancreatectomy, particularly if it was done as keyhole surgery.

On the day you go home you will be given a date to come back for a check-up – usually in about 6 weeks.

It can take several months after you leave hospital before you feel fully back to yourself.

## 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 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.

## Contacting the healthcare team

You will be given contact numbers so that you can reach your doctor, nurse or hospital at any time. Contact a member of the team as soon as possible if you:

- **Have a temperature of 38°C (100.4°F) or higher, or 35°C (95°F) or lower**
- **Have an increasing amount of pain**
- **Have diarrhoea for more than 24 hours**
- **Feel unwell**
- **Have problems with your wound such as redness, swelling or a discharge**

If you have any other worry or symptom that is causing you concern before your check-up date, contact your nurse specialist or hospital ward for advice.

## Pathology report

After surgery, any tissue that has been removed will be looked at closely by a doctor called a pathologist. The pathologist will check to see if all the cancer has been removed and that the edges are clear of cancer cells.

When the edges are clear of cancer under the microscope, this is called an 'R0' resection. It is linked with the best long-term outcome.

The pathologist will also count the number of lymph nodes removed and count how many (if any) contain cancer cells. These findings, together with the stage of your cancer and your general health, will help the doctor to decide whether chemotherapy after surgery (adjuvant chemotherapy) will benefit you.

The pathologist will also check if the biopsy tissue has proteins or genes that could respond to targeted therapies (see page 81).



## Should I change my diet?

Your dietitian will give you advice on what foods to avoid or eat – depending on whether you need insulin or not. In general you will be told to eat little and often. If you are finding it hard to eat well and you are losing weight, you may be advised to eat high-energy foods. You are also very likely to need pancreatic enzyme supplement tablets. These tablets replace the enzymes usually found in your pancreatic juices to help you digest your food.

If your pancreatic duct is blocked by the cancer, taking the enzymes will help your digestion as well. Other symptoms that suggest you are not absorbing or digesting your food include fatty diarrhoea, bloating, wind and failure to gain weight. Your dietitian will advise you about taking enzymes to match your diet.

It may take a while for your stomach to get back to normal function. It may delay emptying food or else 'dump' it into the small intestine quickly. Your dietitian will give you advice about preventing these problems. If you develop diabetes due to the surgery, you will need to make changes to your diet. Your dietitian and diabetic nurse specialist will give you more advice about this. You will also be referred to a doctor who specialises in diabetes called an endocrinologist.

# Chemotherapy

- Chemotherapy uses drugs to kill cancer cells or slow their growth.
- Chemotherapy can cause a range of side-effects.
- Side-effects normally go after treatment ends.

Chemotherapy is a treatment that uses drugs to kill cancer cells. The doctor who specialises in chemotherapy is called a medical oncologist.

Chemotherapy drugs may be given:

- Before surgery or radiotherapy to shrink the cancer and reduce the risk of it coming back. This is called neo-adjuvant treatment.
- At the same time as radiotherapy to make the treatment work better (chemoradiotherapy).
- After surgery to reduce the risk of the cancer coming back. This is called adjuvant treatment.
- As a treatment on its own.



## How often will I have chemotherapy?

Chemotherapy is given in cycles with a rest period between treatments. This rest period allows your body time to recover from the side-effects of treatment. The number of treatments and cycles can vary, depending on your cancer type and how well it is responding to treatment.

## How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (by drip or pump). It may also be given in tablet form. You may have a central venous access device fitted. This is a thin tube (line) which goes directly into a vein and stays in place until your treatment is over. This saves you having repeated injections. There are different types of central venous access devices, such as ports, Hickman lines and PICC lines. Usually your treatment will be given in the oncology day ward.

## What drugs are used?

There are several chemotherapy drugs used to treat pancreatic cancer. Your doctor or nurse will discuss your treatment with you. Chemotherapy drugs can be used on their own or 2 or 3 may be used together. The type of drugs you get depends on how well you are.

## 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 written information to take home with you.

If you know the name of your drug, you can visit the Health Products Regulatory Authority's website at **www.hpra.ie** for information about the drug and possible side-effects.

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

## What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person. Some people have fewer side-effects than others. The type of side-effects you might get and how severe they are mainly depends on the amount of chemotherapy you have and the drugs used. Ask your doctor or nurse if you're worried about side-effects or have any questions.

Most side-effects can be helped by medication. Some side-effects will come and go during treatment. Usually the side-effects go away when the treatment ends or soon after. Side-effects may include:

**Fatigue:** Fatigue is very common. It can make you feel tired and weak. For more information see page 95.

**Nausea and vomiting:** Chemotherapy can cause nausea (feeling sick) and vomiting (getting sick). There are treatments that work well to prevent nausea and vomiting. Tell your doctor or nurses if they are not working well for you. Thinking or talking about the treatment can also make you feel sick. This is called anticipatory nausea. Tell your doctor or nurse if you have these side-effects.



**Risk of infection:** Chemotherapy drugs make you more likely to get infections. You will be given a number to call for advice if you have signs of infection. These signs include feeling shivery and unwell, having a high or low temperature, having a cough or sore throat, or pain passing urine.

If you have a high temperature, or feel unwell (even with a normal temperature), it is very important to call the hospital straight away – never delay. Check with your hospital about the temperature advice to follow.

**Anaemia:** Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red blood cell count will be done during treatment. You may need a blood transfusion to treat your anaemia.

**Bleeding and bruising:** Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.

**Mouth and throat problems:** Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you. You will also be told about how to look after your mouth during treatment to try to prevent mouth problems

**Hair loss (alopecia):** Some chemotherapy drugs can cause hair loss from all over your body. This can be very distressing. It can affect your confidence and make you feel self-conscious about your cancer. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will grow back 3-6 months after you stop chemotherapy.

**Constipation and diarrhoea:** Chemotherapy can cause constipation (not having a bowel movement (poo) often enough) and diarrhoea (frequent loose or watery bowel movements). Your doctor can give you medication to help, if needed.

**Skin and nail changes:** Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle.

**Peripheral neuropathy:** Some drugs can affect your nerve endings. It's important to tell your doctor if you have numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.



**Changes in kidney or liver function:** Some drugs can irritate or damage kidney and liver cells. Decreased urination, swelling of the hands or feet (oedema) or headaches are some of the signs of kidney damage. Yellowing of the skin or eyes (jaundice) can be a sign of liver problems. Tell your doctor if you have these or any other changes in your body. Blood tests will check your kidney and liver function regularly.

**Allergy:** On rare occasions people can have a reaction to certain chemotherapy drugs. Reactions can include rash, itching, low blood pressure and shortness of breath.

**Blood clots:** Chemotherapy and having cancer can both increase your risk of developing blood clots. A blood clot may cause pain, redness and swelling in your leg, or breathlessness and chest pain. Contact your hospital immediately if you have any of these symptoms, as blood clots can be serious. Usually they are treated with medication to thin your blood.

**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. For more tips on coping with a poor appetite, see page 91.

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. You will be given contact details of who to contact before you start your treatment.

For more information on the side-effects of chemotherapy or a copy of the booklet ***Understanding chemotherapy and other cancer drugs***, 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 different side-effects.

Email: supportline@irishcancer.ie

# Radiotherapy

- Radiotherapy uses high-energy rays to kill cancer cells.
- Radiotherapy is painless and only takes a few minutes.
- The treatment is usually just a few short sessions.

Radiotherapy is a treatment that uses high-energy rays to kill cancer cells. The aim of radiotherapy is to destroy the cancer cells with as little damage as possible to normal cells.

Radiotherapy may be given:

- Before surgery in combination with chemotherapy to shrink the cancer, making it easier to remove. This is called neo-adjuvant treatment.
- After surgery to destroy small amounts of the cancer that may be left. This is called adjuvant treatment and is also usually given in combination with chemotherapy.
- To control and relieve symptoms. This is called palliative radiotherapy and can be helpful to treat pain from pancreatic cancer.



## Planning your external radiotherapy treatment

Radiotherapy is usually given as external beam radiation. This is where the radiation comes from machines called linear accelerators, which aim rays directly at your tumour.

Radiotherapy must be carefully planned so that the highest dose is given to the tumour area and as little as possible to the nearby cells.

You will have a planning (simulation) appointment, which includes a CT scan, to pinpoint the area to be treated. The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. The dose of radiation will be decided and tightly controlled for your treatment.

## Getting your treatment

During treatment you will first be positioned carefully on a treatment table. Then the machine will move around you so that you receive the precise treatment at different angles.

The treatment normally takes a few minutes and is painless. You may experience some discomfort from having to stay still in the same position.

## How much radiotherapy do I need?

Radiotherapy can be given Monday to Friday with a break at the weekend, for several weeks. It is usually a shorter course of treatment for pancreatic cancer.

External beam radiotherapy does not make you radioactive. It's completely safe for you to mix with family and friends afterwards, including pregnant women and children.

Radiotherapy is normally given in special cancer treatment centres, so you may have to attend a different department or hospital from where you had surgery or chemotherapy.

For more information on radiotherapy or a copy of our booklet ***Understanding Radiotherapy***, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

## Side-effects of radiotherapy

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

- Diarrhoea
- Tiredness
- Nausea

How severe these side-effects are will vary from person to person. It depends on the amount of treatment received. Most side-effects develop during or shortly after your treatment and can usually be managed with simple medications.

If you feel unwell or have any other side-effects or symptoms – during or at any time after treatment – tell your doctor, nurse or radiation therapist.

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.

Support Line Freephone 1800 200 700



# Targeted therapies

- Targeted therapies target certain parts of cancer cells that make them different from other cells.
- Side-effects depend on the drugs being used and vary from person to person.

Targeted therapies are drugs that target 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 targeted therapies work in different ways. Targeted therapies can work to:

- Block or turn off chemical signals that tell the cancer cells to grow and divide
- Change proteins within the cancer cells so the cells die
- Stop new blood vessels growing to feed the cancer cells
- Carry toxins to the cancer cells to kill them

Some drugs are given in tablet form. Others are given into a vein through a drip.

## New targeted therapies

New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be offered a targeted therapy as part of a clinical trial (see page 84). Ask your doctor if there are any targeted therapies available to treat your cancer or if there are any trials that are suitable for you.

### Side-effects

Side-effects depend on the drugs being used and vary from person to person. Common side-effects include fatigue, nausea, vomiting, dizziness and diarrhoea.

Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects. Always tell your doctor or nurse if you don't feel well or if you are having any symptoms that are troubling you.

For more information on targeted therapies and their side-effects, or a copy of the booklet ***Understanding chemotherapy and other cancer drugs,*** call our Support Line on 1800 200 700 or visit a Daffodil Centre.



## Treatment for cancer that has spread

If the cancer spreads to another part of your body, it is called advanced, metastatic or secondary cancer. Your cancer may be in more than one part of your body when it is first diagnosed. If your cancer has spread, it can still be treated. The aim of treatment is usually to try to control the cancer rather than to cure it. There is a range of treatment options for most advanced cancers and new treatments are being developed all the time.

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

Often advanced cancer is treated with chemotherapy or targeted therapies. There may also be treatments that you can have as part of a clinical trial (see page 84).

You can also have treatment to help with any symptoms (see page 87). You may be referred to the palliative care team, who are experts in managing the symptoms of advanced cancer. See page 101 for more on palliative care.

## 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, or as well as, the standard treatment you may get a new trial treatment. Or you may be given existing treatments used in different ways. For example, you may be given a different dose of a drug or you may be given 2 treatments together.

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

Trials often investigate very specific features of a particular cancer or treatment. 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 pancreatic cancer are pain, jaundice, eating difficulties and fatigue.

Other symptoms such as fluid that collects in your abdomen (ascites) can also cause problems. Some symptoms can be helped by surgery, chemotherapy or radiotherapy. The palliative care team can also help with any symptoms that are causing you problems. See page 101 for more information on palliative care.

### Pain

Pancreatic cancer can cause pain, but usually it can be well controlled. If the cancer has spread, there may be more pain in your tummy area (abdomen) and around your back. Tell your doctor and nurse if you have pain as there are ways to treat it.

Your doctor will try to find out first what is causing the pain. For example, a blockage or pressure on the nerves. Surgery, radiotherapy or chemotherapy can all help to ease pain. There are also a lot of good painkillers (analgesics) available. 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 out different painkillers to find one that suits you best.

There are other ways to treat pain such as nerve blocks and epidural injections. It is important that your pain is under control so that you can enjoy your normal activities. Sometimes your cancer doctor will ask the palliative care team to help to manage your pain, even while you are on treatment. (See page 101 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.
- 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.

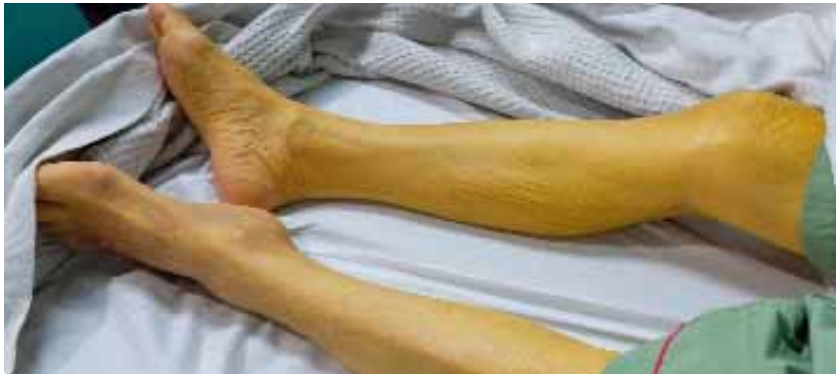
Your doctor or nurse will give you a different laxative if your bowels have not opened for 2 or 3 days.

Tell your doctor if you are 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 happens when the cancer blocks the bile duct in your pancreas or if the cancer has spread to your liver. This causes the bile to be absorbed into your bloodstream, which makes your skin and the whites of your eyes become yellow in colour. Your skin then gets dry and itchy, your urine becomes dark in colour and your stools (poo) become pale. You may feel sick, weak, tired and have wind pain.



Bypass surgery can help to remove the blockage that is causing jaundice. This blockage can also be helped by putting in a small tube (stent). See pages 61 and 62 for more about bypass surgery and 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.

### Tips for itchy, dry skin

Apart from antihistamines, calamine lotion or cool water on your skin can also help to ease itching. Baking soda can help to soothe and soften your skin too. Add a half cup of baking soda to a bath of warm water and soak in it. When washing, use a mild soap on your skin. Moisturise your skin. Your medical team or pharmacist can advice you on suitable creams. For more information on jaundice, ask your doctor or nurse or call our Support Line on 1800 200 700.

## Eating difficulties

Cancer and its treatment can cause eating difficulties, which can make it hard to eat well. Some of the difficulties you may experience include:

- Poor appetite
- Taste and smell changes
- Dry mouth
- Sore mouth, gums or throat
- Difficulty swallowing
- Feeling full quickly
- Feeling bloated
- Nausea
- Vomiting

Other symptoms, such as pain and fatigue, or feeling down, can also affect your ability to eat and your interest in food. If you have lost your appetite, are struggling with food, or you are losing weight, speak to your medical team. Tell them if you have pain or are feeling fatigued, or if your mood is low. (See page 93 for tips about weight loss.)

There are ways to help improve your eating difficulties and nutrition. For example, a dietitian can advise you on your diet. Or your doctor may prescribe pain relief, pancreatic enzymes to help you digest your food or anti-sickness tablets you can take before eating if you have nausea. You may be given a laxative if you are constipated, or medication to stop diarrhoea.

You can also call our Support Line on 1800 200 700 for more advice or for a free copy of our booklet ***Understanding diet and cancer***.



## Hints and tips: Poor appetite

- **Eat well when you can but take care with what you eat if you have diabetes** after pancreatic surgery.
- **Eat small meals and snacks about every 2–3 hours.**
- **Eat nourishing snacks that are high in calories and protein.**
- **Use a smaller plate for your meals.** Large portions can be off-putting if your appetite is small.
- **Eat slowly and chew your food well.**
- **Choose drinks that give some nutrition,** such as milk and fruit juice.
- **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 in 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.

### A note for family and friends – eating difficulties

Sharing food can be an enjoyable experience, so it can be hard to adjust if your loved one has a new eating pattern. For example, eating much smaller amounts or avoiding certain foods. They may feel they are upsetting you if they have to refuse food, eat at different times or don't eat very much. Try to support and reassure them as they get used to these changes.

For more information on caring for someone with eating difficulties, see our booklet ***Understanding diet and cancer***. For a free copy, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also download it from **www.cancer.ie**

## Weight loss

Pancreatic cancer can cause a lot of weight loss. This can leave you feeling weak and tired and not able to eat. Dietitians are experts in the nutritional needs of people who have pancreatic cancer. They can discuss ways to increase calories so that you can feel stronger and improve your quality of life. They can also advise you on how best to take digestive enzymes and help you manage your diet if you have diabetes.

In rare cases, your doctor may feel a feeding tube is necessary (enteral nutrition). Or you may need to get nutrients intravenously (into a vein). This is called total parenteral nutrition (TPN). TPN is usually only given if there is a blockage in the bowel. Your dietitian and doctor will discuss these forms of feeding with you, if they feel you would benefit from them.

Talk to your doctor, dietitian or nurse for more advice. You can also call our Support Line on 1800 200 700 for a free copy of the booklet, ***Understanding diet and cancer***.



### Hints and tips: Weight loss

- **Always tell your medical team if you're losing weight.**
- **Make the most of your appetite when it's good,** while minding what you eat if you have diabetes.
- **Eat nourishing snacks** that are high in calories and protein.
- **Have snacks about every 2–3 hours.** Do not skip meals.
- **Add calories to food,** for example, by adding milk, butter or cream.
- **Avoid drinking liquids before meals.**
- **Take only small sips at mealtimes,** as fluids may make you full.
- **Do not put too much food on your plate.** It can be off-putting if your appetite is small.
- **Take any nutritional supplements recommended by your dietitian or doctor.**
- **Take special high-calorie drinks** to help keep your strength up. Your dietitian will advise you and your doctor will prescribe them if suitable.
- **Encourage your family to eat together** and make mealtimes relaxing and enjoyable.

## Vomiting

Vomiting can sometimes happen if cancer is blocking your small intestine (duodenum). Food builds up where the blockage is and makes you feel sick (nausea) or get sick (vomit). It can affect your appetite as well, so that you do not feel like eating.

You might have bypass surgery or have a stent put in to unblock the area so that food can pass normally. See pages 61 and 62 for more on bypass surgery and stents. Your doctor can prescribe anti-sickness tablets to ease the nausea and vomiting.

### What you can do

Do not eat anything until the vomiting has stopped and is under control. Then try small amounts of clear liquids like water and continue taking sips for as long as you can tolerate them. It may also help to change your eating habits – for example, have 6-8 small meals a day rather than 3 large ones. These small meals might include nourishing drinks such as milk and softer foods like yoghurt or scrambled eggs.

Contact your doctor, nurse or dietitian if vomiting continues or gets worse.



# How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is very common with cancer. 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.

Fatigue when you have cancer 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
- Symptoms like pain, breathlessness or fluid retention

Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count, a transfusion can make you feel better. If you are not eating well, a dietitian may be able to give you some advice to help.

## Hints and tips: Fatigue

- **Ask your doctor about exercising.** Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you. Or you could ask our Cancer Nurses about our free exercise classes. Call our Support Line or visit a Daffodil Centre to talk to a nurse.
- **Plan your days.** Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- **Ask for help at work or at home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor. Our booklet ***Understanding diet and cancer*** has tips to help.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling may help too (see page 114).
- **If you are not sleeping well, have a good bedtime routine and try relaxation techniques.** Avoid alcohol and stimulants like caffeine 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 visit a Daffodil Centre for a free copy. It's also on our website **www.cancer.ie**



# Will treatment affect my sex life?

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

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 may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. Our Support Line 1800 200 700 and our Daffodil Centres can help you to find supportive information and accredited therapists if you would like to talk to someone. Therapy can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

Our booklet ***Understanding sex, sexuality and cancer*** also offers advice. Call our Support Line or drop into a Daffodil Centre for a free copy. Or download it from our website, **www.cancer.ie**

There is no set time for you to be ready to have sex again. It varies from person to person. Your doctor will advise if you can have sex while on radiotherapy. 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

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment. Some chemotherapy and other cancer drugs may harm a developing baby, so it's important to avoid pregnancy during and for a time after treatment.

Many specialists recommend that you wait for up to 2 years after treatment before trying to start a family or having more children. This time gives your body a chance to recover from the effects of the cancer and its treatment.

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

## Asking for advice

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



# Will treatment affect my fertility?

Your fertility may be affected by chemotherapy, targeted therapies or radiotherapy. 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.

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

# Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, massage, reflexology and aromatherapy.

Complementary therapies can't treat or cure cancer, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their cancer and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Tell them also if you're using or considering using over-the-counter or herbal medications or supplements. 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**

# Palliative care

Palliative care helps you to manage your symptoms and improve your quality of life. It 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 to relieve symptoms earlier in your illness.

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 can be given palliative care in hospital, in a nursing home, in a hospice or at home.

For more information on palliative care, visit the Palliative Hub at **www.adultpalliativehub.com** You can also speak to your doctor, nurse or medical social worker if you have one, for more information. If you do not feel well enough, your family can talk to them for you.

## Who can help me at home?

If your family or friends decide to care for you at home, there are many health professionals who can give you practical advice and support. Some work in the community or are attached to hospitals or hospices. Others work between the hospital and your home.

Depending on where you live, services can vary from one HSE area to another. Before you go home, you can get more information from the medical social worker in the hospital or from your local health centre.


Your GP or public health nurse can also tell you what palliative care services are available in your area. For more advice, call our Support Line on 1800 200 700 and ask for the booklet, ***A Time to Care: Caring for someone seriously ill at home***.

Sometimes it may not be possible for someone to care for you at home, if your cancer is advanced and your symptoms are causing you problems. You and your family may need to think about hospice care. The palliative care team can give you and your family advice in this situation.



# After treatment

## What follow-up will I need?

After your cancer treatment has ended you will still need to have regular check-ups. This is called follow-up. The follow-up may involve having a physical exam, blood tests and scans. You will see your consultant more regularly in the first few months after your surgery and then around every 3 to 6 months, depending on your progress. These check-ups will become less frequent over time.

If you have had other treatments, your follow-up may be slightly different. Your nurse specialist, oncology liaison nurse or consultant will give you details about your specific follow-up plan once your cancer treatment has ended.

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.

It's important to attend your follow-up appointments so your doctor can check for signs of the cancer coming back (recurrence) and help with any side-effects that you may have. They can also check for signs of new side-effects that may develop after you have finished treatment. It is better to be aware of these as early as possible so that suitable treatment can be given.

If you are between check-ups and have a symptom or problem that is worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment if necessary.

If you become suddenly unwell and can't contact your specialist nurse or hospital team, go to your GP or the emergency department at the hospital.

## What if the cancer comes back?

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



# Feelings after treatment

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

Feelings you may have include:

- Fear of cancer coming back 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 one of our Cancer Nurses in confidence. See page 115 for other ways to get emotional support. Ask the nurses for a copy of our booklet ***Life after cancer***, which has advice on living well – physically and emotionally.

Email: supportline@irishcancer.ie

## After-treatment workshops

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

# Living a healthy lifestyle

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

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

A healthy lifestyle includes:

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



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

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

> "The physical and emotional effects of cancer can affect you months or years after diagnosis. Don't be afraid to seek medical help or go back to counselling or support services if you feel you need them."

## 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 if you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family.

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

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

## Counselling

If you're feeling 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.

The Irish Cancer Society funds professional one-to-one counselling, remotely and through many local cancer support centres. To find out more about counselling, call our Support Line on Freephone 1800 200 700, visit a Daffodil Centre or email our Cancer Nurses at supportline@irishcancer.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. They can also give you practical advice and support. See page 140 for more about local cancer support services.

**Join a support or educational group:** You might find it reassuring to talk to other people with cancer who are 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:** Psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your healthcare team can refer you to psycho-oncology services if they're available at your hospital.

**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 visit a Daffodil Centre.

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

## Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

To be referred to a Peer Support volunteer, call our Support Line on 1800 200 700 or contact your nearest Daffodil Centre.

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 that it opened up new experiences and relationships.

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

Support Line Freephone 1800 200 700



# You and your family

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

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. It's on our website **www.cancer.ie** or ask our Cancer Nurses for a free copy.

## 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.



# Supporting someone with cancer

# Supporting someone with cancer

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

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

## Learn about cancer

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

## Share worries

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

## Be kind to yourself

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

## Try counselling

You might find it helpful to talk to a counsellor. The Irish Cancer Society funds one-to-one counselling for friends and family members remotely and through many local cancer support centres. Talk to your GP or see page 114.

## Find out about support for carers

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



## How to talk to someone with cancer

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

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

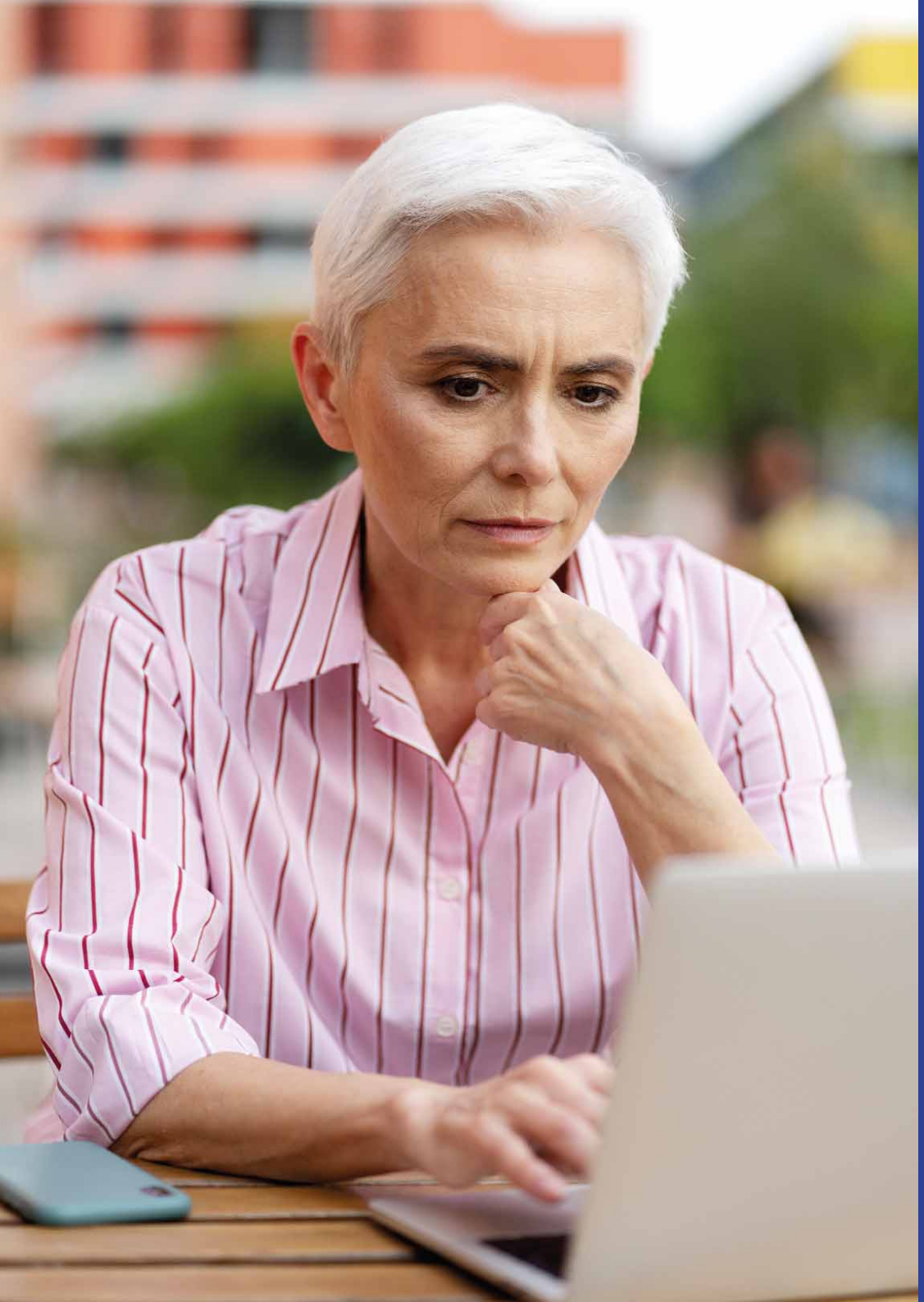
## Support for you

Our Cancer Nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information.

Our booklet, ***Caring for someone with cancer*** has lots of information on:

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

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



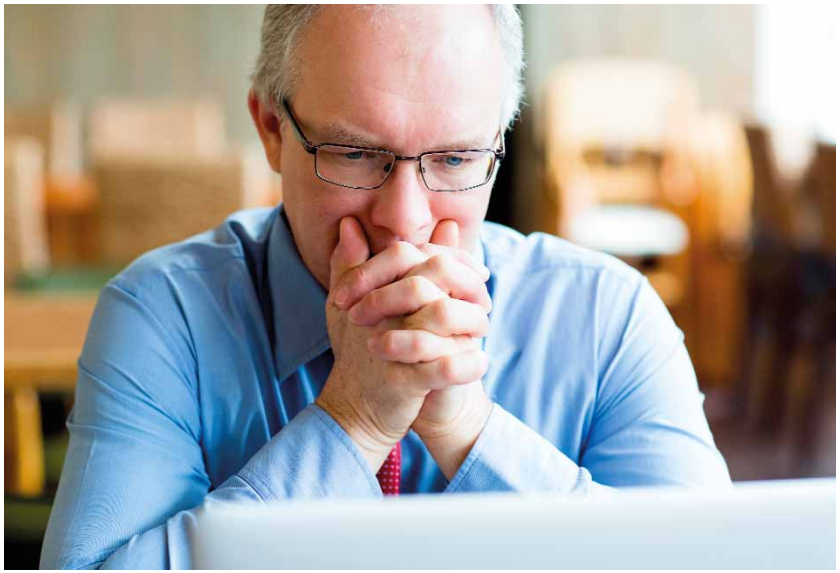
# Support resources

# Money matters

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

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

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



## Our Welfare and Supports Service

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

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

## Medical expenses

Medical expenses that you might have to pay include:

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

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

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

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



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

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

**If you have private 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 tests or treatment to check you're covered.

## Benefits and allowances

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

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

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

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

## If you have money problems

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 137 for more details of our Transport Service and the Travel2Care fund.

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

## Money and finances

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

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

Our website has lots of information on government supports for people who are unwell and their carers. Our Welfare and Supports Service may also be able to help (see page 128).



# Irish Cancer Society services

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

- **Support Line**
- **Daffodil Centres**
- **Telephone Interpreting Service**
- **Patient Education**
- **Peer Support**
- **Eating well information sessions**
- **Exercise information and support**
- **Counselling**
- **Transport Service**
- **Welfare and Supports Service** (see page 128)
- **Publications and online information**
- **Night Nursing**

## Support Line Freephone 1800 200 700

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

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

## Daffodil Centres

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

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


### What information is available?

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

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

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



## Telephone Interpreting Service

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

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

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

## Patient Education

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

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

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

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

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



## Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

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

## Eating well information sessions

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

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

## Exercise information and support

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

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

## Counselling

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

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



## Transport Service

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

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

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

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

## Publications and online information

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

## Night Nursing

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

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

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

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



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

**Visit us at www.cancer.ie**

**Speak with one of our Cancer Nurses:**

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

**Email the nurses at supportline@irishcancer.ie**

**Follow us on:**

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

## Local cancer support centres

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

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

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

Visit **www.hse.ie** to find a cancer support centre in your area or visit **www.cancer.ie** and search '**local cancer support centres**'.

Our Cancer Nurses can also help you to find support and services. Call our Support Line or visit a Daffodil Centre to talk to a nurse.

Support Line Freephone 1800 200 700



## What does that word mean?

**Abdomen:** The part of your body that lies between your chest and and hips. Also known as your belly or tummy.

**Adenocarcinoma:** The most common type of pancreatic cancer. It is found in the cells that line the pancreatic tubes (ducts).

**Adjuvant treatment:** Treatment for cancer given after surgery. For example, chemotherapy or radiotherapy.

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

**Benign:** Not cancer (non-malignant). A tumour that does not spread.

**Bile:** Fluid that helps with digestion. It is produced by the liver and stored in the gallbladder.

**Biopsy:** When a small amount of tissue is taken from your body and examined under a microscope to find out if cancer cells are present.

**Bypass surgery:** An operation that bypasses the cancer and relieves a blockage.

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

**Chemotherapy:** A treatment that uses drugs to cure or control cancer.

**Enzyme:** Proteins that cause chemical reactions in the body. For example, they can break down food in the stomach and intestines.

**Fatigue:** Severe tiredness.

**Jaundice:** When your skin and the whites of your eyes turn yellow and your urine turns dark. It can be caused by a blockage in the bile duct.

**Malignant:** Cancer. A tumour that can spread to other parts of the body.

**Metastasis:** The spread of cancer cells from where they first started to other parts of the body. Also known as advanced or secondary cancer.

**Nausea:** Feeling sick or wanting to be sick.

**Nerve block:** A treatment used to relieve pain caused by cancer. It helps to stop the nerves around the pancreas causing pain.

**Nutrients:** Proteins, carbohydrates, fats, vitamins and minerals found in food. They are needed for you to grow and stay healthy.

**Oncology:** The study of cancer.

**Palliative care team:** A team of doctors and nurses and other health professionals who are trained to manage pain and other physical symptoms caused by cancer. They will also help you cope with emotional distress. Palliative care teams work in hospitals, hospices and in the community.

**Prognosis:** The expected outcome of a disease – how your tumour is likely to progress, including average survival times or life expectancy.

**Radiotherapy:** The treatment of cancer using high-energy X-rays.

**Staging:** Tests that measure the size of your cancer and if it has spread.

**Stent:** A small hollow tube put into the bile duct to hold it open. This allows bile to drain into the small intestine as normal.

**Total parenteral nutrition (TPN):** Giving nutrients directly into a vein through a drip.

**Tube feeding:** Giving nutrients through a feeding tube passed into your stomach or intestine. Also known as enteral nutrition.

**Tumour:** An abnormal lump of tissue formed by a collection of cells. It may be benign (not cancer) or malignant (cancerous).



## Notes/Questions

## Notes/Questions



## Notes/Questions

# Acknowledgments

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

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

- *National Cancer Strategy 2017-2026.* National Cancer Control Programme (published 2017, updated 2024)
- *Cancer in Ireland 1994-2022.* National Cancer Registry Ireland (2024)
- *NCCN Guidelines – Pancreatic Adenocarcinoma.* National Comprehensive Cancer Network (Version 2. 2026)
- *ESMO Clinical Practice Guideline Express Update on the management of metastatic pancreatic cancer.* T Conroy and M Ducreux on behalf of the ESMO Guidelines Committee, ESMO Open 2025 Apr;10(4):104528 (2025).
- *Pancreatic cancer: ESMO Clinical Practice Guideline for diagnosis, treatment and follow-up.* T Conroy, P Pfieiffer, V Vilgrain, et al., on behalf of the ESMO Guidelines Committee. Ann Oncol;34(11):987-1002 (2023)
- *Guidelines for Perioperative Care for Pancreatoduodenectomy: Enhanced Recovery After Surgery (ERAS) Recommendations 2019.* E Melloul, et at. World Journal of Surgery, 44(7), 2056-2084 (2019)
- *Moving towards the New International Study Group for Pancreatic Surgery (ISGPS) Definitions: Impact on Reported Morbidity Rates.* S van Roessel, et al. Annals of Surgery. 2019;269(2):339-345 (2019)
- *Borderline resectable pancreatic cancer: a consensus statement by the International Study of Pancreatic Surgery (ISGPS).* M Bockhorn, FG Uzunoglu, M Adham, et al., on behalf of the International Study Group of Pancreatic Surgery. Surgery;155(6):977-88 (2014)
- *Treatment of Pancreatic Adenocarcinoma: A European Perspective.* DJ Gouma, ORC Busch, TM van Gulik, Surgical Oncology Clinics of North America 2008 Jul;17(3):569-8617 (2008)
- *Guidelines for the Management of Patients with Pancreatic Cancer Periampullary and Ampullary Carcinomas. P*ancreatic Section of the British Society of Gastroenterology, Pancreatic Society of Great Britain and Ireland, Association of Upper Gastrointestinal Surgeons of Great Britain and Ireland, Royal College of Pathologists, Special Interest Group for Gastro-Intestinal Radiology, Gut 2005 Jun;54 Suppl 5(Suppl 5):v1-1654 (2005)
- *Cancer Nursing: Principles and Practice.* Jones and Bartlett, 8th edition (2018)
- *The Chemotherapy Source Book.* M Perry. Lippincott Williams and Wilkins, 5th edition (2012)

First published by the Irish Cancer Society in 2010.

# Join the Irish Cancer Society team

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

## Support people affected by cancer

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

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

## Share your experiences

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

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

## Raise money

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

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

## Did you like this booklet?

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

Irish Cancer Society

Our cancer nurses are here for you:

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

**Irish Cancer Society**

www.cancer.ie