

Understanding

Cancer of the Bladder

Caring for people with cancer

Understanding cancer of the bladder

This booklet has been written to help you understand more about cancer of the bladder. It has been prepared and checked by surgeons, cancer doctors, nurses, radiation therapists and patients. The information in this booklet is an agreed view on this cancer, its diagnosis and treatment and the key aspects of living with it.

If you are a patient, your doctor or nurse may wish to go through the booklet with you and mark sections that are important for you. You can also make a note below of the contact names and information you may need.



Specialist nurse	Tel:
Family doctor (GP)	Tel:
Urologist	Tel:
Stoma care nurse	Tel:
Radiation oncologist	Tel:
Radiation therapist	Tel:
Medical oncologist	Tel:
Emergency number	Tel:
Treatments	Review dates



Irish Cancer Society, 43/45 Northumberland Road, Dublin 4
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Email: info@irishcancer.ie Website: www.cancer.ie

If you like, you can also add:

Your name _____

Address _____

This booklet has been produced by Nursing Services of the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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

- *Guidelines on Bladder Cancer: Muscle-Invasive and Metastatic*, European Association of Urology, 2010.
- *Guidelines on Non Muscle-Invasive Bladder Cancer*, European Association of Urology, 2010.
- *A Strategy for Cancer Control in Ireland*, National Cancer Forum, 2006.
- *Cancer in Ireland: A Summary, 1994–2005*, National Cancer Registry Ireland, 2005.
- *Cancer Nursing: Principles and Practice*, CH Yarbro, MH Frogge, M Goodman & SL Groenwald, Jones and Bartlett, 2000.
- *The Chemotherapy Source Book*, M Perry, Lippincott Williams and Wilkins, 1997.

First published by the Irish Cancer Society in 2011.

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Next revise: 2013



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ISBN 0-95323-690-1

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Introduction

This booklet has been written to help you understand more about cancer of the bladder. By reading it, you can learn what it means and about its diagnosis and treatment. We hope that it answers some of the questions you may have.

We cannot advise you about which treatment to choose. You can only make this decision along with your doctors, when all your test results are ready. But we can tell you about some ways to treat this cancer and the side-effects that may happen.

This booklet also discusses some of the feelings you and those close to you might have when your cancer is diagnosed. At the end of the booklet you will find a list of books that are useful to read. There is also a list of websites and special groups to help and support you at this time.



Reading this booklet

Remember you do not need to know everything about bladder cancer straight away. Read a section about a particular item as it happens to you. Then when you feel relaxed and want to know more, read another section.

If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the freefone National Cancer Helpline on 1800 200 700.



What does that word mean?

Abdomen	The part of your body between your chest and hipbones. Also known as your tummy.
Adjuvant treatment	Treatment for cancer given soon after surgery.
Alopecia	Loss of hair where you normally have hair.
Benign	Not cancer. A tumour that does not spread.
Biopsy	Removing a small amount of tissue from your bladder to find out if abnormal cells are present.
Catheter	A thin flexible tube that drains urine from your bladder.
Chemotherapy	A treatment that uses drugs to cure or control cancer.
Cystoscopy	A test that uses a thin flexible tube with a light at one end to look inside your bladder.
Invasive bladder cancer	Cancer that has spread into the muscle layer of your bladder.
Malignant	Cancer.
Metastasis	The spread of cancer from one part of your body to other tissues and organs.
Pelvis	The lower part of your abdomen found between your hipbones. It contains your bladder and bowels as well as lymph glands. In women it also contains the womb and ovaries. In men it contains the prostate gland.

Radiotherapy	A treatment that uses high-energy X-rays to cure or control cancer and other diseases.
Staging	Finding out the size and extent of cancer.
Stoma	An artificial opening on the surface of your abdomen. See also urostomy.
Superficial bladder cancer	An early type of bladder cancer that affects the cells in the inner lining of your bladder.
Transitional cells	Cells in the lining of your bladder.
Urethra	The tube through which you pass urine. Also known as the water pipe.
Ureter	The tube that drains urine from your kidneys to your bladder.
Urostomy	An opening onto the surface of your abdomen. Part of your bowel is used to drain urine after your bladder has been removed. A bag is worn over the opening to collect the urine. It is also called an ileal conduit.

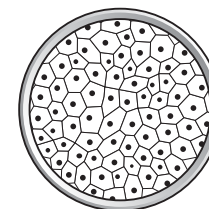
Before diagnosis

What is cancer?

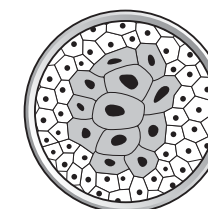
Cancer is a word used to describe a group of diseases. Each one has its own name. For example, skin cancer, lung cancer and breast cancer. Each has an individual type of treatment and chance of being cured.

In the body, the organs and tissues are made up of tiny building blocks called cells. All cancers are a disease of the body's cells. In healthy tissue these cells replace or repair themselves when they get worn out or injured. With cancer, the cells do not behave as normal and keep on growing, even when there is no need.

These groups of abnormal cells can form a lump or tumour. Tumours can be either benign or malignant. Benign tumours do not spread to other parts of your body and so are not called cancer. Malignant tumours are cancer cells that can spread from where they first grew. This happens when a cell or group of cells breaks away and is carried by the bloodstream or lymph glands to form a new tumour somewhere else in your body. This is called a metastasis or secondary tumour.



Normal cells



Cells forming a tumour

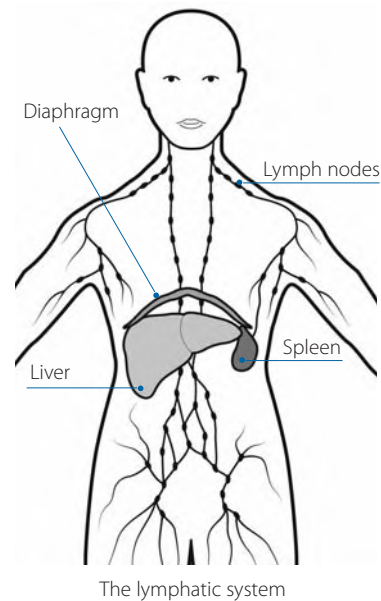
What is the lymphatic system?

Every day your body defends itself against infection in many ways. The lymphatic system is one way. Like the bloodstream it carries material around your body. It is made up of a network of tiny tubes that pass through most of the tissues in your body. These tubes carry a clear watery fluid called lymph.

Along the network are hundreds of small glands shaped like beans. These are called lymph nodes and they remove unwanted material from the lymph like a sieve. They also help white blood cells called lymphocytes to protect your body against infection.

Lymph nodes are found in groups throughout your body, such as in your neck, armpits and groin. Sometimes you may notice these glands if they become swollen. More of these lymph nodes are found in larger groups in your chest and abdomen. Other parts of the lymphatic system include your spleen, thymus, tonsils and bone marrow.

Lymph nodes can also spread cancer cells.



To sum up

- Cancer is a disease of the cells of the body.
- With cancer, the cells do not behave as normal. They keep on growing even when there is no need.
- If a tumour is malignant, cells can break away and be carried by the bloodstream or lymph somewhere else. This is called a metastasis or secondary tumour.

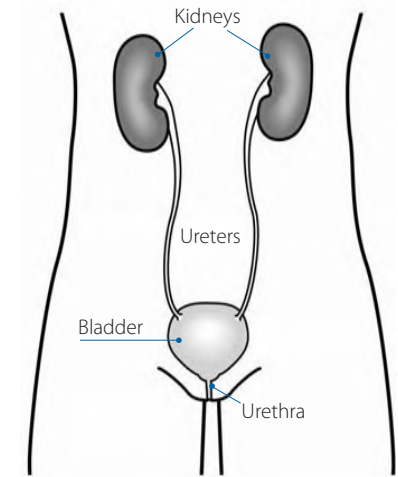
What is the bladder?

Your bladder is a hollow organ like a balloon that sits in your pelvis. This is the lower part of your abdomen. The bladder wall is made of muscles and lined with cells known as urothelial cells.

Your bladder stores urine until it is full. Urine is made in your kidneys

and contains water and waste products. The urine leaves your kidneys through tubes called ureters. When your bladder is full, nerves send a message to your brain that you need to pass urine. When you are ready to pass urine, the bladder muscle contracts. This forces the urine out through a tube called the urethra. It is often called the water pipe.

In women, the urethra is short and leaves your body just next to your vagina. In men, the urethra is much longer and goes through your prostate gland and penis to leave your body.



The bladder and kidneys

What is cancer of the bladder?

Cancer of the bladder happens when abnormal cells appear in the lining of your bladder or in the bladder wall. The lining of the bladder is called the urothelium. The cells in the lining are known as transitional cells. Cancer cells can affect how the bladder works normally.

Bladder cancer affects about 482 people in Ireland each year. It is more common in men than women.

Types of bladder cancer

Bladder cancer can grow in different ways.

Transitional cell cancer: This is the most common type of bladder cancer. About 9 out of 10 bladder cancers are of this type. These cancers begin in the transitional cells that line your bladder and usually appear as small growths. This is known as **early** or **superficial bladder cancer**.

Occasionally these abnormal cells grow very quickly and spread to the muscle wall in the bladder and nearby tissues. This is known as **invasive bladder cancer**.

Carcinoma in situ: This type appears as red ulcers inside your bladder. The cells are very abnormal. There is a higher risk that it can lead to invasive bladder cancer than with other superficial bladder cancers.

Squamous cell and glandular cell bladder cancer: Squamous cells and gland cells are also found in your bladder. Invasive bladder cancer can also affect these cells.

Advanced bladder cancer

Bladder cancer can also spread beyond the bladder. If this happens, it is called advanced bladder cancer. If the tumour has spread to nearby organs, it is called locally advanced disease. For example, to the womb and vagina in women or to the prostate in men.

The lymph nodes in your pelvis can also be affected. If the cancer has spread to the liver, bones, lungs, or other parts of your body, these are known as distant metastases.



To sum up

- Cancer of the bladder happens when abnormal cells appear in the lining of the bladder wall.
- Bladder cancer can be either superficial or invasive.

National Cancer Helpline 1800 200 700

What causes bladder cancer?

The exact cause of bladder cancer is unknown. But there are certain things called risk factors that can increase your chance of developing it. The biggest risk factors are smoking and industrial chemicals. The following factors can raise your risk of developing bladder cancer:

- **Smoking:** If you smoke, you are much more likely to develop bladder cancer than a non-smoker. Your risk is higher the longer you have smoked and the more cigarettes you smoke. Once you have bladder cancer, stopping smoking will reduce your risk of further bladder tumours.
- **Chemicals:** If you once worked with certain chemicals, you could be at risk. For example, chemicals used in textile, rubber, leather, dye, paint or print industries. These chemicals are now banned and no longer in use.
- **Age:** As you get older, your risk increases. Most bladder cancers occur in men and women over the age of 50.
- **Gender:** If you are male, you are three to four times more likely to get bladder cancer than women.
- **Race:** White people are more likely to get bladder cancer than black people. Asian people have a lower rate again.
- **Radiotherapy:** If you have had radiotherapy to your pelvis, your risk of bladder cancer is slightly increased.
- **Chemotherapy:** If you ever received the chemotherapy drug cyclophosphamide (Cytosan), you have a higher risk of bladder cancer.
- **Infection:** Your risk of bladder cancer increases if you have repeated urinary tract infections or bladder stones. An untreated infection with the parasite schistosoma (also called bilharzia) can lead to bladder cancer. This parasite is often found in water in the developing world.

If you feel you may be at risk, talk to your family doctor (GP) about your concerns.

What are the symptoms of bladder cancer?

The most common symptom of bladder cancer is blood in your urine. This is known as haematuria. Symptoms of bladder cancer can include:

- Blood in your urine – from rusty brown to deep red
- Need to pass urine more often
- Need to pass urine urgently
- A burning feeling when you pass urine

Symptoms of advanced bladder cancer can include:

- Pain
- Change in your bowel habits
- Unexplained loss of appetite
- Weight loss

The blood in your urine may not be present all the time, but can come and go. It may even disappear for weeks or months.

Remember the urine symptoms above can also be signs of an infection or inflammation in your bladder, kidney stones, or an enlarged prostate gland. Do have the symptoms checked out by your doctor, as you may need tests.



To sum up

- The most common symptom of bladder cancer is blood in your urine.
- Your urine may vary from rusty brown to deep red.
- The blood in your urine may disappear but come back again.
- Your symptoms can be caused by conditions other than cancer, so do have them checked out by your doctor.

How is bladder cancer diagnosed?

If you have any symptoms, visit your family doctor (GP) first. He or she may test a sample of your urine for blood. Sometimes urine tests can show up even tiny amounts of blood that cannot be seen with the naked eye. If you do have blood in your urine, your GP will refer you to a specialist called a urologist.

At the hospital, the doctor will ask you questions about your symptoms and general health. He or she will also do a physical exam by feeling your tummy and examining the organs close to your bladder. This includes the back passage (rectum) in men and vagina in women.

Special tests

You are likely to have the following tests done:

- Blood tests
- Urine tests
- Cystoscopy and biopsy
- Ultrasound scan
- Intravenous pyelogram (IVP)

If you are tested for bladder cancer, you will have either an ultrasound scan or IVP as well as a cystoscopy.

Cystoscopy and biopsy: A cystoscopy uses a small flexible tube to see inside your bladder. The tube is called a cystoscope and is like a telescope with a camera at one end. You will be given a local anaesthetic before the test. This is done by placing a special gel in your water pipe (urethra). Your doctor will then put the camera up through your water pipe to look into your bladder.

If your doctor sees any abnormal tissue, he or she will do a biopsy. This involves taking a sample of tissue and looking at it under a microscope in the laboratory. Sometimes you might need to have a second biopsy and exam under a general anaesthetic. This is because biopsies taken under local anaesthetic are often very small.

A biopsy is the only way to diagnose bladder cancer. It will tell which type of bladder cancer you have and the grade. See page 15 for more about the grades of bladder cancer.

Ultrasound scan: An ultrasound scan uses sound waves to build up a picture of the tissues inside your body. This test looks at your kidneys and also your bladder. Before the scan you will need to drink plenty of fluids and not empty your bladder. Better pictures of your bladder can be taken if your bladder is full. A gel will be placed on your tummy before the scan and a probe is then rubbed over it. This probe makes pictures that can be seen on a computer screen. The test is not painful or uncomfortable and lasts about 15 minutes.

Intravenous pyelogram (IVP): In this test a dye is injected into your bloodstream. The dye contains iodine which can show up on X-rays. After the dye passes through your kidneys, it enters your urine. This helps your bladder to appear more clearly on an X-ray and show up the outline of any tumour in your bladder wall. This test can also show up any abnormal areas in the kidneys.



Intravenous pyelogram (IVP)

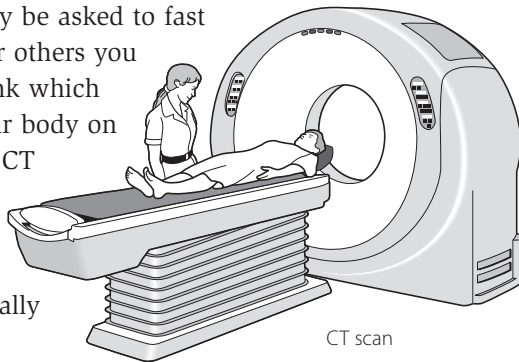
Further tests

Your doctor may also decide to do more tests. This will depend on the stage and grade of your cancer. These tests include:

- CT scan
- MRI scan
- Bone scan

CT scan: This is a special type of X-ray that gives a detailed picture of the tissues inside your body. The scan is painless.

For some CT scans you may be asked to fast for 4 hours beforehand. For others you may be given a special drink which helps show up parts of your body on the scan. Preparation for a CT scan can vary between hospitals. Your doctor or nurse will let you know what to do. The test is usually done as an outpatient.



CT scan

MRI scan: This is a special scan that uses magnetic energy to build up a picture of the tissues inside your bladder and nearby organs. It does not hurt but can be very noisy. But you will be given earplugs to wear during it. You might have an injection before the scan to show up certain parts of your body.

You cannot wear any metal jewellery during the scan. If you have medical devices implanted, like pacemakers, you are not suitable for the test. Usually you can go home afterwards.

Bone scan: Bone scans are very sensitive and can find cancer cells before they show up on an X-ray. For this test, a very small amount of a mildly radioactive substance is injected into a vein, usually in your arm. A scan is then taken of all the bones in your body. Because abnormal bone absorbs more of the radioactive substance than normal bone, it can show up on the scan.

After you get the injection, you must wait for up to 3 hours before the scan can be taken. The amount of radioactivity used in these scans is very low and safe. It disappears from your body within a few hours.

Waiting for results

It may take some time for all the test results to come back. Naturally, this can be an anxious time for you. It can help to talk things over with the specialist nurse or with a relative or close friend. You may also wish to call the National Cancer Helpline 1800 200 700 and speak to one of our specially trained nurses.

What are the grades of bladder cancer?

The grade of a cancer is known by looking at its cells under a microscope. These cells are usually from a biopsy. The grade describes how much the tumour tissue looks like normal bladder tissue. It helps your doctors to find out how quickly the cancer may grow and spread. That way, they can decide on further tests and the best treatment for you.

There are different ways to grade bladder cancer. The most commonly used system has three grades.

- Grade 1 – low grade
- Grade 2 – moderate grade
- Grade 3 – high grade

Low grade cancer cells grow slowly and are less likely to spread. High grade cells grow faster and are more likely to spread. Grade 2 is in between.

What are the stages of bladder cancer?

Your doctor may arrange some tests to stage the cancer. Some of these tests are mentioned on page 14. Staging means finding out the size of the tumour and if it has spread anywhere else in your body. Staging helps your doctor to plan the best treatment for you.

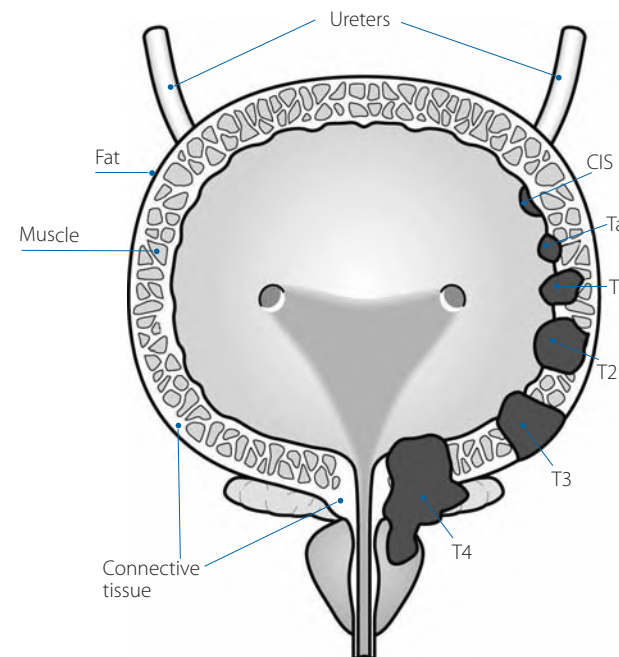
The staging system normally used in bladder cancer is called TNM. This stands for ‘tumour, node, metastasis’. It refers to how deeply the tumour has grown into your bladder (T), if there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M).

»» Staging allows your doctor to plan the best treatment for you.

Tumour

Carcinoma in situ (CIS) is a form of early bladder cancer. It appears as flat, red areas in your bladder. This type of bladder cancer often comes back after treatment, often as another superficial cancer in the bladder. CIS can grow more quickly and can become invasive. This means it may need different treatment to other early bladder cancers.

Ta and T1 tumours refer to superficial or early bladder cancer. It is not uncommon to have more than one tumour in your bladder at any one time. These superficial bladder cancers appear as small tumours inside your bladder. Cancer that has grown further into your bladder is given a T number from 2 to 4. T2 and T3 are classed as invasive bladder cancer. T4 is advanced bladder cancer.



Stages of bladder cancer

- **Ta:** Here the tumour is found only in the innermost lining of your bladder.
- **T1:** The tumour has started to grow into the connective tissue just below the bladder lining.
- **T2:** The tumour has grown into the muscle layer in your bladder.
- **T3:** The tumour has spread through the muscle layer to the outer fat layer around your bladder.
- **T4:** The cancer has spread outside your bladder to other organs. For example, the abdominal wall, the pelvic wall, the prostate in men, or the womb and vagina in women.

Nodes

There are four lymph node stages in bladder cancer.

- **N0:** No cancer is found in any of your lymph nodes.
- **N1:** Cancer is found in one lymph node and is smaller than 2 cm.

- **N2:** Cancer is found in one lymph node and is bigger than 2 cm but less than 5 cm. Or the cancer has spread to more than one lymph node, but is smaller than 5 cm.
- **N3:** Cancer is found in at least one lymph node and is 5 cm in size.

Metastasis

There are two stages if the cancer has spread beyond the bladder (metastasis).

- **M0:** The cancer has not spread to other parts of your body.
- **M1:** The cancer has spread to other parts of your body. This is also known as secondary, metastatic or advanced bladder cancer. The organs likely to be affected are your bones, liver or lungs.



To sum up

- A biopsy can give information about the grade and stage of the cancer.
- The grade describes how much the tumour tissue looks like normal bladder tissue.
- The stage refers to the size and if the cancer has spread.
- Further tests will be needed to find out if the cancer has spread.
- Once the stage of the cancer is known, your doctors can plan the best treatment for you.

Treatment and side-effects

How is bladder cancer treated?

The way bladder cancer is treated mainly depends on the stage of the disease at diagnosis. The type of treatment you receive will depend on:

- The size and stage of your cancer
- The type and grade of cancer
- If it has spread or not
- Your general health

Surgery, chemotherapy and radiotherapy can all be used to treat bladder cancer. Superficial or early bladder cancer is treated differently to invasive bladder cancer.

How is superficial bladder cancer treated?

Early or superficial cancers are usually small tumours that appear on the inner lining of your bladder. There may be more than one tumour. Surgery is the main treatment but you may need some drug treatment into your bladder afterwards. This is known as intravesical chemotherapy.

Surgery

TURBT: This surgery is called transurethral resection of bladder tumour (TURBT). For this, your surgeon puts a tube called a cystoscope into your bladder through your water pipe (urethra). The tube is like the one used in a cystoscopy (see page 13). You will be given a general anaesthetic or epidural so you will not feel anything. Your surgeon will put a special wire loop through the tube and will cut or burn off the tumour. An electric current seals the wound so stitches are not needed.

National Cancer Helpline 1800 200 700

Catheter: After surgery, you may have a thin, flexible tube in your bladder for a day or two. This tube is called a catheter and drains your urine into a bag. Don't be alarmed if your urine is bloodstained at first. This is normal. Large bags of fluid may be used to flush out your bladder continuously. This prevents blood clots forming and blocking the tube.

Removing the tube: The tube will be removed once you are drinking normally and your urine looks fairly clear. Removing the tube is not painful but may be a little uncomfortable. Once the tube is removed, you can go home. This is usually about a couple of days after the surgery. It is not unusual to see blood in your urine for some weeks after this operation. It may clear up for a few days and then come back again. This is normal.

Will I need more treatment?

Superficial bladder tumours often come back and if this happens you may need another TURBT in the future. For this reason you will be reviewed with regular bladder checks for many years.

Higher grade cancers often need more treatment than lower grade tumours. Sometimes they need to be treated in the same way as invasive bladder cancer. In this case, your doctor and nurse will give you more details.

Intravesical chemotherapy: Your doctor may decide to give you chemotherapy directly into your bladder. This treatment is known as intravesical chemotherapy. It is done by putting the drug through a catheter tube to reach your bladder directly. You might receive it on the day you have the TURBT or later. The drug reduces the risk of the cancer coming back.

Some people need a short course of drugs into the bladder after the TURBT. These drugs are usually given once a week for 6 weeks. Two drugs often used are the BCG vaccine or mitomycin C. They only work for cancer cells that are in the lining of your bladder (superficial). They do not work for cancer that has spread to your bladder wall. Your doctor or nurse will give you more information if needed.

Maintenance therapy: Sometimes the above drug treatments are repeated and given regularly. This is known as maintenance therapy. It reduces the chance of the tumour coming back for certain grades and stages of early bladder cancer.

Follow-up: The nature of superficial bladder tumours is that they come back from time to time. You will usually need to see your surgeon (urologist) every few months for the first year or two. After that it will be every 6 months for about 2 years, and once a year after that. If your tumour comes back you may need to be seen more often. At each visit, you will have a cystoscopy with or without a biopsy and urine tests. These are to make sure the cancer has not come back. Your surgeon will let you know how often you need to visit him or her.

How is invasive bladder cancer treated?

The following are used to treat invasive bladder cancer:

- Surgery
- Radiotherapy
- Chemotherapy

Surgery: Surgery for invasive bladder cancer usually involves removing your bladder. This means you can no longer pass urine in the usual way. See page 25 for more about surgery.

Radiotherapy: This involves using high energy X-rays to kill the cancer cells. Your bladder will not be removed but may be affected in the long term by radiotherapy side-effects. See page 31 for more about radiotherapy.

Chemotherapy: This is the use of drugs to kill or control the cancer cells. If the cancer has spread to the bladder muscle or elsewhere in your body, the drugs may be given into a vein. This means the drugs travel around your body in your bloodstream and can reach any cancer cells. Chemotherapy may be used along with either surgery or radiotherapy. In rare cases, chemotherapy on its own may be used. See page 37 for more about chemotherapy.

Your doctor will let you know which treatments are most suitable for you. He or she will try to save all or part of your bladder wherever possible. In some cases both surgery and radiotherapy may be suitable and you may be offered a choice. Your doctor and specialist nurse can help you make your decision. You can also call the National Cancer Helpline on 1800 200 700 for advice and help.

Deciding on treatment

Treatment options: Your doctor and nurse will explain your treatment options to you. Do ask as many questions as you like, no matter how small or trivial you think they are. All questions are important. You could use the fill-in page at the back of this booklet for your questions and answers.

Time to think: When faced with a life-threatening illness, it can be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You might even want more time to think things through. Remember there is always time for you to consider what sort of treatment you want.

Second opinion: If you are anxious, you might find it reassuring to have another medical opinion. This can help you decide about your treatment. Your doctor will 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 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 informed of the benefits and risks.

>>> No medical treatment will be given without your consent.

Giving consent for treatment

You may be asked to sign a consent form saying that you give permission for the treatment to take place. No medical treatment can

be given without your consent. Before treatment, you should know:

- The type of treatment you are advised to have
- The benefits and risks of the treatment
- Any other treatments that may be available
- Any major side-effects of the treatment

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.

Individual treatment

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



Who will be involved in my care?

Some of the following health professionals may be involved in your care at the hospital. Usually, a team of cancer care doctors plans your treatment.



Urologist	A doctor who specialises in treating diseases of the bladder and kidneys.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
Oncology liaison nurse / clinical nurse specialist	A specially trained nurse who cares for patients who have bladder cancer. They can give you information and reassure you and your family from diagnosis and throughout treatment.

Stoma care nurse	A specially trained nurse who can teach you how to care for a urostomy (stoma).
Radiation therapist	A radiotherapist who specialises in giving radiotherapy and advice to cancer patients.
Physiotherapist	A therapist who treats injury or illness with exercises and other physical treatments related to the illness.
Dietitian	An expert on food and nutrition. They are trained to give you advice on diet during your illness and use diet to help your symptoms.
Occupational therapist (OT)	A therapist who specialises in helping you manage your daily activities. For example, caring for yourself. They are mainly concerned with hand strength and the use of arms and legs.
Medical social worker	A person specially trained to help you and your family with all your social issues and practical needs. They are skilled in giving counselling and emotional support to children and families at times of stress and change. They can give advice on benefits, entitlements and services available to you when you go home.
Psychologist	A specialist who can talk to you and your family about emotional and personal matters and can help you make decisions.
Counsellor	A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.

Surgery

The aim of surgery for invasive bladder cancer is to remove the cancer and the area close to it. Surgery to remove the bladder is called a cystectomy. It is also known as a radical or total cystectomy. It is the most common type of surgery for invasive bladder cancer. If your surgeon removes just part of your bladder, it is called a partial cystectomy.

In a radical cystectomy, your surgeon not only removes your entire bladder but also nearby tissues and organs. Lymph nodes in your pelvis are also removed. Your surgeon will let you know exactly which organs need to be removed. He or she will also discuss any side-effects linked to the surgery.

Ways of draining urine

Once your bladder is removed, you can no longer pass urine in the usual way. A new way will be made to drain urine from your body. This will be done in the same operation to remove your bladder. Sometimes it is possible to make a new bladder. Your surgeon will explain the different ways of draining urine. These include:

- Urostomy (ileal conduit)
- Continent urinary diversion
- Bladder reconstruction

Urostomy: Your surgeon can use part of your small bowel to bring urine to an opening outside your body. This is known as a urostomy or an ileal conduit. To do this, your surgeon uses about 6 inches of your small bowel to make a passage. The two kidney tubes (ureters) will be then be attached to it. One end of the passage is closed up with stitches, while the other end is brought through to the surface of your tummy. The open end is called a stoma and looks like the skin inside your cheek. You will need to wear a bag attached to the stoma to collect and drain your urine.

Continent urinary diversion: It may be possible for your surgeon to make a urinary reservoir. This is a storage pouch that sits inside your body. It is made by using a part of your small or large bowel.

Sometimes the pouch is connected to the skin on your tummy by a small opening (stoma). In this case, you do not need a urinary pad or bag. You can drain the pouch regularly yourself by putting a thin tube (catheter) through the small opening, then removing the tube and covering the opening with a bandage.

Bladder reconstruction: Your surgeon may be able to make an artificial bladder by connecting the pouch to your water pipe (urethra). This is known as a neobladder. In this case, you can pass urine more normally.

How do I prepare for surgery?

Tests: To make sure you are fit for surgery, some extra tests may be done. These could include a chest X-ray, heart test (ECG), blood pressure and more blood tests.

Deep breathing exercises: A physiotherapist will show you how to do deep breathing exercises. These will help to prevent a chest infection or blood clots after surgery. Your nurse will arrange for you to have a pair of elastic stockings as well. These are to prevent you getting blood clots in your legs after surgery.

Stoma nurse: This is a nurse who specialises in the care of people who have a stoma (urostomy). The stoma nurse will visit you before surgery to discuss having a stoma. She or he will mark on your skin the best place for the new stoma to be located.

Bowel preparation: Your nurse will give you advice on how to clear out your bowels fully. This is so that your surgeon can get a clean segment of bowel to make the urostomy. You may have to drink a special solution or take clear fluids only.

Night before surgery: You will not be allowed to eat anything from 12 midnight. You might get an injection of heparin to prevent blood clots forming in your legs.

Morning of surgery: You will continue to fast at this time. Before you go to theatre, you may get a tablet to make you feel sleepy and more relaxed.

After the surgery

After surgery you will have a wound as well as tubes, drips and drains attached to your body. These are normal in an operation like this. Most patients stay in hospital for 7 to 14 days.

- **Wound:** The wound site will be along your tummy. The line of stitches will go from below your breastbone to your pubic bone. Stitches or staples are usually removed 7 to 10 days after your surgery. An opening (urostomy) will be on the right-hand side of your tummy just below your waist.
- **Urostomy bag and ureteric stents:** The urostomy bag is the bag that collects urine and attaches to the skin around your newly formed stoma. Ureteric stents are fine tubes that help the flow of urine from your kidneys.
- **Wound drains:** These tubes drain away any blood from your wound site. They are removed when there is little or no drainage and the area is healing.
- **Drips:** A drip will be put into a vein in your arm or neck to give fluids into your bloodstream. This will be removed once you can drink fluids by mouth again.
- **Nasogastric tube:** This is a thin tube in your nose which goes down into your stomach. It helps to keep your stomach empty and stop you feeling sick but also to allow your bowel to heal after surgery.
- **Epidural:** You may have a thin tube in your back to relieve any pain. This is called an epidural. Your doctors and nurses will help to ease any pain or discomfort you have. There are several ways to relieve pain and they may be used singly or together.
- **Bowel motions:** The surgery will slow down your bowels and they will need time to heal as well. As a result, it will take a few days before you can return to normal eating and drinking. At first, you will be able to take sips of water. Gradually the amount of fluids will be increased and you can begin to take light meals.

- **Exercising:** You must move your legs while in bed and do deep breathing exercises at least once an hour. On the day after surgery, your nurses will help you get out of bed and take you for a short walk. As you get better, these walks will become longer and you can go on your own. Sitting down may not be easy at first but should get better as your wound begins to heal.

Caring for your urostomy

After the surgery, your urine will pass down the ureters from your kidneys, through the piece of bowel and out through the stoma. You will need to wear a waterproof bag over the stoma to collect the urine. This bag is called a urostomy bag and it sticks over the stoma. You can empty the bag as often as needed. The bag clicks onto a special bib called a flange that sticks to the skin around the opening.

For the first 7 to 10 days, fine plastic tubes will be placed up through the ureters. These are called ureteric stents and they support the new system while healing occurs. The stents can be seen coming out of the stoma into the urostomy bag.

After surgery, your stoma nurse will visit you to check how you are getting on. It can take a while to adjust to having a stoma. Your stoma nurse and other nurses will teach you how to care for your urostomy.



Urostomy

She or he will show you how to put the bag on correctly so that it protects the skin around the stoma. That way, your skin will not be damaged by urine.

It can take a while before you feel confident about managing the urostomy bags. Once you go home, there is further help available. The community stoma nurse can visit you at home to discuss any concerns.

What are the side-effects of surgery?

General side-effects: With all surgeries there is a small risk of bleeding and infection. For example, infection in your wound, chest or urine. Your doctors and nurses will watch you closely to make sure these risks are reduced, or treated quickly if they happen. You can also help to prevent infection yourself by having good hygiene and doing deep breathing exercises.

Bowel side-effects: There is a small risk that your bowel will become inactive and take a while to return to normal. This is known as paralytic ileus. It can happen after any surgery that involves handling of the bowel. There is also a very small risk of a bowel leak. This is because your bowel has been divided to take a part out and the two ends have been joined together.

Sexual problems: Surgery to remove your bladder can cause damage to the muscles and nerves in your pelvic floor. This means that you may experience physical problems when having sex. There are also emotional issues relating to a change in body image and loss of libido. See page 44 for more about the side-effects of treatment and sex life.

What happens when I go home?

Getting supplies: When you leave hospital, you will be given some dressings and urostomy bags to last a few days. You will also be given a prescription for more supplies from your pharmacy. Go to the pharmacy to get these as soon as possible. Most pharmacies do not keep them in stock and it may take a few days for supplies to arrive. Some pharmacies have a direct delivery service where you can telephone in your order and they will send out your supplies by post. Ask your stoma nurse if this service is available in your area.

Support at home: You can contact the hospital or stoma nurse if you have any problems at home. Your local public health nurse and/or community stoma nurse may also come out to see you. This visit can be arranged before you go home.

Being comfortable: There are many stoma accessories to help make life more comfortable for you. These include girdles, support belts, deodorisers, wipes, skin protective wipes, lotions and creams, adhesive removers, stoma paste, rings and disposal bags. There are also snug clothes like underwear and swimwear you can wear.

Support group: The Urostomy Association, based in the UK, is run by people who have had similar surgery and have a stoma. They have a range of leaflets and a DVD which can be ordered online or by post. See www.urostomyassociation.org.uk for more details.



Hints & Tips – living with a urostomy

- The urostomy bag will usually last 3 to 5 days. Do not change it earlier unless needed. If you remove the adhesive flange more frequently, it may irritate and damage the skin around your stoma, causing soreness.
- If the bag leaks, change it as soon as you can. The longer your skin is exposed to urine, the more damage to your skin will occur.
- The flange will not stick so well to moist or damaged skin. This may cause odours and leaking bags.
- Empty the pouch before it gets too full as the weight of the urine may 'pull' on the flange. This can cause the flange to come away from your skin.
- It is normal to find mucus in your urine. The part of your bowel used to form the urostomy makes the mucus.
- Make sure you are using a flange of the correct size. Your stoma may get smaller as time goes by.
- Keep enough supplies so you don't run out. You may wish to keep a spare bag in the car or at work in case the urostomy needs to be changed. Keep a plastic bag handy for getting rid of your old bag.
- When you go on holiday, remember to take enough supplies with you.



To sum up

- Your doctor will decide which type of surgery is best for you.
- Most people are ready to go home within 7–14 days.
- This is major surgery and you will need to give yourself time to recover once you are home.
- You will be taught how to care for your urostomy before you are discharged from hospital.
- You will be given a small supply of stoma bags and information on how to get more bags by the stoma nurse.

Radiotherapy

Radiotherapy is the use of high-energy X-rays to kill cancer cells. It is also called radiation oncology. The doctor who specialises in radiotherapy is called a radiation oncologist, while the person who delivers the treatment is called a radiation therapist.

Radiotherapy for invasive bladder cancer can be given at different times and for different reasons:

- Instead of surgery
- Before surgery to shrink a tumour
- After surgery to destroy any remaining tumour
- With chemotherapy to make the treatment work better
- To relieve symptoms if the cancer is advanced or has come back. For example, pain, discomfort, bleeding or blockage
- To treat a single spread of cancer, such as in your brain or bone

After radiotherapy for bladder cancer, you will need close follow-up. This is to make sure the cancer does not come back. You will need to have regular cystoscopies (see page 13) after your radiotherapy. If the cancer does come back, your bladder might need to be removed.

There are different types of radiotherapy but external beam is used most commonly in bladder cancer. This is radiation given from a machine outside your body.

External beam radiotherapy

With external beam radiotherapy, the X-rays come from a machine called a linear accelerator. They are aimed directly at your cancer cells to destroy or shrink them. The radiation only affects the cells in the treated area. Your doctor will let you know how many sessions or treatments you need. The treatment is usually given Monday to Friday with a rest at the weekend. Each treatment session takes about 10–15 minutes. The sessions are given over a period of 4–7 weeks but this will depend on your doctor's decision.

>>> The radiation only affects the cells in the treated area.

Planning your external radiotherapy

First, your doctors and other specialists plan how best to give you the treatment. They work out how to give you the right amount of radiotherapy with the least damage to normal cells.

Treatment planning is a very important part of radiotherapy. It may take a few visits to the radiotherapy department before your treatment can go ahead. On your first visit, you may be asked to lie under a machine called a simulator. This takes X-rays of the area to be treated. Or you may have a CT scan for planning your treatment instead.

The area to be treated will be marked on your skin. These marks are like dots and are made with a permanent tattoo. That way the X-rays can be aimed at the same area each day. Before starting radiotherapy, you will be told how to look after your skin during and after treatment. If you have any queries, do ask your radiation therapist or nurse for advice.

Getting your radiotherapy

External radiotherapy treatment is quite straightforward. Each treatment session only lasts a few minutes. It will not cause you any pain during treatment but you will be asked to lie still. How much you need will depend on the type and size of your tumour. Your doctors will discuss this with you.

Each time you go for treatment you will go into a special room. The radiation therapist will ask you to lie or sit in a certain position under the machine. To prevent less radiation reaching your bowel and so reduce any side-effects, a special piece of equipment called a belly board may be used.

When you are ready the radiation therapist will leave the room. The machine will then be turned on and your treatment given. Even though you are on your own in the room, your radiation therapist can see you all the time through a closed circuit camera. You can talk through an intercom to the staff if you wish.

For more information about radiotherapy, call the National Cancer Helpline 1800 200 700. Ask for the booklet called *Understanding Radiotherapy* or the DVD called *Radiation Therapy: A Patient Pathway*.

Will I have any side-effects?

Radiotherapy is given directly to the area where the cancer is found. As a result, side-effects will only occur in the part of your body being treated. How severe these side-effects are will vary from person to person and depend on the dose and length of treatment. Side-effects can be either short term or long term.

Some common side-effects in the short term are:

- Bladder irritation
- Diarrhoea or constipation
- Irritation to back passage
- Skin changes
- Fatigue



Linear accelerator

Bladder irritation: Sometimes the bladder can become irritated during radiotherapy to the pelvic area. This can make you pass urine more often, sometimes with a stinging or burning feeling. There may also be a trace of blood in your urine. If you get these side-effects, discuss them with your nurse or radiation therapist.

Diarrhoea or constipation: Passing more than three watery bowel motions a day is known as diarrhoea. This is a fairly common side-effect of radiotherapy to the pelvis. You may also have stomach cramps and wind. If this happens, drink lots of fluids to replace the fluid you are losing. It is also best to eat a low fibre diet and cut down on fruit and vegetables, brown bread, porridge and beans if you suffer with diarrhoea. There is also medication that can help to stop diarrhoea. Do talk to your radiation therapist and nurse for advice.

Constipation can be a problem too. It is best to continue on your normal diet until your bowel motions become looser. This may happen towards the end of your radiotherapy treatment. Do talk to your radiation therapist or nurse for advice about bowel problems during radiotherapy.

Diarrhoea and constipation may continue for some weeks after your treatment. Once they settle down you can return to a normal healthy diet.

Irritation to back passage: Radiotherapy can cause irritation to your back passage (rectum) and anus. It can cause a feeling of fullness and pressure there. You may have the urge to empty your bowel but without success when you go to the toilet. It may also be itchy around your anus as well as sore. Bleeding from the back passage can happen sometimes with radiotherapy to the bladder. You might notice a slimy mucous discharge too. Piles can also get irritated from the treatment. There are creams and suppositories that you can take to relieve these problems. Do talk to your radiation therapist or nurse about them.

Skin changes: During radiotherapy the skin in the treated area may become red, sore and itchy. This can be helped by special creams. Your radiation therapist or nurse will give you advice on suitable creams.

You can take baths and showers while on treatment, but avoid perfumed soaps or powders to the treated area. Do not rub the area and when drying your skin, pat it gently with a soft towel. There may also be loss of hair in the treated area. But this will grow back once the treatment is over.

Fatigue: Fatigue or ongoing tiredness can build up over the course of your treatment. It may be due to the treatment itself or because you have to travel long distances for treatment. Rest as much as you can. While on treatment cut down on the things you normally do if you suffer with tiredness. A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy. For more about fatigue, see page 42.

Is radiotherapy dangerous?

Some people are scared of radiotherapy at first, but there is no cause for concern. Radiotherapy does not make you radioactive. There is no danger to you and your family and you can mix freely with them. You do not have to avoid children or pregnant women.

Other effects

These side-effects or any other problems you develop will be watched carefully during your treatments. You will be given information on how to prevent side-effects and medication will be prescribed if needed.

All these side-effects should go away when treatment is over, but do let your doctor and nurse know if they continue. A helpful booklet called *Understanding Radiotherapy* is available from the Irish Cancer Society and also a DVD called *Radiation Therapy: A Patient Pathway*. Call the National Cancer Helpline 1800 200 700 for a free copy.

Side-effects in the long term

You may develop more permanent side-effects a year or two after your treatment. Often there are lasting problems to your bladder or bowel.

These side-effects in the long term can include:

- Passing urine more often because your bladder has shrunk in size.
- Blood in your urine because small blood vessels have grown on the surface of your bladder. If this happens, tell your doctor straight away so a cystoscopy to check your bladder can be done.
- A change in your bowel habits. For example, diarrhoea or blood in your bowel motions.
- Difficulty getting an erection is common in men after radiotherapy to this area. This is known as erectile dysfunction. It can happen some time after the radiotherapy has finished.
- Shorter vagina in women, making sex difficult or uncomfortable.
- Infertility.

Do let your doctor know if you have any changes to your bowel habit or blood in your urine. Tests can be done and further treatment given. See page 44 for more about erectile dysfunction and a shorter vagina. See page 46 for more about infertility.



To sum up

- Radiotherapy is a treatment using high-energy X-rays to kill cancer cells.
- The X-rays are aimed directly at the cancer to cure or shrink it.
- A lot of preparation is needed before the actual treatment is given.
- Radiotherapy is painless and only takes a few minutes.
- The treatment can continue for several weeks.
- Side-effects to radiotherapy depend on the area being treated and the type of radiotherapy given.
- The side-effects can include bladder irritation, diarrhoea or constipation, irritation to back passage, skin changes, and fatigue.

Chemotherapy

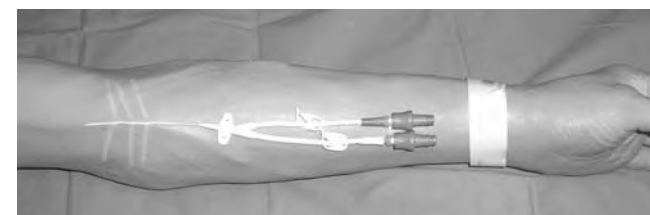
Chemotherapy is a treatment using drugs that cure or control cancer. It can also reduce the risk of cancer returning. The doctor who specialises in chemotherapy is called a medical oncologist.

You can be given chemotherapy for bladder cancer at different times and for different reasons:

- Before surgery or radiotherapy to shrink the cancer and reduce the risk of it coming back
- At the same time as radiotherapy to make the treatment work better
- After surgery to reduce a high risk of the cancer coming back
- As a treatment on its own for advanced bladder cancer

How is chemotherapy given?

Chemotherapy is usually given directly into a vein as an injection or through an infusion or drip. A central line that gives drugs into a large vein in your chest may be used. Or a PICC line that gives drugs into your arm may be more suitable. Some drugs can be given in tablet form. The chemotherapy drugs are carried in your bloodstream to almost every part of your body.



PICC line

Chemotherapy is often given in cycles. For example, every 3–4 weeks with a rest period between treatments. Usually the treatment is given to you as a day patient in the hospital. Chemotherapy drugs are often given in combination. Your doctor will decide which drugs you should have. See the Irish Cancer Society's website www.cancer.ie for more information about the drugs chosen by your doctor.

If you would like more information on chemotherapy, call the National Cancer Helpline 1800 200 700. Ask for a copy of the booklet, *Understanding Chemotherapy*, or the DVD called *A Guide to Chemotherapy*.

Side-effects of chemotherapy

The side-effects of chemotherapy vary from person to person and depend on the drugs used. These unwanted side-effects happen because chemotherapy can affect both cancer cells and normal cells. The side-effects can be short term or long term. In most cases the side-effects go away once the treatment ends or soon after.

Your doctor or nurse can give you something to stop most side-effects or make them easier to cope with. They will discuss the side-effects with you in more detail.

>>> Side-effects usually go away once the treatment ends or soon after.

Side-effects in the short term may include:

- Infection
- Anaemia
- Bruising or bleeding
- Feeling sick (nausea) and vomiting
- Sore mouth
- Loss of appetite
- Ongoing tiredness (fatigue)
- Hair loss (alopecia)

Infection: Chemotherapy can make you more likely to get infections. This happens because the drugs affect the bone marrow that makes white blood cells. These are the cells that fight infection. If you do not have enough white blood cells, even minor infections such as a cold or sore throat could make you quite ill.

During treatment you will have blood tests to make sure you have enough white blood cells. If your white cell count is low, your doctor may ask you to watch out for signs of infection when at home. These signs could include feeling shivery and unwell or running a high temperature of 37.5°C or higher. If this happens, tell your hospital

doctor or nurse straight away. He or she will tell you what to do. Some hospitals prefer you to ring them directly. Check this with your doctor or nurse before you start treatment. If you have a high temperature, you will need to have a blood test. Depending on the results, your doctor may prescribe antibiotics.



Hints & Tips – infection



- If you have a high temperature of 37.5°C or higher, contact the hospital.
- Avoid close contact (such as hugging or kissing) with people who have colds or flu or other infections such as chickenpox, shingles or measles.
- Let your doctor know if you are in contact with any infections.
- Wash your hands often during the day, especially before you eat and after going to the toilet.

Anaemia: Chemotherapy can also cause the bone marrow to make fewer red blood cells. Fewer red blood cells is called anaemia. You need red blood cells to carry oxygen around your body. With anaemia, your heart must work harder to get enough oxygen. It can make you feel tired and weak, short of breath, dizzy, faint or light-headed and your muscles and joints can ache. Regular blood tests to check your red cell count will be done during treatment. You may be given a blood transfusion to help your breathlessness and give you more energy. Once the chemotherapy is over, the tiredness will ease off gradually. But some people still feel tired for a year or more after treatment.

Your doctor may give you a drug called erythropoietin to help the bone marrow make more red blood cells quickly. It is given as an injection in your thigh or abdomen, once or three times a week. Sometimes your doctor and dietitian may give you advice about taking iron or vitamins.

Bleeding and bruising: The drugs can also reduce the amount of platelets in your blood. This is called thrombocytopenia. If you do not

have enough platelets, you may bleed or bruise more easily, even from a minor injury. Let your doctor or nurse know straight away if you are bruising easily. Or if you notice tiny red spots under your skin that can look like a rash (petechiae). You may need a platelet transfusion.

Feeling sick (nausea) or vomiting: You may or may not feel sick or vomit during chemotherapy. It all depends on the drugs being used. But if you do, it can happen before, during or after treatment. It may last for several hours. Your doctor or nurse will give you medication to stop you feeling sick. This may be in injection or tablet form. While on treatment it is best to take all medication as advised by your doctor or nurse.

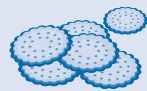
Sore mouth: Some drugs may cause a sore mouth. They can also cause little ulcers to appear on your tongue, gums and inside the cheeks of your mouth. Try to keep your teeth, gums and mouth very clean, as this will reduce the risk of getting a mouth infection. Clean your teeth after every meal, using a soft toothbrush. If you have dentures remove them if your gums are sore. There are special mouthwashes that you can use too. Your nurse will advise you about these.

Loss of appetite: Some chemotherapy drugs can affect your appetite. This may happen for a short time while on treatment. It is best to get advice from the hospital dietitian if this happens. A booklet with useful tips is also available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy of *Diet and Cancer: A Guide for Patients with Cancer*.



Hints & Tips – nausea and loss of appetite

- Let your doctor know if the anti-sickness tablets are not working well.
- Eat bland, easy-to-digest foods and drinks. For example, cream crackers, toast or plain biscuits.
- Eat about 5 or 6 small meals or snacks each day.
- Do not fill your stomach with fluids before eating.



- Take fluids slowly, with small sips. Ice cubes can help too.
- Do not eat or prepare food if you feel sick.
- Avoid food and drinks with a strong smell. For example, garlic, onions, fried foods, etc.
- Find out when is best for you to eat and drink before treatment. Some people need a light snack, while others need an empty stomach.
- Some complementary therapies, like acupuncture, may help. Do discuss any complementary therapies with your doctor.

Ongoing tiredness (fatigue): You may have ongoing tiredness or fatigue during treatment. This tiredness can last for some weeks after treatment has ended. Sometimes it can last for months. If you are fatigued, do take things easier. Do less than you normally would and rest more if you can. Ask your family or friends to help you at work or at home. Some gentle exercise like walking may help you to sleep better at night. Do tell your doctor about the way you are feeling as most side-effects can be eased with medication. See page 42 for more about fatigue. You can also call the National Cancer Helpline 1800 200 700 for a copy of the free booklet, *Coping with Fatigue*.

Hair loss (alopecia): The drugs may also cause some hair loss. The amount of hair loss depends on the drugs you are given. Your hair might just thin out a little bit. If you do lose your hair, it will happen quite quickly. You may get a tingling sensation in your scalp a day or two beforehand. Try not to worry as your hair will grow again once treatment ends.

It is normal to feel upset at the thought of losing your hair. Talk to your nurse or medical social worker about your feelings. He or she will help you to find ways to cope with hair loss. Ask them if you can get financial assistance towards the cost of a wig. For some patients the amount of hair loss is small and a wig may not be needed. For more information, call the National Cancer Helpline for a copy of the free factsheet on hair loss.

Other side-effects

If you have symptoms that are troubling you, and different from those listed above, let your doctor or nurse know. He or she will tell you what to do. A helpful booklet called *Understanding Chemotherapy* is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy.



To sum up

- Chemotherapy is a treatment that uses drugs to cure or control cancer.
- It can be given before or after surgery and radiotherapy or on its own.
- If the cancer comes back after having been treated, chemotherapy may be given.
- The drugs can be given directly into a vein as an injection or in a drip, or may be given in tablet form.
- Side-effects to chemotherapy vary between people and depend on the drugs used.
- Some side-effects include less resistance to infection, anaemia, bruising, sore mouth, loss of appetite, nausea and vomiting, fatigue, and hair loss.

How can I cope with fatigue?

Fatigue is a common symptom with cancer and is often described as an overwhelming tiredness that is not eased by rest. You might also find it hard to concentrate or make decisions. The reason for this fatigue can be hard to identify at first. It can be caused by worry when a diagnosis of cancer is made or the added stress caused by treatment.

The treatment itself can also cause fatigue. Even though you may find it hard to identify the reasons for your tiredness, there are ways to help.

Ways to relieve fatigue

For many patients, treatment may help by relieving symptoms such as pain and nausea, allowing you to get back to your normal routine. Ask your doctor before you start treatment what side-effects you can expect.

If you are feeling very worried, you may find it hard to sleep at night. Do tell your doctor or nurse, who may be able to help. Getting plenty of fresh air might improve your night's sleep. Also, try talking to your family or close friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to cope.

If your illness allows you to do physical exercise, get some regularly. For example, a 30-minute walk 3 days a week might be a realistic goal and will boost your morale when you achieve it.

Having to worry about housework or work or children does not help fatigue. Get others to help you around the house, with travelling to hospital, at work, with the children or with shopping. Use the extra free time to do something that you especially enjoy.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.



Hints & Tips – fatigue

- Build rest periods into your day. If you are going somewhere special, have a rest before you go out.
- Save your energy for doing the things you most enjoy.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Keep your energy for eating. Eat little and often and use ready-made meals or snacks.
- Sit down when getting dressed or doing household jobs such as ironing, etc.
- Do some gentle exercise each day. Ask your doctor or nurse for advice.



- Go to bed each night at the same time. Each morning get up at same time and do not lie in.
- Use relaxation techniques to get to sleep: gentle exercise, relaxation tapes, etc. Make sure your bedroom is quiet and not too hot or cold.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, coke or chocolate.

Will treatment affect my sex life?

Physical effects of treatment

Surgery to remove your bladder can cause damage to the muscles and nerves in your pelvic floor. This means that you may experience physical problems when having sex. It may make sex more uncomfortable or there may be a loss of libido (sex drive).

You may be afraid that the urostomy bag will become dislodged or cause damage to the stoma. These are all normal fears. Do empty the bag before sexual intimacy and roll it up or tape it down so it will not get in the way, if you wish.

If you need more advice talk to your doctor, specialist nurse or stoma nurse, they are all experienced in dealing with these issues.

Women

For women, bladder surgery might shorten or narrow your vagina. This can make sex uncomfortable. You may also get a loss of sensation in your pelvis and having an orgasm may be affected.

During your surgery, your ovaries and womb may have been removed. If this was needed, it can also have a deep impact on your life. For example, it can lead to infertility. This may also be a problem if you have chemotherapy or radiotherapy to your pelvis. Do talk to your doctor and nurse for advice.

Men

For men, impotence may become a problem after surgery or radiotherapy. You may not be able to get or maintain an erection. This

is also called erectile dysfunction. In fact, this happens to most men who have bladder surgery. If your prostate gland and seminal vesicles are removed during the surgery, it can cause impotence and infertility. Discuss with your doctor before surgery if there is a way for you to have erections again. Nowadays there is type of surgery that can protect the nerves near your bladder and prostate. This is called a nerve-sparing cystoprostatectomy.

If you experience erectile dysfunction, there are ways to help the problem. These include medication, vacuum devices, prostaglandin injections, and penile implants. Your doctor will discuss this issue with you in more detail.

Emotional and psychological effects

Your sex life can be affected by not only your physical health but also your emotional health. It takes some time to adjust to the effects of surgery, radiotherapy or chemotherapy on your body. In particular, dealing with a urostomy. Having a urostomy may change the way you feel about your body. You may also have concerns about how your partner will react.

Issues such as discomfort, change in body image, fatigue, fear and anxiety can all have an impact on your sex life. These problems usually resolve with time and with the support of those close to you.

It is natural to lose the desire for sex during treatment. Coming to terms with the fact that you have cancer and a stoma can take quite a while. Your emotions will be turned upside down. It can be hard to relax as well when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment. This is all quite normal.

If you have a supportive partner, you may find that talking about your feelings may ease your anxiety. Even if you are not able or feel like having sex, you can still enjoy a close and loving relationship with your partner. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist counselling if you feel that would be helpful.

Some people fear that cancer can be passed on to a partner during

sex. There is no truth to this. It is quite safe for you to have sex with your partner unless your doctor advises you not.

Asking for advice

If you have any queries about how treatment may affect your sex life, do ask your doctor. Don't be put off by thinking the question is small or trivial or that you'll be embarrassed. Your doctor is well used to taking about these matters and will give you advice.

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments. For example, surgery, chemotherapy and radiotherapy. Sadly, you may not be able to have a child in the future.

Discuss this possible side-effect with your doctor or nurse before treatment starts. It may be possible to store sperm or eggs for future assisted reproduction at the HARI Unit at the Rotunda Hospital in Dublin. Your doctor or nurse will give you more information. If you prefer, you can contact the National Cancer Helpline 1800 200 700 for advice in confidence.

If your fertility is not affected, it is best to wait before you become pregnant. For example, it is better for you or your partner not to get pregnant for 2 years after chemotherapy ends. This time gives your body a chance to recover from the effects of the cancer and its treatment.

Infertility

Dealing with infertility may not be easy, depending on your age. Younger men or women may find it hard to accept that they can no longer have children. This can be even harder than having cancer itself, and feelings of anger and loss of identity are common at this time.

It is important to talk openly to your partner or a friend about these feelings. If you are finding it hard to deal with infertility, it may help to talk to your nurse or doctor. Do not be afraid to ask for help in dealing with this matter. Your doctor may arrange for you to speak to a trained counsellor or a specialist.

>>> Your fertility will be affected by some treatments.

What follow-up do I need?

No matter what type of cancer treatment you get, you will still need to come back for regular check-ups. This is known as follow-up. At first these visits to the specialist will be quite often, sometimes every 6 weeks to 3 months. The follow-up may involve having a physical exam, blood tests or scans. You will also get the chance to talk to the stoma nurse. The visits will continue for a number of years but will gradually become less frequent. If your bladder was not surgically removed, you will need repeated cystoscopies.

If you are between check-ups and have a symptom or problem that is worrying you, let your doctor or specialist nurse know. Make an appointment to see him or her as soon as possible.

>>> If you are between check-ups and have a problem worrying you, let your doctor know without delay.

What if the cancer comes back?

Invasive bladder cancer: Sometimes after treatment the cancer recurs, either in the pelvic area where the bladder once was or somewhere else. If it does come back, there are still treatment options available to you. Your doctor will discuss these treatments with you if he or she thinks they would help.

Metastatic bladder cancer: If the cancer has spread to other parts of your body after treatment, chemotherapy may be given. The aim of treatment in this case is usually to control the cancer rather than cure it.

Recurrent bladder cancer: If cancer comes back after having been treated, it may be hard to treat it again. Even so, there are options available to you.



Research – what is a clinical trial?



Research into new ways of treating bladder cancer goes on all the time. By using new drugs or new combinations of drugs and treatments that are already in use, doctors can find new and better ways of treating cancer. Many patients with cancer take part in research studies today. Even though the word 'research' or 'new drug' sometimes scares people, there is no need for fear. Before a drug or treatment is used on patients, it goes through many stages to make sure it is safe.

Phases of research

There are many stages or phases when research is done. If a drug or treatment looks as if it might be useful in treating cancer, it is given to patients in research studies called clinical trials. These aim to find a safe dose, see what side-effects may occur and see which cancers can be treated.

If early studies suggest that a new drug may be both safe and effective, further trials are carried out. These aim to:

- Find out if the treatment is better than ones already in use.
- Find out if there are more benefits when the new treatment is given together with current ones.
- Compare the new treatment with current best standard treatments.

Taking part in clinical trials

Your doctor may ask you to try a new treatment. There are many benefits to this. You will be helping to improve knowledge about cancer and new treatments. There is no need for worry as you will be carefully watched during and after the study.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, so that you understand what it is about. This is called informed consent. You will also need time to think about it and discuss it with your family or friends.

If you decide not to take part, you will still be given the best proven treatment available. Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind. As part of research into the causes of cancer, your doctors may ask your permission to store some samples of your cancer cells or blood.

For more information, call the National Cancer Helpline 1800 200 700.

Cancer and complementary therapies

There is great interest today in complementary treatments for cancer. Some people find them very helpful during their illness. The way cancer is treated often depends on the culture of the country in which you live. In Ireland cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted. You may hear about the following types of treatments or therapies.

Conventional therapies

Conventional therapies are treatments that doctors most often use to treat people with cancer. These include surgery, radiotherapy, chemotherapy and biological therapy. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

Complementary therapies

Complementary therapies are treatments that are sometimes given **together with** conventional treatment. They include therapies such as:

- Meditation
- Relaxation
- Visualisation
- Gentle massage
- Aromatherapy
- Reflexology
- Music, art and dance therapy
- Nutrition therapy
- Shiatsu
- Yoga
- Acupuncture
- Hypnotherapy

Many people find complementary therapies are very helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that it can often bring. Some complementary therapies also focus on the spiritual dimension of a person to aid healing.

Alternative therapies

Alternative therapies are generally treatments that are used **instead** of conventional treatments. These therapies include diet therapy, megavitamin therapy and herbalism. The diet therapy can often be restrictive. This means it does not allow you to eat foods that could be nutritious for you. Some restrictive diets can harm your health and may even cause malnutrition.

Most doctors do not believe that alternative treatments can cure or control cancer.



If you decide to have complementary or alternative treatments...



Before you decide to change your treatment or add any methods of your own, be sure to talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, do talk openly with your GP or cancer specialist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you.

Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present in Ireland, this area is not fully regulated. Make sure the practitioners you plan to visit are properly qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

More information is available in a free booklet from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies. A Guide for Cancer Patients*. If you would like a copy or more advice, call the National Cancer Helpline on 1800 200 700.

Coping and emotions

How can I cope with my feelings?

There are many reactions when told you have bladder cancer. Reactions can differ from person to person. In fact, there is no right or wrong way to feel. There is also no set time to have one particular emotion or not. Some reactions may occur at the time of diagnosis, while others might appear or reappear later during your treatment. Or indeed it may not be until you recover from your illness that your emotions hit hard.

Common reactions include:

- Shock and disbelief
- Fear and uncertainty
- Loss of control
- Sorrow and sadness
- Denial
- Anger
- Resentment
- Blame and guilt
- Withdrawal and isolation



Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet that discusses them in detail is called *Understanding the Emotional Effects of Cancer* and is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy.

Shock and disbelief

'It can't be me.' 'Has there been a mistake?' 'Cancer happens to other people, not me.'

Shock is often the first reaction to a cancer diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think cancer will never happen to them and are quite shocked when it does. Even if your doctor and nurse discuss the cancer with you, the news may not sink in for a while. You may find yourself confused, asking the same

questions over and over again. Or else you may accept the news calmly and say nothing because you don't really believe what is happening to you.

Fear and uncertainty

'I'm going to die.'
'Will it be painful?'
'Will I become a different person?'

There is no doubt that cancer is a scary word. Not surprisingly, you may have many fears when first told of your diagnosis. Often the first thing people think about is dying. They think the worst. But nowadays many cancers can be cured or controlled with modern treatments. Another great fear about cancer is pain. The fear of pain can sometimes overwhelm everything else. However, some cancers cause no physical pain at all or else can be controlled with good painkillers.

You may also have fears that your experience of cancer will change who you are or that people will reject or avoid you. For example, after some cancer treatments, like surgery, your body image may be different. It will take some time for you and for others to adjust to your new look. You may also have practical worries and fears about the effect of your illness on your family, your finances, your job, and your lifestyle.

It is natural for you to be afraid or concerned about the future too. You may wonder if you will be cured or if your cancer will recur. Living with this uncertainty can make you feel anxious and fearful. You may not wish to make any plans or decisions. Discuss your concerns with your doctor, nurse or medical social worker, who will give you advice and help. If living with uncertainty overwhelms you, it may help to talk to someone in a support group.

Loss of control

'I can't cope with this.' *'I'll never get through it.'*

After a cancer diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom.

Because you don't know enough about your illness at first, you may rely totally on the advice of your doctors and nurses. You may not feel confident to make any decisions about your treatment. When you experience a loss of control, it can lead to feelings of helplessness. You may also feel that you will be unable to cope with your treatment or that you will 'fall to pieces' or 'go crazy'. You may even lose hope.

It takes a while to know what is within your control and what is beyond it. Finding out as much as possible about your illness can help you regain some control. Taking an active part in making decisions about your treatment can also make you feel even more in control of your illness.

»»» Learning more about your illness and treatment can help you feel more in control.

Sorrow and sadness

'I used to be so healthy.' *'I had so many plans.'* *'I've let my family down.'*

It is natural to feel sad when told you have cancer. You may feel sad for a variety of reasons: for the loss of your good health, for the plans that are put on hold, for the people you feel you've let down, and for any changes to your body due to treatment. Depending on your type of cancer, your body image or fertility may be affected by treatment. In this case, the sadness or sorrow can come from feeling as if a part of you has died. These feelings may not be there all the time and may come and go, but will gradually fade.

Denial

'I'm fine, really.'
'I don't have cancer.'

Sometimes after being told their diagnosis, people deny they have cancer. While this may seem unusual, it is a valid way of coping. As a result, you may not wish to mention or discuss your illness. Or else you may talk as if your illness is nothing serious. Denial may last for a short or long time, depending on how

long it takes for you to adjust to your illness. Tell your family and close friends that you would prefer not to talk about your illness, at least for the time being. Your doctors and nurses will also understand if you don't want to hear any information about your cancer until you're ready.

Anger

'Why me? I always took care of my health.' 'Why did this happen now?'

It is normal too to be very upset when told you have cancer. Many aspects of your illness can result in anger and distress. Anger can often hide other feelings such as fear, sadness or frustration. You may feel angry towards the doctors and nurses who are caring for you. Or

if you have a religious belief, you may feel angry with God for allowing cancer to occur. You may vent your anger on those closest to you. Indeed being unable to protect the ones you love may frustrate you a lot.

Your family and friends may not always be aware that you are angry at your illness and not at them. It may be helpful to talk to them when you are calm, rather than feeling guilty or trying to bottle up your angry thoughts. Anger can sometimes affect your ability to think clearly. So if it persists and you are finding it hard to talk to your family, tell your nurse or doctor.

Resentment

'How can you talk – you don't have to deal with cancer.' 'How come I'm not getting better?'

It is natural that you might be resentful and unhappy – even jealous – because you have cancer while other people are well. During the course of your illness similar feelings of resentment may occur for many reasons. You may resent that another patient receiving the same treatment as you is doing better or has responded quicker than you have. You may even resent your healthy relatives or for having to change your lifestyle in some way.

On the other hand, sometimes relatives, especially teenagers, can resent the changes that your illness makes to their lives. It is best to admit that these feelings of resentment exist and to express them. Bottling up resentment helps no one. Instead everyone ends up feeling angry and guilty.

>>> Don't bottle up your feelings – express them.

Blame and guilt

'I should've been more careful.' 'If only I had a more positive attitude, I wouldn't have got sick.'

When diagnosed with a serious illness such as cancer, it is natural to want to know what caused it. Sometimes people blame themselves or others for their illness. As cancer experts rarely know exactly what has caused cancer, there is no good in blaming yourself. Other times, people feel guilty because they delayed going to the doctor with their symptoms, fearing the worst. No matter what the reason, don't torture yourself at this time.

Don't feel guilty if you can't keep a positive attitude, especially when you feel unwell. Low periods are to be expected. There is no evidence at all that your attitude will affect your health or cancer. Regret and guilt serve no useful purpose. Instead focus on what you can change or do to make you feel more in control of your illness.

Withdrawal and isolation

'I just need to be on my own.'

A cancer diagnosis is stressful without doubt. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may want to be left alone and withdraw from people. It is a normal for you to want to be alone to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope.

But it is not a good idea to spend long hours on your own every day. Sometimes depression can make you avoid family and friends and stop you wanting to talk. If you isolate yourself, it can be hard for your family and friends, as they will want to share this difficult time with you. They may worry about you needlessly. Let your family and friends know that you will talk to them once you are ready.

If you would like more information on how to talk about your cancer, there is a useful booklet available called *Who Can Ever Understand?: Talking about Your Cancer*. If you would like a copy, call the National Cancer Helpline on 1800 200 700.

Learning to cope

After any treatment for cancer it can take some time to come to terms with your emotions. Coping with the physical effects of treatment can also add to the burden of dealing with cancer.

While it is true that some treatments can have some unpleasant side-effects, many people can live a normal life during treatment. You will need to take some time off for your treatment as well as time afterwards to recover. Just do as much as you feel like and take plenty of rest. It is not a sign of failure to ask for help or to feel unable to cope on your own. Once other people understand how you are feeling, they can give you more support.

>>> Positive emotions

A cancer experience can also bring positive emotions. However, it may be some time before you are ready to accept these emotions as positive. You may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and even the healthcare team. With that can come a sense of gratitude too. The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what is important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.



How can my family and friends help?

Your family and friends can support you through your cancer journey in different ways. Some family members and friends can offer a listening ear and give you advice if needed. Some may gather up-to-date information on cancer to know what you can expect and what you are going through. Others may prefer to help you in a practical way with travelling to and from the hospital, with childcare, cooking, shopping or housework. It may take time to know which way suits you and your family or friend best.



How to talk to someone with cancer



When someone close to you has cancer it can be hard to know what to do. Their welfare may be a priority for you, but you might still be unsure when to visit or what to talk about. You may be afraid of upsetting them or saying the wrong thing. So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or what might happen in the future. Although some people do die from cancer, many do not. Be honest with own your feelings too.

Often those with cancer do not wish to burden their family and friends with their worries and concerns. Gentle encouragement can sometimes help. But don't rush into talking about their illness – knowing that you are always ready to listen and give help may reassure them. You may not think you are doing much by just listening. In fact, it is one of the best ways to help.

Be patient

Sometimes your friend or relative may get cross or irritable for what may seem to be no good reason. These feelings are completely normal. Be as patient and understanding as you can. Give them the space and time to adjust to the changes in their life. Above all, let them know that you are there, if they want to talk or need help. In time, life will begin to be normal again.

Lost for Words: How to Talk to Someone with Cancer is a useful booklet written for relatives and friends of people with cancer. It is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy.

How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes that may be either great or small. Even so, it is best to keep family life as normal as possible. Continue with school and other activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to big changes in their lives.

Every family deals with cancer in its own way. You may feel that you do not want your illness to upset family life, or feel guilty that you cannot do activities with your children or that you're letting them down. These are all natural feelings to have at this time.

Be honest

The main thing to remember is that being honest with your family really helps. Keeping your illness a secret may not be the best thing for your children. It can put added pressures on your family and lead to confusion. Children are very sensitive to stress and tension and if you try to protect them by saying nothing, they may feel isolated. In fact, they may have greater fears if told nothing.

It is best that you or your partner tell your children about your cancer diagnosis. If this is not possible, then someone else close to your children should break the news.

How much you tell children will depend on their age and level of maturity. Very young children do not understand illness and need a simple reason why their parent or friend is sick and has to go to hospital regularly. A story about good cells and bad cells usually works well. Most children over 10 years of age can take in fairly full explanations of why you are sick. Adolescents can understand far more.

It is best to prepare children for the side-effects of treatment before they happen and to answer their questions simply and honestly. For example, if you have hair loss. It is also important not to force your children to talk about your illness. If they rebel or turn quiet, it may be their way of showing their feelings.

Coping with children's emotions

During your illness, your children may experience a range of emotions from fear, guilt and anger to neglect, loneliness, isolation and embarrassment. They need to be reassured that your illness is not their fault. Whether they show it or not, children may feel that they somehow are to blame. But by having an open honest approach, it may bring you a sense of relief too. Your family may also find new depths of love and inner strength that will boost your life together.

If you need extra help in dealing with children, talk to your nurse or medical social worker. A useful booklet called *Talking to Children about Cancer. A Guide for Parents* gives practical advice on talking to children about cancer. If you would like a free copy, call the National Cancer Helpline on 1800 200 700.

What else can I do?

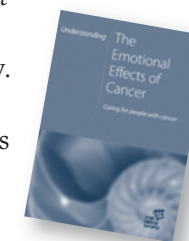
Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope, only your way. During your illness there are many things that you can learn, not only about cancer itself but also about you as a person. Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

- **Communicate with your family and close friends:** Do not keep your worries or symptoms secret from the people closest to you. This includes physical or emotional problems. Ask the person closest to you to come with you when visiting the doctor and when treatments will be discussed.
- **Live one day at a time:** Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

- **Live well:** Try to eat as well as you can. Eat little and often, using lots of different types of foods with plenty of fresh fruit and vegetables. Do some regular exercise that you enjoy. Take it easy at first, building up the amount you do as you feel stronger.
- **Expect change in your life:** Even though you may want to stick to your old routines, sometimes this may not be possible. It may take a while for you to adjust to your new routine. Remember that change may bring new opportunities and blessings.
- **Keep an open mind:** Don't feel you have to be positive all the time. Expect ups and downs during your cancer journey. There will be times when you feel low but don't feel guilty about it, as it will pass.
- **Seek information:** Be sure to ask your doctor as many questions as you can and get involved in decisions about your treatment. Always ask for information that is personal to you. Ask what side-effects you can expect so you can prepare for them. Build up as much information about your cancer and treatment as possible. Follow your doctor's instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor or nurse. Keep a notebook of all your dates for blood tests, X-rays, scans, treatments, symptoms, side-effects, medications, and your general health. Keep a record of any emotions you are feeling too, especially strong ones.
- **Find what works for you:** It can help to use whatever way of coping that has helped you solve problems in the past. Some people are comfortable taking about their illness, others are not. You may prefer relaxation, meditation, walking, listening to music, or other approaches helpful. Do whatever suits you. But if it's not working, be open to finding a new way to cope.
- **Build a support network:** Be realistic about what you can manage by yourself. No man is an island, so seek help from those who want to support you. Talk to your family, friends, nurses or doctors. Meet with other patients in support groups and self-help groups as they can understand what you are going through. If the group does not suit you and is not helping, leave it.

- **Seek professional help:** If you have any low moods or strong emotions, talk to your close friends and family – or someone who is a good listener. If the emotions are still getting the better of you, discuss them with your nurse and doctor. They may recommend you talk to a trained counsellor or other specialist.
- **Spiritual care:** When faced with a cancer diagnosis and treatment, you may start thinking about the meaning of life and the afterlife. For some people spiritual and religious beliefs can bring comfort and hope. Prayer or meditation can help you to focus on what has value and meaning in your life. Even if you do not consider yourself a religious or spiritual person, it is still possible to get support from a belief system. Some complementary therapies that have a spiritual dimension may also help you to focus on being positive and hopeful.
- **Express yourself:** Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of your cancer journey and can bring great healing and relief. Other forms of creative expression, such as music and art, may help too.

A useful booklet called *Understanding the Emotional Effects of Cancer* has been written for people with cancer and is available from the Irish Cancer Society. There is also a special notebook available called the *Journey Journal*, where you can record all the details of your cancer treatment. Call the National Cancer Helpline 1800 200 700 if you would like a free copy of these booklets.



National Cancer Helpline 1800 200 700

Support resources

Who else can help?

There are many people ready to help you and your family throughout treatment and afterwards.

- Family doctor (GP)
- Medical social worker
- Cancer nurse specialists
- Psycho-oncology services
- Community welfare officer and community health services
- Support groups and cancer support centres
- Irish Cancer Society helpline nurses



Family doctor (GP): Because your GP knows you, you may feel comfortable talking to him or her about your condition. He or she can discuss any queries you have and offer advice. If you wish, your GP might recommend you speak to another patient who has had treatment for bladder cancer and who lives locally.

Medical social worker: The medical social worker in your hospital can help in many ways. He or she can give support and counselling to you and your family as well as advice on benefits, entitlements and services available when you go home.

Cancer nurse specialists: Some of the major cancer treatment hospitals have oncology liaison nurses and/or cancer nurse co-ordinators. These specially trained nurses can support you and your family from the time of diagnosis and throughout treatment. These experts along with other members of your medical team work together to meet your needs.

Psycho-oncology services: In some larger hospitals there are special units that provide psycho-oncology services. This means that you can receive psychological care and support during your diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together.

Community health services: When you go home, there are various community health services available from your local health centre. These centres have family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far from the hospital where you have been treated, your community welfare officer can also help with practical issues such as transport costs, financial worries, etc. All these people in community health services can provide advice and support. More information on these services is available from the social worker in your hospital or from your local health centre.

Support groups: Joining a support group can put you in touch with people who have been in a similar situation. They can give you practical advice about living with bladder cancer. There are a range of support groups that will support you and your family at time of diagnosis, throughout treatment and afterwards. Cancer support centres and groups are found in most counties in Ireland and can offer a wide range of services. Some of these are listed at the back of this booklet.

Irish Cancer Society: The staff of the National Cancer Helpline will be happy to discuss any concerns you or your family may have, at any stage of your illness. This can range from treatment information or practical advice about your financial matters, e.g. getting a mortgage or travel insurance. Call 1800 200 700 for information about any of the services outlined above or for support services in your area.

>>> Remember that there are many people ready to help you.

Health cover

Health cover falls into two categories – cover for medical card holders and cover for all other categories. Details of the following are given here:

- Hospital cover
- Outpatient cover
- Medical card
- GP visit card
- Drug Payments Scheme (DPS)
- Private healthcare cover
- Benefits and allowances



At the end of this section there are also some useful telephone numbers and addresses for further help.

Hospital cover

At present, everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €75 a night charge up to a limit of €750 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

Outpatient cover

If you go to the outpatients or A&E unit of a public hospital, without being referred there by a GP, you may be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the A&E unit first.

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances. You will have to pay a prescription charge of 50c per item up to a limit of €10 per family.

To qualify for a medical card depends on a means test. If you are over 70 and your weekly income is €700 or less, you can apply for a card. Financial guidelines are set out each year and are available from your

local Health Service Executive (HSE) office. If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. Also, you may qualify for a medical card because you have a cancer diagnosis. In this case, your spouse and children will not be covered if your means are over the limit.

GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at the hospital or your HSE office to see if you are eligible.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €120 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your local pharmacy.

Private healthcare cover

Private health insurance is used to pay for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available through the VHI, Quinn Healthcare, AVIVA Health and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. Before attending hospital, it is best to check the level of cover provided by your insurance company, both for inpatient and outpatient services.

If you have private insurance, you may not always be able to have your tests done as quickly as you would like. Your health insurer has to approve some tests in advance, e.g. MRI scan, PET scan. In some cases, it may take 24–48 hours to get approval from your health insurer.

Benefits and allowances

Information on the following is given in this section:

- Illness Benefit
- Disability Allowance
- Invalidity Pension
- Carer's Allowance
- Carer's Benefit
- Carer's Leave
- Appliances
- Travel to hospital



Illness Benefit

This is a benefit for insured people. Your eligibility will depend on your PRSI contributions. You must be under 66 and unable to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social Protection, PO Box 1650, Dublin 1. Tel (01) 679 7777. These certificates are available from your GP and from the hospital you attend during inpatient care. You should send your claim to the Department within 7 days of becoming ill and unable to attend work. A delay might result in loss of payment. The benefit lasts for 2 years.

Disability Allowance

You might qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least 1 year. Disability allowance is a weekly allowance paid to people with an injury, disease or a disability who are aged between 16 and 66. For this allowance, you must satisfy a means test, live in Ireland and be medically suitable. To be medically suitable, you should have an illness that has continued or may continue for at least 1 year.

You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Invalidity Pension

This is a pension paid instead of an illness benefit or disability allowance,

if you are unable to work permanently. There are three cases where you can be eligible. (1) If you have been incapable of work for at least 12 months and likely to be incapable for at least another 12 months. (2) If you are permanently incapable of work. (3) If you are over the age of 60 and have a serious illness or incapacity.

Your eligibility will also depend on your PRSI contributions. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Allowance

This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. You must be aged 18 or over, live in Ireland, satisfy a means test, not be self-employed or work more than 15 hours a week outside the home, and not live in a hospital or nursing home. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a respite care payment every year. For more advice, talk to your social worker and/or the Dept of Social Protection.

Application forms are available from your social welfare office or from the Carer's Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Benefit

If you are employed but wish to care for a sick relative full time, you might qualify for a carer's benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. You must be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged 16 or over, live in Ireland, not be self-employed or employed while

caring for the person, and not live in a hospital or nursing home. More information is available from the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Leave

Under carer's leave legislation, you may be entitled to unpaid temporary leave from your employment. Carer's leave allows you to leave your employment for up to 104 weeks to care for someone in need of full-time care and attention. The leave will be unpaid, but you will have your job kept open for you while you are on leave. You do not need to be eligible for carer's allowance or carer's benefit to apply for carer's leave. You must have worked for your employer for a continuous period of 12 months to be eligible to apply for carer's leave. The person you are caring for can be a partner or family member, friend or colleague. The family doctor (GP) of the person you are caring for will also need to fill in part of your application form.

You can work while you are on carer's leave for up to 15 hours a week. But you must make sure your income from employment or self-employment is less than a weekly income limit set by the Department of Social Protection. For more information, contact the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Appliances

For patients who have medical cards most appliances are free of charge. For example, you are entitled to urostomy bags regularly. Or if you receive chemotherapy and suffer from hair loss, you can get a new hairpiece or wig every 6 months.

Travel to hospital

You may be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres. Sometimes the HSE may assist with transport costs for a person who has to travel a long distance to a hospital.

In general, those who do not have a medical card may be charged for the service. However, the practice varies between HSE areas and often depends on personal circumstances. Charges may be waived in certain cases, like hardship.

Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you.

Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending

For social welfare queries contact:

Dept of Social Protection – Information Service Oisín House 212–213 Pearse Street Dublin 2	Tel: 1850 662 244 Leaflet line: 1890 202 325 Email: info@welfare.ie Website: www.welfare.ie
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If you have queries about health and social services, contact the HSE office in your area: HSE Dublin North East, HSE Dublin Mid-Leinster, HSE South, and HSE West. For more information contact:

HSE infoline: 1850 24 1850; **Email:** info@hse.ie; **Website:** www.hse.ie

HSE East Coast Area

[Co Wicklow, South East Dublin]
Southern Cross House
Southern Cross Business Park
Boghall Road
Bray
Co Wicklow
Tel: 01 201 4200

HSE Northern Area

[North Dublin]
Swords Business Campus
Balheary Road
Swords
Co Dublin
Tel: 01 813 1800

HSE South Western Area

[Co Kildare, West Wicklow, South Dublin]
Oak House
Millennium Park
Naas
Co Kildare
Tel: 045 880 400

HSE Midland Area

[Counties Laois, Offaly, Longford,
Westmeath]
Head Office
Arden Road
Tullamore
Co Offaly
Tel: 057 932 1868

HSE Mid-Western Area

[Counties Clare, Limerick, Tipperary North]
Head Office
31/33 Catherine Street
Limerick
Tel: 061 483 286

HSE North Eastern Area

[Counties Cavan, Monaghan, Louth and
Meath]
Head Office
Navan Road
Kells
Co Meath
Tel: 046 928 0500

HSE North Western Area

[Counties Donegal, Sligo, Leitrim and
West Cavan]
Head Office
Manorhamilton
Co Leitrim
Tel: 071 982 0400 / 1850 636 313

HSE South Eastern Area

[Counties Carlow, Kilkenny, Wexford,
Waterford, South Tipperary]
Head Office
Lacken
Dublin Road
Kilkenny
Tel: 056 778 4100

HSE Southern Area

[Counties Cork and Kerry]
Head Office
Wilton Road
Cork
Tel: 021 454 5011

HSE Western Area

[Counties Galway, Mayo and
Roscommon]
Head Office
Merlin Park Regional Hospital
Galway
Tel: 091 751 131

Information is also available from your local Citizens Advice Centre. A list of these centres is available from:

Citizens Information Board (formerly Comhairle)

Ground Floor, George's Quay House, 43 Townsend Street, Dublin 2

Tel: 01 605 9000; Locall 1800 777 121

Email: info@ciboard.ie; Website: www.citizensinformation.ie

There are also some booklets available that may help you. These include:

- *Information Guide to Health Services* (published by the Dept of Health and Children). Copies are available from your local HSE area office. Tel: 01 671 4711 for local HSE numbers.
- *Guide to Social Welfare Services* (published by the Dept of Social Protection). Copies are available from the Dept of Social Protection. Tel: 01 874 8444. Email: info@welfare.ie. Website: www.welfare.ie
- *Entitlements for People with Disabilities* (published by Comhairle). Copies are available from the Citizens Information Board. Tel: 01 605 9000 / 1890 777 121. Email: info@ciboard.ie; Website: www.citizensinformationboard.ie



If you have financial worries...

A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses as well as your normal outgoings, such as medication, travel, food, heating, laundry, clothing and childcare costs. If you are not able to work or unemployed, this may cause even more stress. It may be hard for you to recover from cancer if you are worried about providing for your family and keeping a roof over your head.



There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 74 for more details. You can also call the National Cancer Helpline 1800 200 700 for ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 1890 283 438. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. See page 76 for contact details.

Irish Cancer Society services

The Irish Cancer Society funds a range of cancer support services that give care and support for people with cancer at home and in hospital.

- Cancer Information Service (CIS)
- Cancer support groups
- Peer-to-peer support
- Counselling
- Night nursing
- Oncology liaison nurses
- Financial aid
- Cancer information booklets



Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The **National Cancer Helpline** is a freefone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put you in contact with the various support groups that are available. The helpline 1800 200 700 runs Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- All queries or concerns about cancer can be emailed to the CIS at **helpline@irishcancer.ie**
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- **Message Board** is a bulletin board on our website (**www.irishcancer.ie**) that gives you the chance to post your comments.
- The **CancerChat** service is a live chatroom with a link to a CIS nurse.

Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See page 76 for more details.

Peer-to-peer support

Many patients find it helpful to talk to someone who has had a diagnosis of cancer and who has recovered. The Irish Cancer Society can put you in touch with someone who has been trained to give you emotional and practical support. All volunteers have had a personal experience of cancer and understand the emotional and physical impact of the disease. If you would like to make contact with a volunteer, please call the National Cancer Helpline 1800 200 700.

Counselling

Coping with a diagnosis of cancer can be very stressful at times. Patients and their families sometimes find it difficult to come to terms with the illness. Many people also feel that they cannot talk to a close friend or relative. In this case, counselling can provide emotional support in a safe and confidential environment. Call the helpline 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Night nursing

The Irish Cancer Society can provide a night nurse, free of charge, for up to 70 hours (mainly at night) to patients seriously ill at home and give support for their families. If you need help, you can find out more about this service from a member of the homecare team, your GP or local public health nurse. Homecare nurses are specialist palliative care nurses who offer advice on pain control and other symptoms. ICS night nurses can care for you in your own home and support your family.

Oncology liaison nurses

The Irish Cancer Society funds oncology liaison nurses who provide information as well as emotional and practical support to you and your family. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

Financial aid

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial help to patients in need. You may be suitable for schemes such as Travel2Care or Financial Aid. If you would like to request this kind of help, contact your oncology or medical social worker at the hospital where you have been treated. He/she should fill in an application form and return it the Irish Cancer Society. If there is no social worker available, another health professional involved in your care may apply on your behalf.

Cancer information booklets

These booklets provide information on all aspects of cancer and its treatment. They also offer practical advice on learning how to cope with your illness. The booklets are available free of charge from the Irish Cancer Society.



If you would like more information on any of the above services, call the National Cancer Helpline 1800 200 700.



Useful organisations

Irish Cancer Society

43/45 Northumberland Road
Dublin 4
Tel: 01 231 0500
National Cancer Helpline:
1800 200 700
Email: helpline@irishcancer.ie
Website: www.cancer.ie

Cancer Research Ireland

Website: www.cancer.ie/research/why.php

The Carers Association

Market Square
Tullamore
Co Offaly
Tel: 057 932 2933
Email: info@carersireland.com
Website: www.carersireland.com

Citizens Information Board (formerly

Comhairle)
Ground Floor
George's Quay House
43 Townsend Street
Dublin 2
Citizen Information Service: 1890 777 121
Tel: 01 605 9000
Email: info@ciboard.ie
Website: www.citizensinformation.ie

Dept of Social Protection – Information Service

Oisín House
212–213 Pearse Street
Dublin 2
Tel: 1850 662 244
Email: info@welfare.ie
Website: www.welfare.ie

HARI Unit (Human Assisted Reproduction Ireland)

Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Website: www.rotunda.ie

Health Promotion HSE

Website: www.healthpromotion.ie

Irish Clinical Oncology Research Group

Website: www.icorg.ie

Irish Nutrition & Dietetic Institute

Ashgrove House
Kill Avenue
Dún Laoghaire
Co Dublin
Tel: 01 280 4839
Email: info@indi.ie
Website: www.indi.ie

Irish Patients Association

Unit 1, 21 Church Road
Ballybrack
Co Dublin
Tel: 01 272 2552
Emergency: 087 652 9448
Email: info@irishpatients.ie
Website: www.irishpatients.ie

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Freefone 1890 283 438
Email: helpline@mabs.ie
Website: www.mabs.ie

Health insurers**AVIVA Health** (formerly VIVAS Health)

One Park Place
Hatch Street
Dublin 2
Tel: 1850 717 717
Email: info@avivahealth.ie
Websites: www.avivahealth.ie

Quinn Healthcare (formerly BUPA)

Mill Island
Fermoy
Co Cork
Locall: 1890 700 890
Email: info@quinn-healthcare.com
Website: www.quinn-healthcare.com

Voluntary Health Insurance (VHI)

VHI House
Lower Abbey Street
Dublin 1
Tel: 01 872 4499
CallSave 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support groups**Bowel Cancer Support Group**

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

CanTeen Ireland

Young Peoples' Cancer Support Group
Carmichael Centre
North Brunswick Street
Dublin 7
Tel: 01 872 2012
Email: canteen@oceanfree.net
Website: www.canteen.net

Lymphoma Support Ireland

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone 1800 200 700
Email: info@lymphoma.ie
Website: www.lymphoma.ie

Men Against Cancer (MAC)

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

Reach to Recovery

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

Support groups & support centres**ARC Cancer Support Centre**

ARC House
65 Eccles Street
Dublin 7
Tel: 01 830 7333
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

ARC Cancer Support Centre

ARC House
559 South Circular Road
Dublin 8
Tel: 01 707 8880
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

Beacon Cancer Support Centre

Suite 15
Beacon Court
Sandyford
Dublin 18
Tel: 01 213 5654

Bray Cancer Support & Information Centre

36B Main Street
Bray
Co Wicklow
Tel: 01 286 6966
Email: bcsc@iol.ie
Website: www.braycancersupport.ie

Cancer Information & Support Centre

Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 485 163
Website: www.midwesterncancercentre.ie

Cara Iorrais Cancer Support Centre

2 Church Street
Belmullet
Co Mayo
Tel: 097 20590
Email: caraiorrais@gmail.com

CARE – South Tipperary Cancer Support Centre

14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 82667
Email: caresupport@eircom.net
Website: www.cancercare.ie

CD's Helping Hands

Lakeview Point
Corporate Park
Claregalway
Co Galway
Tel: 091 799 749

Email: info@cdshelpinghands.ie
Website: www.cdshelpinghands.ie

Cootehill Community Centre Support Group

Cootehill
Co Cavan
Tel: 087 622 0000

Cork ARC Cancer Support House

Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: karen@corkcancersupport.ie
Website: www.corkcancersupport.ie

Cuisle Centre

Cancer Support Group
Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: cuislecentre@eircom.net

Dóchas – Offaly Cancer Support

Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: dochasoffaly@eircom.net
Website: www.dochasoffaly.ie

Dundalk Cancer Support Group

Philipstown
Hackballs Cross
Dundalk
Co Louth
Tel: 086 107 4257
Website: www.dconroy@actioncancer.org

Éist – Carlow Cancer Support Group

Tel: 087 767 3240 /
086 316 3838 / 085 144 0510

Éist – East Inishowen Cancer Support Group

Moville
Co Donegal
Tel: 074 938 2874

Gary Kelly Support Centre

Georges Street
Drogheda
Co Louth
Tel: 041 980 5100
Email: services@gkcancersupport.com
Website: www.gkcancersupport.com

Gary Kelly Support Centre

Monaghan
Tel: 086 195 9864

Greystones Cancer Support

La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email:
greystonescancersupport@eircom.net

HOPE

Enniscorthy Cancer Support &
Information Centre
22 Upper Weafer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555
Email: mary@hopesupportcentre.ie

Inis Aoibhinn – Cancer Care West

Costello Road
University College Hospital Galway
Tel: 091 545 000
Email: info@cancercarewest.ie
Website: www.cancercarewest.ie

Kerry Cancer Support Group

Kerry Lee
Oakpark Road
Tralee
Co Kerry
Tel: 087 230 8734
Email: kerrycancersupport@live.ie

LARCC Retreat Centre

Ballinalack
Mullingar
Co Westmeath
Tel: 044 937 1971
Callsave 1850 719 719
Email: info@larcc.ie
Website: www.larcc.ie

Listowel Cancer Support Group

Bedford
Listowel
Co Kerry
Tel: 068 21741 / 087 237 0766

Little Way Cancer Support Centre

4 Woods Way
College Road
Clane
Co Kildare
Tel: 045 902 996
Email: littlewayclane@eircom.net
Website: www.littlewaycancersupport.com

Little Way Cancer Support Centre

8 Stanhope Street
Athy
Co Kildare
Tel: 059 863 3725

Living Beyond Cancer

c/o Oncology Department
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 912 5888 (Bleep 674)

Manorhamilton Cancer Support Group

Tel: Maura Farry 071 985 6220

Mayo Cancer Support Association

Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407

Rathdrum Cancer Support Centre

Rathdrum
Co Wicklow
Tel: 087 292 8660

Recovery Haven

5 Haig's Terrace
Tralee
Co Kerry
Tel: 066 719 2122
Email: recoveryhaven@gmail.com
Website: www.recoveryhaven.com

Roscommon Cancer Support Group

Vita House Family Centre
Abbey Street
Roscommon
Tel: 090 662 5898
Email: vitahouse@eircom.net

Sláinte an Chláir: Clare Cancer Support

Kilnamona
Ennis
Co Clare
Tel: 1850 211 630
Mobile: 087 691 2396
Email: admin@clarecancersupport.com
Website: www.clarecancersupport.com

Sligo Cancer Support Centre

2A Wine Street
Sligo
Tel: 071 967 0399
Email: scsc@eircom.net
Website: www.sligocancersupport.ie

Solace – Donegal Cancer Support Centre

St Joseph's Avenue
Donegal Town
Tel: 074 974 0837
Email: solacedonegal@eircom.net

South East Cancer Foundation

7 Sealy Close
Earlscourt
Waterford
Tel: 051 876 629
Email: infosec@eircom.net

Suimhneas Cancer Support

Pastoral Centre
Church Road
Nenagh
Co Tipperary
Tel: 067 37403

Suir Haven

Clongour Road
Thurles
Co Tipperary
Tel: 0504 21197

Tallaght Cancer Support Group

Tel: 087 217 6486

Tuam Cancer Care Centre

Cricknet Court
Dunmore Road
Tuam
Co Galway
Tel: 093 28522
Email: tccg@eircom.net
Website: www.tuamcancercare.ie

Wicklow Cancer Support

1 Morton's Lane
Wicklow Town
Tel: 087 691 4657 / 0404 32696

Useful contacts outside Republic of Ireland**Action Cancer**

Action Cancer House
1 Marlborough Park
Belfast BT9 6XS
Tel: 028 9080 3344
Email: info@actioncancer.org
Website: www.actioncancer.org

American Cancer Society

Website: www.cancer.org

Cancer Network Buddies

www.cancerbuddiesnetwork.org

Cancer Research UK

Tel: 0044 20 7242 0200
Website: www.cancerresearchuk.org
Website: www.cancerhelp.org.uk

Healthtalkonline

www.healthtalkonline.org

Macmillan Cancer Support (UK)

89 Albert Embankment
London SE1 7UQ
Tel: 0044 207 840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk
Website: www.cancerbackup.org.uk

Macmillan Support & Information Centre

Belfast City Hospital Trust
79–83 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Email: cancer.info@bch.n-i.nhs.uk
Website: www.actioncancer.org

Mayo Clinic (US)Website: www.mayoclinic.com**Memorial Sloan-Kettering Cancer Center (US)**Website: www.mskcc.org**National Cancer Institute (US)**Website: www.nci.nih.gov**Royal Marsden Hospital Foundation NHS Trust**Website: www.royalmarsden.org**Ulster Cancer Foundation**

40/42 Eglantine Avenue

Belfast BT9 6DX

Tel: 048 906 63281

Website: www.ulstercancer.co.uk**Urostomy Association (UK)**

Central Office

18 Foxglove Avenue

Uttoxeter

Staffordshire ST14 8UN

Tel: 0044 8452 412 159

Tel: 0044 1889 563 191

Email: secretary.ua@classmail.co.ukWeb: www.urostomyassociation.org.uk

Helpful books

Free booklets from the Irish Cancer Society:

- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Understanding Cancer and Complementary Therapies*
- *Diet and Cancer*
- *Coping with Fatigue*
- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Taking About Your Cancer*
- *Talking to Children about Cancer: A Guide for Parents*
- *A Time to Care: Caring for Someone Seriously Ill at Home*

***Cancer at Your Fingertips***

Val Speechley & Maxine Rosenfeld

Class Publishing, 2001

ISBN 1-85959-036-5

Challenging Cancer: Fighting Back, Taking Control, Finding Options

Maurice Slevin & Nira Kfir

Class Publishing, 2002

ISBN 1-85959-068-3

The Chemotherapy and Radiation Therapy Survival Guide: Information, Suggestions, and Support to Help You Get through Treatment

Judith McKay, Nancee Hirano & Myles E

Lampenfeld

New Harbinger, 1998

ISBN 1-57224-070-9

The Bristol Approach to Living with Cancer

Helen Cooke

Robinson, 2003

ISBN 1-84119-680-0

Taking Control of Cancer

Beverley van der Molen

Class Publishing, 2003

ISBN 1-85959-091-8

What You Really Need to Know about Cancer

Dr Robert Buckman

Pan, 1997

ISBN 0-33033-628-2

Explaining cancer to children

The Secret C: Straight Talking About Cancer

Julie A Stokes

Winston's Wish, 2000

ISBN 0-95391-230-2

Why Mum? A Small Child with a Big Problem

Catherine Thornton

Veritas, 2005

ISBN 1-85390-891-6

Helpful DVDs

Understanding Radiation Therapy: A Patient Pathway

Call 1800 200 800 for a copy.

Website: www.cancer.ie***A Guide to Chemotherapy***

HSE/Mid-Western Cancer Centre/ICS, 2008

Call 1800 200 700 for a copy.

Questions to ask your doctor

Here is a list of questions that you may want to ask. There is also some space for you to write down your own questions if you would like. Never be shy about asking questions. It is always better to ask than to worry.

- How long will it take to get the test results?
- What type of bladder cancer do I have?
- What stage is my cancer at?
- What treatment will I need?
- Will surgery cure my cancer?
- Are there other treatment options? Why is this one best for me?
- Would I be suitable for a clinical trial?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- What side-effects or after-effects will I get?
- Is there anything I can do to help myself during treatment?
- Will treatment affect my sex life?
- Will I be able to have children?
- How often will I need check-ups?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

6

Answer

7

Answer

Acknowledgements

We would like to extend a special word of thanks to the following for their invaluable contributions to this booklet:

Karen Flynn, Cancer Information Nurse

Sheila Kiely, Urology Clinical Nurse Manager

Sonya Bowen, Clinical Nurse Specialist in Urology

Would you like more information?

We hope this booklet has been of help to you. If you feel you would like more information or someone to talk to, please phone our National Cancer Helpline 1800 200 700.

Would you like to be a patient reviewer?

If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers. Please fill in the postcard in the pocket inside the back cover, and post it back to us for free.

If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at **reviewers@irishcancer.ie**. If you would prefer to phone or write to us, see contact details below.

Would you like to help us?

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The mission of the Irish Cancer Society is to play a vital role in achieving world-class cancer services in Ireland, to ensure fewer people get cancer and those that do have better outcomes. Our goals are focused around prevention, survival and quality of life, with three programme areas to achieve them: advocacy, cancer services and research.

