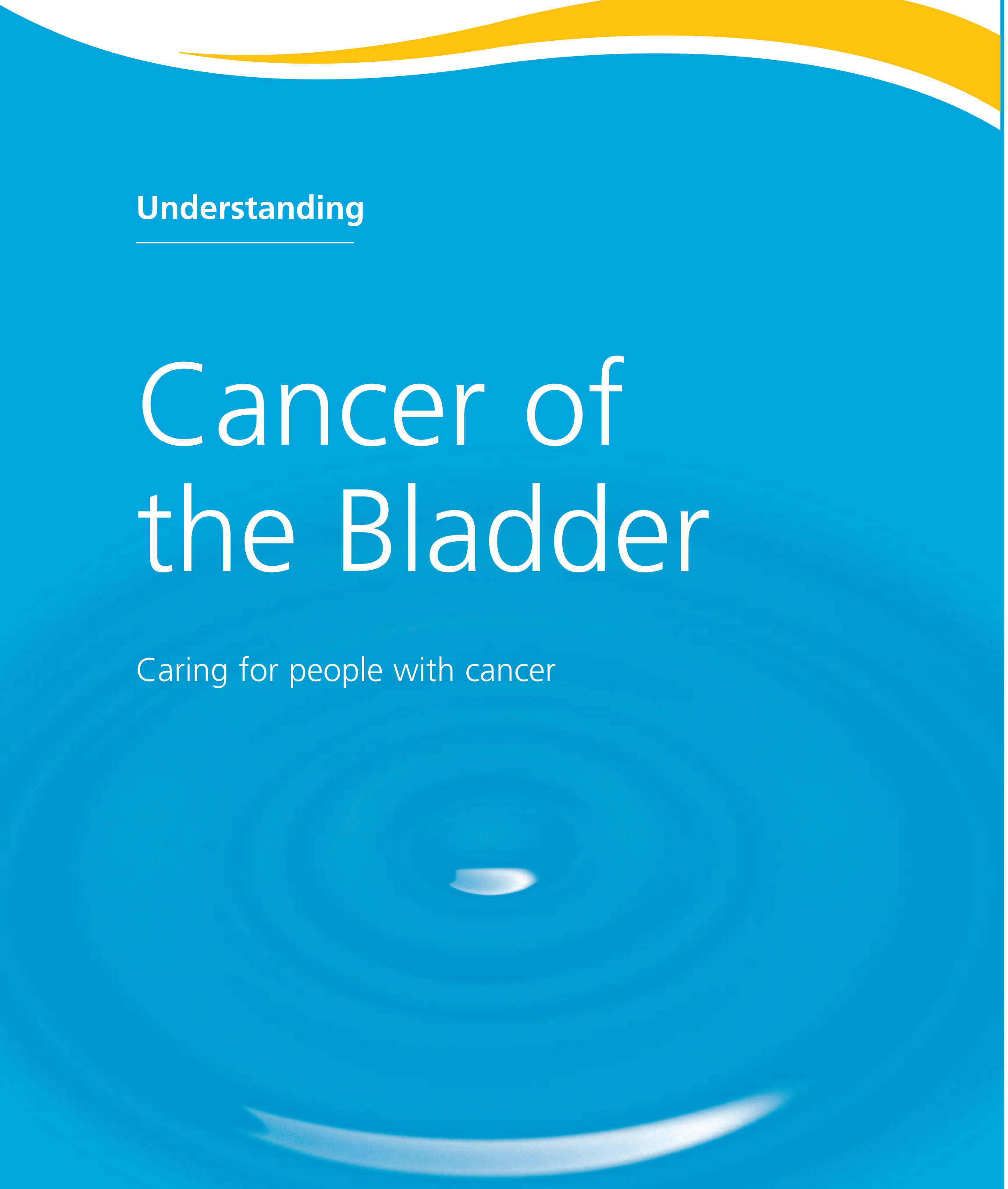
Irish Cancer Society

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 treatment, and how it may affect you.

If you are a patient, your doctor or nurse may 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.

	Name	Telephone
Specialist nurse		
Family doctor (GP)		
Urologist		
Stoma care nurse		
Medical oncologist		
Radiation oncologist		
Radiation therapist		
Medical social worker		
Emergency		

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

BLADDER CANCER ADVISERS
Mr Robert Flynn, Consultant Urologist
Mr David Quinlan, Consultant Urologist
Christine McManus-Lynch, Clinical Nurse Manager in Urology
Karen Thomas, Endoscopy and Urology Manager

CONTRIBUTOR
Milie Mathew, Cancer Nurseline Nurse

EDITOR
Sarah Lane

ILLUSTRATOR
Michael H Phillips

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

- *Guidelines on Muscle-Invasive and Metastatic Bladder Cancer,* European Association of Urology, 2015.
- *Guidelines on Non Muscle-Invasive Bladder Cancer (Ta, T1, and CIS),* European Association of Urology, 2015.
- *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, 2010.
- *The Chemotherapy Source Book,* M Perry, Lippincott Williams and Wilkins, 2012.

First published by the Irish Cancer Society in 2011.

Next revision: 2018

ISBN 0953236901

Contents

About bladder cancer

Treatment and side-effects

Coping and emotions

Support resources

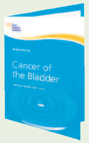
Introduction

This booklet has been written to help you to learn more about cancer of the bladder. The booklet is divided into 4 parts:

- **About cancer of the bladder** gives an introduction to cancer of the bladder.
- **Treatment and side-effects** discusses the different treatments used for cancer of the bladder and possible side-effects.
- **Coping and emotions** discusses how you can cope with your feelings and the emotional effects of having cancer.
- **Support resources** gives information where to get help and support. You will also find an easy-to-read explanation of words and terms used throughout this booklet.

We hope the booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. Talk to your doctor about your treatment and care. The best choice for you will depend on your particular cancer and your individual circumstances.

Reading this booklet



Remember you do not need to know everything about cancer of the bladder straight away. Read a section about a particular item as it happens to you or if you are interested in it. Then when you 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 our Cancer Nurseline on Freephone 1800 200 700. You can also email us at cancernurseline@irishcancer.ie or visit a Daffodil Centre. See page 61 for more about Daffodil Centres.

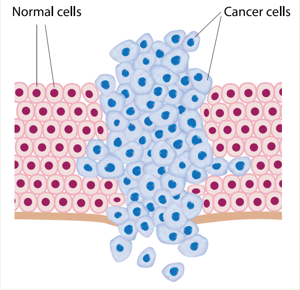
About bladder cancer

What is cancer?

Cancer is a word used to describe a group of diseases, not just one. There are more than 200 different types of cancer. Each is named after the organ or type of cell in which the cancer first grows. For example, prostate cancer starts in cells in the prostate gland, breast cancer starts in cells in the breast.

All cancers are a disease of the body's cells, which are the building blocks of your body. Normally, cells grow and divide in a controlled way and replace old cells to keep the body healthy. But with cancer, the abnormal cells grow without control. Groups of abnormal cells can form a growth or tumour.

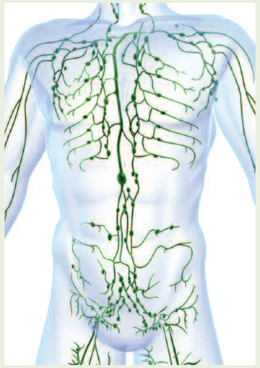
Tumours can be either benign or malignant. Benign tumours are not cancerous and do not spread to other parts of your body. Malignant tumours are cancerous and can spread to other parts of your body. This happens when a cell or group of cells breaks away and is carried by your bloodstream or lymph vessels to other tissues and organs in your body. These cells can then grow into a new tumour. This is called a metastasis or secondary tumour.



Cancer cells

What is the lymphatic system?

The lymphatic system is made up of groups of lymph nodes throughout the body. Lymph nodes are found mainly in the neck, armpit, groin and tummy. Lymph nodes are connected by a network of lymph vessels. These lymph vessels are tiny tubes, which usually lie just under the skin. The lymph vessels transport lymph fluid, which carries extra fluid and waste from body tissues. Sometimes cancer cells spread into lymph nodes or start in the lymph nodes themselves. If this happens the lymph nodes become swollen.



Lymphatic system

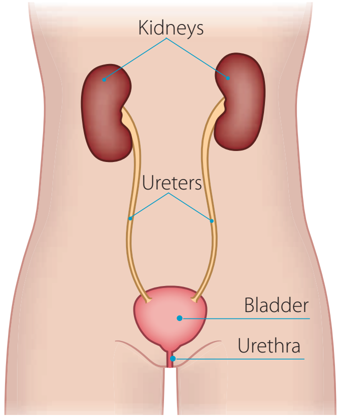
To sum up

- Cancer is a disease of the cells of your 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 your bloodstream or lymph vessels and form a tumour 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.



The bladder and the kidneys

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 is made up of a number of layers. Bladder cancer starts in the innermost lining. How your specialist treats your bladder cancer will depend on how far the cancer has grown into these layers. This tells your doctor the stage of your bladder cancer (see page 15).

The inside of the bladder has a special type of lining that stretches as the bladder fills up. This lining is called the urothelium or transitional epithelium. It stops the urine being absorbed back into the body. Below this first layer is a thin layer of connective tissue called the lamina propria. Underneath this layer is muscle tissue called the muscularis propria. Around the muscle tissue is a fatty layer.

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. Cancer cells can affect how the bladder works normally.

The cells in the lining of the bladder (urothelium) are known as transitional cells. Because these cells line the bladder, they come into contact with waste products in the urine that may cause cancer, such as chemicals in cigarette smoke. About 90% of bladder cancers diagnosed in Ireland are the transitional cell type. Bladder cancer affects about 450 people in Ireland each year. It is more common in men than women.

Bladder cancer can grow in different ways:

Non-muscle-invasive bladder cancer

This cancer is also known as superficial bladder cancer. Non-muscle-invasive bladder cancer is the most common type of bladder cancer. It only affects the lining of the bladder and hasn't grown into the deeper layers of the bladder wall. It usually appears as small growths, shaped like mushrooms, growing out of the bladder lining. Your surgeon can remove these growths and they may never come back.

But some types of superficial bladder cancer are more likely to come back. These include carcinoma in situ (CIS) and high grade T1 tumours.

Carcinoma in situ (CIS): This type appears as red ulcers inside your bladder. The cells are very abnormal. They can grow quickly. Without treatment there is a high risk of them developing into invasive bladder cancer.

T1 tumours: These are superficial cancers that have grown from the bladder lining into the next layer underneath, called the lamina propria.

Occasionally carcinoma in situ and T1 tumours can grow very quickly and spread to the muscle wall in the bladder and nearby tissues. This is known as muscle-invasive bladder cancer.

Muscle-invasive bladder cancer

This means the cancer cells have grown into the muscle layer of the bladder, or beyond. Muscle-invasive bladder cancer needs more intensive treatment than non-muscle-invasive bladder cancer. This is because there is a risk that it could spread to other parts of the body.

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 classified as non-muscle invasive bladder cancer or muscle-invasive bladder cancer.

What are the risk factors for bladder cancer?

The exact cause of bladder cancer is unknown. But there are certain things called risk factors that can increase your chance of getting the disease. Having a risk factor doesn’t mean you will definitely get cancer. And sometimes people without any known risk factors develop cancer.

The biggest risk factors for bladder cancer are smoking and industrial chemicals.

- **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 65.
- **Gender:** Males 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 an even lower rate.
- **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 (Cytoxan®), 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).

Being diagnosed with bladder cancer

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

- **Upset and overwhelmed** by your emotions
- **Confused** by all the information being given to you
- **Worried** about what will happen next
- **Scared** about the future

However you feel, you are not alone. There are many people who can help and support you at this time.

If you need to talk to someone, or if you want more information or advice:

- Ask to speak to the medical social worker or cancer liaison nurse at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to one of our cancer nurses in confidence – call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre
- Email our cancer nurses at cancernurseline@irishcancer.ie
- Talk to other people going through the same thing. Join our online community at http://www.cancer.ie/community

We hope this booklet will help you too. It has information on what to expect when you have been diagnosed with cancer. It also has tips on how to cope – practically, emotionally and financially. More helpful information is available on our website **www.cancer.ie**.

Telling people about your diagnosis

It can be hard to tell other people the news that you have been diagnosed with cancer.

You may want to talk about your diagnosis, or you may prefer not to tell people straight away. Talking can help you to get support from friends and family. On the other hand, you may find it hard to cope with other people's reactions when they hear the news. For example, they may fuss over you or be upset.

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you would like to talk things over with a cancer nurse. You can also email the nurses at cancernurseline@irishcancer.ie

You could also ask the nurses for free copies of our booklet *Who can ever understand?* This booklet can help you to find ways to talk about your cancer and ask for the help and support you need.

What tests will I have?

After you have been diagnosed with bladder cancer, your doctor may want to do more tests to find out more about your cancer and your general health.

Tests you may have include:

Biopsy: A biopsy is where a small sample of tissue is removed from your bladder and examined under a microscope. This can give your doctor more information about what type of bladder cancer it is and its grade (see page 17).You usually have a biopsy during a cystoscopy (see below) as part of diagnosing your cancer. You may also have a biopsy after diagnosis. For example, you may have a biopsy and exam under general anaesthetic if the first biopsy sample was very small. Or the surgeon may take a sample of tissue during surgery to make sure all the cancer has been removed.

Cytoscopy: A cystoscopy is usually done to diagnose bladder cancer, but you may have one later or as part of your follow-up care (see page 46). 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 surgeon will then put the camera up through your water pipe to look into your bladder. Instruments can also be passed through the cystoscope so that the surgeon can take a biopsy.

CT scan (CAT scan) / CT urogram (CTU): This is a special type of X-ray that gives a detailed picture of the tissues inside your body. The scan itself is painless and takes 10-30 minutes. For a CT scan of your urinary tract you might be asked not to eat (fast) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparations for a CT scan can vary but the doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should not need to stay in hospital.

MRI scan: This is a scan that uses magnetic energy to build up a picture of the tissues inside your body. During the scan you will lie inside a tunnel-like machine. Some people feel anxious about this and are afraid they may feel claustrophobic during the scan. If you are anxious about this, contact the radiographer the day before. They may be able to give you medication to relax you on the day.

Having the scan does not hurt but can be very noisy. You will be given earplugs to wear during it. You might get an injection before the scan to show up certain parts of your body. During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test. Usually you can go home after the scan.

Other tests

In some cases a bone scan or PET scan may be recommended, but these tests are not normally needed, especially with non-muscle invasive bladder cancer.

Bone scan: Bone scans can check for signs that cancer has spread to the bones.

Before the scan, you will have an injection of a very small amount of a mildly radioactive substance, or radionuclide, usually into your arm. You will then have to wait for up to 3 hours for the radionuclides to travel through your body.

When the radionuclides have passed through your body, you'll be asked to lie down on an X-ray table. A camera will then scan your entire body. Abnormal bone absorbs more radioactivity than normal bone, so these areas will show up on the scan as areas of activity known as 'hot spots'.

The scan lasts for up to an hour and you'll be able to go home immediately afterwards. The amount of radioactivity used in these scans is very low and safe and will disappear from your body within a few hours.

PET scan: PET stands for positron emission tomography. PET uses a low dose of radioactive sugar to measure the activity of your cells. This sugar is first injected into your arm and travels to all the cells in your body. Because cancer cells absorb large amounts of the sugar, there will be more radioactivity where the cancer cells are found. An hour after the injection, the scan is taken and can show if the cancer has spread to other tissues and organs. Before the test, you may have to fast (not eat) for a few hours. PET is safe to use and there are no side-effects.

Waiting for test results

It usually takes about a week for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Staging and grading bladder cancer

The tests you have after diagnosis help the doctor to give your cancer a stage and a grade.

Staging: Staging means finding out how deeply the cancer has grown into the bladder and if it has spread to other parts of your body.

Grading: Grading describes how quickly the cancer may grow and spread. Knowing the stage and grade of your cancer is very important, as it helps your doctor to decide the best treatment for you.

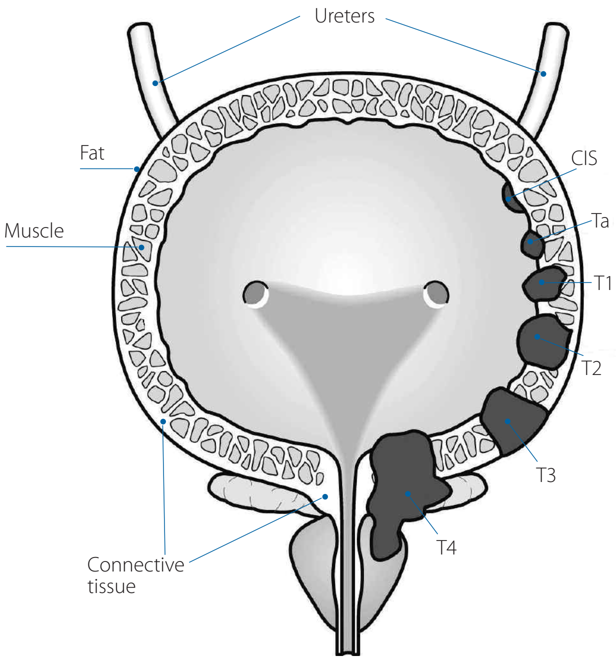
How is bladder cancer staged?

There are different ways to describe the stages of cancer. The staging system normally refers to the size of the tumour (T), whether there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis). Your doctor often uses this information to give your cancer a number stage – from 1 to 4. A higher number, such as stage 4, means a more serious cancer. Some stages are further divided into stage A and B. Staging can be hard to understand, so ask your doctor and nurse for more information if you need it.

In general, the lower the number, the less the cancer has spread.

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

What are the stages of bladder cancer?



Stages of bladder cancer

Non-muscle invasive bladder cancer

Non-muscle invasive bladder cancer will be staged as CIS, Ta or T1

Carcinoma in situ (CIS): This appears as flat, red areas in your bladder. This type of bladder cancer is more likely to back after treatment, often as another non-invasive cancer in the bladder. CIS can grow more quickly and can become invasive. This means it may need different treatment to other non-muscle invasive bladder cancers.

Ta: Here the tumour is found as a mushroom-like growth (papillary cancer) growing only in the innermost lining of your bladder.

T1: The tumour has started to grow into the connective tissue just below the bladder lining.

Muscle invasive bladder cancer

- **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.

Advanced bladder cancer

- **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.

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

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 grades the cancer as either low grade or high grade.

- **Low grade bladder cancer:** The cancer cells look very much like normal bladder cells or they may look slightly abnormal. The cancer is usually slow-growing and less likely to spread than high grade bladder cancer.
- **High grade bladder cancer:** The cancer cells look fairly abnormal or very abnormal and are more likely to grow quickly.

Carcinoma in situ (CIS) is always classed as high grade.

To sum up

- If you have a diagnosis of bladder cancer your doctor will do more tests to get more information about the cancer.
- Your doctor will give your cancer a grade and a stage.
- The stage refers to how deeply the cancer has grown into the bladder and if it has spread.
- The grade describes how quickly the cancer is likely to grow.
- Once the stage of the cancer is known, your doctors can plan the best treatment for you.

Asking about your prognosis

Your prognosis is information about how your disease is likely to progress, including average survival times for your type of cancer (life expectancy). Many people with cancer have questions about their prognosis.

If your prognosis is better than expected, you may feel more hopeful about your illness and your future. Some people feel more in control when they have as much information as possible. Other people don't want to know about their prognosis – they may prefer not to think about the future too much or they may worry how they will cope if they get bad news.

It is not always easy to answer a question about life expectancy, as the answer is based on a 'typical' experience. In reality, everybody is different and experiences can vary a lot from person to person. What happens to you might be quite different from what the doctor expects.

If you decide you want information on your prognosis:

- **Think about how you will cope with the information** before asking for your prognosis.
- **Get information on prognosis from your doctor.** He or she knows your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Avoid looking online.** It can sometimes be hard to understand what the figures you find online mean without an expert like a doctor to help. The information may not really apply to your situation or your particular cancer type.
- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treatment and side-effects

How is bladder cancer treated?

The way bladder cancer is treated mainly depends on the stage of the disease at diagnosis. Non-muscle-invasive bladder cancer is treated differently to muscle invasive bladder cancer.

Surgery, chemotherapy and radiotherapy can all be used to treat bladder cancer. 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

You may receive a different treatment as part of a clinical trial. Your doctor will tell you if there are any trials suitable for you. See page 40 for more information on clinical trials.

For more about treatment of non-muscle invasive bladder cancer see page 23.

For more about treatment of muscle invasive bladder cancer see page 26.

Specialist cancer centres

Bladder cancer is treated in specialist cancer centres in Ireland. The staff at these centres have great expertise in managing patients with bladder cancer. As a result, you may be transferred to another hospital from the one where you received your diagnosis.

Deciding on treatment

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

Treatment options: Your doctor and nurse will explain your treatment options to you. 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. If you forget a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to one of our cancer nurses.

Time to think: When faced with a serious 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 can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.

Second opinion: You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your doctor 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 aware of the benefits and risks.

Giving consent for treatment

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

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

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again.

Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

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.

Surgeon	A doctor who specialises in surgery and can remove a tumour from your body.
Urologist	A doctor who specialises in treating diseases of the bladder and kidneys.
Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Radiation therapist	A specially trained person who delivers radiotherapy and gives advice to cancer patients about their radiation treatment.
Oncology liaison nurse / clinical nurse specialist	A specially trained nurse who works in a cancer care unit. She or he gives information and reassurance to you and your family throughout your treatment.
Stoma care nurse	A specially trained nurse who can teach you how to care for a urostomy (stoma).

Medical social worker	A person trained to help you and your family with all your social issues and practical needs. They can give counselling and emotional support. They can also give advice on benefits, entitlements and practical support and services available to you when you go home.
GP (family doctor)	You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope.
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.
Psycho-oncology team	These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.
Psychologist	A specialist who can talk to you and your family about emotional and personal matters and can help you to 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.

Palliative care team	This team is specially trained in managing pain and other symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the 'homecare team' or the 'hospice homecare team'. A specialist palliative care service is available in most general hospitals.
Community health services	This includes family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

How is non-muscle invasive bladder cancer treated?

Non muscle invasive bladder 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 treatment (see page 25).

Surgery for non-muscle invasive bladder cancer

Transurethral resection of a bladder tumour (TURBT): This surgery aims to remove the tumour from your bladder. You will be given a general anaesthetic or an anaesthetic injection into your lower back (spinal anaesthetic) so that you will not feel anything. If you have a spinal anaesthetic, you will be awake during the operation.

During the operation the surgeon will put a tube called a cystoscope into your bladder through your water pipe (urethra). Then special instruments are put through the cytoscope to cut or burn off the tumour. The surgeon may use a mild electrical current to seal the wound and stop any bleeding (cauterisation)

Catheter: After surgery, you may have a thin, flexible tube called a catheter in your bladder for a day or two. It drains your urine into a bag and you can walk around with this. Don't be alarmed if your urine is bloodstained at first. This is normal and you will be encouraged to drink plenty of fluids to flush out your bladder and to reduce the risk of developing a urine infection. 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.

Possible risk of surgery

Removing a bladder tumour is generally a safe procedure. But, as with any operation, there are some possible risks. For example, a urinary infection. If you feel cold, shivery, hot or sweaty, feel generally unwell, or your urine is smelly or cloudy, or if you have blood in your urine please contact your doctor.

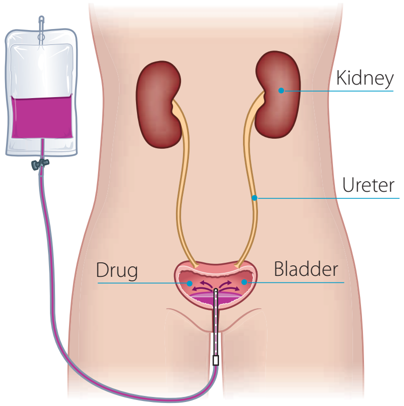
Will I need more treatment?

Superficial bladder tumours can come back after treatment. If this happens you may need another TURBT in the future. For this reason you will be have regular check-ups for many years.

Higher grade tumours 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.

Treatment after TURBT surgery

Intravesical chemotherapy: Your doctor may decide to give you chemotherapy after your surgery to reduce the risk of the cancer coming back. With non-muscle invasive bladder cancer, the chemotherapy drug is normally put directly into your bladder. This treatment is known as intravesical chemotherapy. It is done by putting a liquid chemotherapy drug through a catheter tube into your bladder. You might have your treatment on the day you have the TURBT or later.



Examples of drugs used in intravesical chemotherapy are mitomycin-C, epirubicin and doxorubicin. After treatment the doctor or nurse will remove the catheter. You have to try not to pass any urine for the next 2 hours. This gives the chemotherapy drug time to be in contact with the lining of the bladder. You then pass urine naturally to get rid of the drug. Or your nurse may drain the chemotherapy out through a catheter. You may have a single treatment or a course of treatments, depending on the stage and grade of your cancer.

BCG treatment: Some people may be advised to have BCG treatment into their bladder (intravesical BCG) as part of their treatment for bladder cancer. BCG can help to stop bladder cancers coming back or spreading deeper into the bladder. The treatment is usually given once a week for 6 weeks. As with chemotherapy, the drug is given as a liquid, which is passed into the bladder through your urethra.

These treatments 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. BCG is usually used for CIS and higher-grade bladder tumours. 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 is usually used to try to stop high grade tumours and CIS from coming back.

Follow-up: It is not unusual for superficial bladder tumours to come back from time to time. For this reason you will have regular visits to your surgeon. 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 cytoscopy, 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 muscle invasive bladder cancer treated?

The following can be used to treat invasive bladder cancer:

- Surgery
- Radiotherapy
- Chemotherapy

Surgery: Surgery for invasive bladder cancer usually involves removing the whole bladder and then constructing a new way to pass urine. See opposite 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 side-effects from the radiotherapy. See page 35 for more about radiotherapy.

Chemotherapy: This is the use of drugs to kill or control the cancer cells. Chemotherapy for muscle invasive bladder cancer may be given:

- Before surgery or radiation to shrink the cancer and reduce the risk of it coming back. This is called neo-adjuvant chemotherapy.
- With radiotherapy. This is called chemoradiation.
- On its own for advanced bladder cancer.
- After surgery if there is a high risk of the cancer coming back (recurrence). This is called adjuvant treatment.

See page 38 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice and support from a cancer nurse.

Surgery for muscle invasive bladder cancer

The aim of surgery for muscle invasive bladder cancer is to remove the cancer and the area close to it.

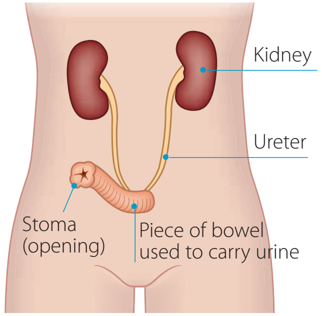
Surgery to remove the whole bladder and some nearby tissues and organs including the lymph nodes is called a radical or total cystectomy. It is the most common type of surgery for muscle invasive bladder cancer. Your surgeon will let you know exactly which organs need to be removed. He or she will also discuss any side-effects linked to the surgery. If your surgeon removes just part of your bladder, it is called a partial cystectomy.

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 to store urine. This is called a urinary diversion. Your surgeon will explain the different ways of draining urine. These include:

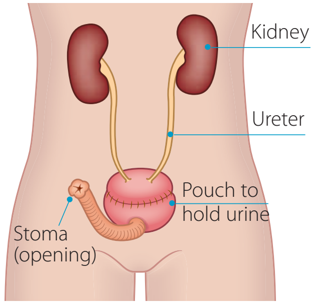
- Urostomy (ileal conduit)
- Continent urinary diversion
- Bladder reconstruction (neobladder)

Urostomy: This is the most common type of urinary diversion. 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.



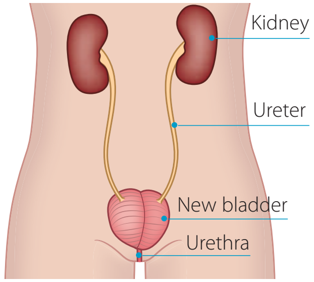
To do this, your surgeon uses about 6 inches of your small bowel to make a passage. The two kidney tubes (ureters) will be then be attached to it. One end of the passage is closed up with stitches, while the other end is brought through to the surface of your tummy. The open end is called a stoma and looks like the skin inside your cheek. You will need to wear a bag attached to the stoma to collect and drain your urine.

A flat, watertight bag is placed over the stoma to collect your urine. It's kept in place with a special type of glue. The bag will fill with urine, and you will need to empty it regularly. A stoma nurse will show you how to take care of it.



Continent urinary diversion: With this type of urinary diversion, you don't need an external bag to collect your urine. Your surgeon uses a piece of your bowel to make an internal pouch that can store urine inside your tummy. The two kidney tubes (ureters) will be then be attached to it. Urine will drain through the ureters into this pouch.

The internal pouch that replaces your bladder is connected to your tummy wall by a stoma. You empty urine from the pouch through the stoma using a thin tube called catheter. You will need to do it about 5 or 6 times a day. A stoma nurse will teach you how to do it. In this case, you do not need a urinary pad or bag. The stoma is covered with a bandage.



Bladder reconstruction: In this type of surgery, instead of making a stoma the surgeon connects the new pouch to your urethra. The pouch is able to store urine like your bladder did and you pass urine out through your urethra. This is known as a neobladder.

To empty the pouch you will need to use your abdominal muscles. This can be done by holding your breath and pushing down into the tummy. If you are having a neobladder, your hospital team will be able to give you more detailed information about it.

Getting ready for surgery

Tests: To make sure you are fit for surgery, some 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 may 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 be asked to follow a special diet for a few days before the surgery or to drink a laxative.

Night before surgery: You will not be allowed to eat anything for a few hours before your surgery. You might get an injection of heparin to prevent blood clots forming in your legs.

Morning of surgery: You will continue to fast (not eat) at this time. Before you go to theatre, you may get a tablet to make you feel sleepy and more relaxed.

After the surgery

Most people will be looked after in the intensive care or a high dependence unit for a few days after their operation. This is normal and doesn't mean your operation has gone wrong. 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.

- **Wound:** The wound site will be along your tummy. The line of stitches will go from your navel 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 fluid, like blood, from your wound site. They are removed when there is little or no fluid 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 may use different types of medication to ease any pain or discomfort you have.
- **Eating and drinking:** 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.
- **Bowel motions:** The surgery will slow down your bowels and they will need time to heal as well. You will be monitored to make sure your bowel habits get back to normal.
- **Exercising:** The nurses will encourage you to start moving about as soon as possible after your surgery. This is important to prevent problems such as chest infection or blood clots. While you are in bed, the nurses will encourage you to do regular leg movements and deep breathing exercises.

  After surgery your nurses will help you to get out of bed and will encourage you to go for a short walk as soon as you can. 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 will get better as your wound begins to heal.
- **Pain:** You may have some pain after surgery, especially when you cough or try to move, but most patients are very comfortable with the epidural pain relief. You may have a patient controlled analgesia pump (PCA). This sends pain medication into your blood when you press a button. This pump is designed so that you can’t overdose, so it’s fine to press it whenever you are uncomfortable. If your medicine isn't controlling your pain tell your doctor or nurse as soon as possible. This will help them to give you the combination and dose of painkillers that’s right for you.

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. They will usually be removed when you return for your outpatient appointment.

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.

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. You may also find it helpful to talk to someone who has already learned to live with a urostomy. Your nurse may be able to arrange for someone to talk to you and tell you about how they coped. This advice can be very helpful, especially in the first few months after your operation. If you need to information and support from a cancer nurse, you can call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre.

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. Men will have difficulty getting or keeping an erection after cystectomy. This is called erectile dysfunction or ED. There are also emotional issues relating to a change in body image and loss of libido (sex drive). See page 42 for more about the side-effects of treatment and your sex life.

Going home

Most patients are ready to go home 7 to 14 days after surgery, but it varies from patient to patient. Before you go home your nurse will make sure you have the necessary arrangements for removal of wound clips and supplies of urostomy bags.

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.

Tips & Hints – 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.

Support at home: If you live alone or have problems getting around the house, talk to your nurse or medical social worker on your ward as soon as you are admitted to hospital. That way he or she can put in place any community services that you may need after you leave hospital. For example, they can contact your local public health nurse and/or community stoma nurse, so that they can come out to see you when you are home. You can also contact the hospital or stoma nurse if you have any problems at 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. Talk to your stoma nurse about what is best for you.

Follow up: You will be given a date to come back for a check-up, often about 6 weeks after your surgery. Your doctor will check how you are and discuss any test results with you. You doctor will also talk to you about any further treatment you may need. For more about follow-up, see page 46.

> If you have a worry or symptom before your check-up, contact your doctor, specialist nurse or hospital ward for advice.

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

Radiotherapy for muscle 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 (chemoradiation)
- 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 11) after your radiotherapy. If the cancer does come back, your bladder might need to be removed.

With bladder cancer the type of radiotherapy used is called external beam radiotherapy. This means the radiation comes from special machines that aim X-rays directly at your tumour or the tumour site. The radiation is also aimed at a small area of normal tissue around the tumour just in case any cancer cells have spread.

Planning your treatment

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

In external radiotherapy an important part of the planning process is simulation. This involves using a CT scanner to pinpoint the area to be treated. You may have extra scans or X-rays taken to plan your treatment. The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. The dose of radiation will be decided and tightly controlled for your treatment.

Getting your treatment

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

Usually treatment takes several minutes and is painless. Most people receive radiotherapy as outpatients, travelling to the radiotherapy unit each day with a break over the weekend.

Radiotherapy is normally given in special cancer treatment centres, usually hospitals or clinics. These centres need highly trained staff and space for the large equipment involved. As a result, the centre may be some distance from the hospital where you received surgery or chemotherapy.

External radiotherapy does not make you radioactive. It is completely safe for you to mix with family and friends. Pregnant women or children are not at risk.

How much radiotherapy do I need?

The course can be several treatments over a number of days or weeks (6 to 8 weeks) or between 1 and 10 doses for palliative treatment.

Side-effects of treatment

Radiotherapy is given directly to the site of the cancer. Therefore, side-effects are usually related to the part of your body being treated. How severe these side-effects are will vary from person to person, depending on the amount of treatment received. Most side-effects develop during or shortly after your treatment and get better within a few weeks. Late side-effects may develop some time after treatment. Some side-effects are long-term or may even be permanent. When the bladder is being treated, the most common side-effects are:

Short term possible side-effects

- Bladder and back passage irritation
- Changes to your bowel habits (constipation or diarrhoea)
- Skin irritation and rashes
- Tiredness (fatigue)
- Loss of hair in genital area

Longer term possible side-effects

- Blood in your urine or bowel motions
- Narrowing of the vagina
- Effects on ability to have erections (erectile dysfunction)
- Infertility

See pages 42-43 for more about the physical effects of treatment. See page 45 for more about infertility.

For more information on radiotherapy and its side effects, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet *Understanding Radiotherapy*, or the DVD *Radiation Therapy: A Patient Pathway*.

> External radiotherapy does not make you radioactive. There is no danger to you and your family. You do not have to avoid children or pregnant women.

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.
- Side-effects of 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 to kill cancer cells. The doctor who specialises in chemotherapy is called a medical oncologist.

Chemotherapy for muscle invasive bladder cancer may be given:

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

This type of chemotherapy is different to intravesical chemotherapy, which is used to treat non-muscle invasive bladder cancer (see page 25).

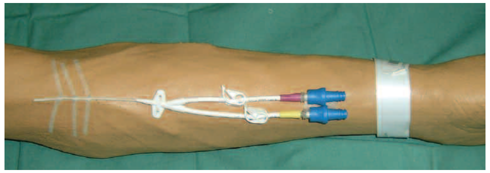
A combination of different chemotherapy drugs is often used for muscle invasive bladder cancer. Your doctor or nurse will discuss your treatment with you. For more information on different types of chemotherapy or a copy of the booklet *Understanding Chemotherapy*, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

How often will I need chemotherapy?

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

How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (drip). It may also be given in tablet form. Usually your treatment will be given in the chemotherapy day care unit.



Side-effects of treatment

The side-effects of chemotherapy vary from person to person and depend on the drugs used. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells.

Side-effects may include:

- **Higher risk of infection.** Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high temperature, having a cough, or pain passing urine.
- **Bruising or bleeding.** Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. You will have regular blood tests to count the number of platelets in your blood. Tell your doctor if you have any bleeding that you can't explain, such as nosebleeds or bleeding gums.
- **Anaemia.** Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment.
- **Nausea and vomiting.** Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments to prevent nausea and vomiting.
- **Sore mouth.** Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.
- **Hair loss (alopecia).** Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Before treatment your doctor and nurse will tell you if you are likely to have any hair loss.
- **Fatigue.** Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 41.

In most cases the side-effects go away when the treatment ends or soon after. If you have any symptoms or you feel unwell let your doctor or nurse know. Most side effects can be helped by medication.

For more information on the side-effects of chemotherapy or a copy of the booklet *Understanding Chemotherapy*, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

To sum up

- Chemotherapy is a treatment that uses drugs to kill cancer cells.
- 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 of chemotherapy vary from person to person and depend on the drugs used.
- Some side-effects include less resistance to infection, anaemia, bruising, sore mouth, nausea and vomiting, fatigue, and hair loss.
- Most side-effects are well controlled with medication.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing cancer.

Patients with cancer are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment you get a new trial drug. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using two treatments together.

When a drug is being used in a clinical trial it has already been carefully tested to make sure it is safe to use in a clinical trial.

Your doctor can tell you if there are any clinical trials suitable for you.

More information

If you are interested in taking part in a clinical trial or want more information, you can read our factsheet *Cancer and Clinical Trials*. It's available to read or download on our website, www.cancer.ie. You can also get a free copy by calling our Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre.

How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is a very common symptom of cancer.

Fatigue when you have cancer can be caused by many things, including:

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

Usually fatigue improves once treatment is over, but it can carry on for some people. It is important to tell your doctor or nurse if fatigue is affecting you, so that they can help you.

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

Tips & Hints – fatigue

- Try to do some exercise – ask your doctor for advice about the best exercise for you
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Try to eat well and drink plenty of fluids.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself.
- If you are not sleeping well, try relaxation techniques and avoid stimulants like caffeine and alcohol before bedtime.
- Try complementary therapies like meditation, acupuncture or massage.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 or call into a Daffodil Centre for a free copy.

Will treatment affect my sex life and fertility?

Physical effects of treatment

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

Women

Shortening or narrowing of the vagina: For women, bladder surgery or radiotherapy might shorten or narrow your vagina. This can make sex uncomfortable. Regular gentle sex or using a special device called a dilator can help with this side-effect. Dilators are tampon-shaped plastic tubes of different sizes that you use with a lubricant.

Your specialist nurse will advise you on how helpful a dilator may be in your situation and explain how to use them. You may feel embarrassed or uncomfortable but your specialist nurse will understand your concerns and will always respect your feelings.

Vaginal dryness: Radiotherapy to the pelvis can cause vaginal dryness. This can make having sex uncomfortable. Vaginal creams or moisturisers can be used regularly to help with day-to-day dryness. Vaginal lubricants can be used during sex to make it more comfortable and pleasurable. Hormonal creams and moisturisers can also help with vaginal dryness. Your doctor or nurse specialist can give you advice about the best products to help.

Men

Erectile dysfunction: Many men find it hard to get or keep an erection after surgery or radiotherapy for bladder cancer. This is called erectile dysfunction or impotence. After cystectomy you will be unable to father a child naturally. See page 45 for more about fertility and bladder cancer.

There are medications and other treatments that can help with erectile dysfunction. For example, tablets, injections, vacuum pumps or implants to help you get an erection. Your doctor can advise you about treatment that may help. You can also talk to a cancer nurse in confidence by calling our Cancer Nurseline on 1800 200 700. You can also email the nurses: cancernurseline@irishcancer.ie

Sex after urostomy

As well as the physical effects of bladder surgery, having a urostomy can affect how you feel about your body. You may also be afraid that the urostomy bag will become dislodged or cause damage to the stoma. 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.

Feelings and emotions

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take quite a while. You may have concerns about how your partner will react if you have a urostomy or other changes to the way your body looks.

It can be hard to relax when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment and lose interest in sex as a result.

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

Issues such as discomfort, change in body image, fatigue, fear and anxiety usually resolve with time and with the support of those close to you. You may find that talking about your feelings may ease any worries you have.

If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist relationships counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

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

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Don't be put off by thinking the question is small or trivial or that you'll be embarrassed. Your doctor and nurse are well used to taking about these matters and will give you advice. You can also call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at cancernurseline@irishcancer.ie

Contraception

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment. For example, there is a risk of miscarriage or birth defects in children conceived during or just after chemotherapy.

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

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

Will treatment affect my fertility?

Many treatments for bladder cancer will affect your fertility, so that you may not be able to have a child in the future.

Discuss any worries you have about infertility with your doctor before treatment starts. He or she can tell you if there are any options open to you at this time. For example, it may be possible to freeze your eggs or sperm before treatment begins. Rotunda IVF at the Rotunda Hospital in Dublin provides a service where eggs or sperm can be frozen for later use.

Infertility

Dealing with infertility may not be easy, depending on your age and if you have had children. It can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener or with a professional counsellor. You can also call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

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

Cancer and complementary therapies

Some people with cancer find it helpful to try complementary therapies as well as their standard treatment.

Complementary therapies: Complementary therapies are treatments that can be given in addition to standard medical treatment. Examples of complementary therapies are yoga, meditation, acupuncture, aromatherapy and massage.

Standard treatment: Standard or conventional cancer treatments are things like chemotherapy, radiotherapy and surgery. The effects and the side-effects of standard treatments have been scientifically tested.

Alternative therapies: Alternative therapies are generally treatments that are used instead of standard treatments. For example, diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health.

If you decide to have complementary or alternative treatments…
Before you decide to change your treatment or add any methods of

your own, 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.

More information

If you want to know more about the different complementary and alternative therapies read our booklet *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. If you would like a copy or more advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read or download the booklet on our website **www.cancer.ie**

What follow up do I need?

After your cancer treatment has ended you will still need to go back to the hospital for regular check-ups. This is called follow-up. The follow-up may involve having a physical exam, blood tests and scans. If your bladder was not surgically removed, you will need repeated cystoscopies (see page 11). You will also get the chance to talk to the stoma nurse. At first these visits to the specialist will be quite often, sometimes every 3 months. The visits will continue for a number of years but will gradually become less frequent.

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope. Sometimes it helps to write down what you want to say before you see the doctor. That way you won't forget what you wanted to say.

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

Staying healthy after treatment

Many people want to make positive changes to their lives after their treatment has ended.

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

- Feel better
- Heal and recover faster
- Keep up your energy and strength
- Cope better with the side-effects of treatment

Research suggests that a healthy lifestyle may also lower your risk of the cancer coming back.

A healthy lifestyle includes:

- Exercising
- Eating healthy foods
- Staying at a healthy weight
- Not smoking
- Protecting yourself from the sun

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

How is advanced bladder cancer treated?

Advanced cancer is when the cancer has spread to another part of your body. Cancer that has spread to another part of your body is also called metastatic or secondary cancer. Your cancer may be advanced when it is first diagnosed. Or it may have come back sometime after you were first treated. This is called recurrence.

If your cancer is advanced, it can still be treated. There are a range of treatment options for advanced bladder cancer and new treatments are being developed all the time.

With advanced cancer the aim of treatment is usually to try to control the cancer rather than to cure it. Your doctor may advise chemotherapy or radiotherapy. There may also be treatments that you can have as part of a clinical trial. Your doctor will tell you if there are any clinical trials that might be helpful for you.

You doctor may refer you to specialist palliative care doctors and nurses, who are experts in managing the symptoms of advanced cancer. Palliative care also offers emotional support and comfort to patients and their families.

Coping and emotions

How can I cope with my feelings?

There are many reactions when told you have cancer. Reactions differ from person to person. There is no right or wrong way to feel and there is no set time to have one particular emotion or not.

Common reactions include:

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

A helpful booklet that discusses in detail how you may be feeling is called *Understanding the Emotional Effects of Cancer.* Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy.

Anxiety and depression

Sometimes a cancer diagnosis can cause anxiety and depression. If you feel that your low moods are getting the better of you or you are finding it hard to cope, it's important to get help. It is not a sign of failure to ask for help or to feel unable to cope on your own. Try to talk with someone you know who is a good listener or tell your GP. Medical social workers can also offer support to you and your family.

If you are finding it difficult to get over a period of depression, your doctor may suggest a treatment. Often a short course of antidepressants can work well. Professional counselling can also be very helpful.

Counselling

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. A trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support and help you to make decisions and cope better.

Counselling is available free of charge at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. Our cancer nurses can give you details of where free counselling is available and also provide confidential advice, support and information on any aspect of cancer. You can also contact the nurses by email: cancernurseline@irishcancer.ie

Ways to get support

Find out about cancer support services in your area. There are lots of local cancer support services that provide a range of helpful services such as counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 63 for more about cancer support services.

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

Get online support. There are special websites called online communities where people with cancer can write questions, share stories, and give and receive advice and support from each other. Visit www.cancer.ie/community to join the Irish Cancer Society online community.

Talk things through. It can be a great weight off your mind to share your feelings and concerns. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital. To speak to one of our cancer nurses in confidence visit a Daffodil Centre or call our Cancer Nurseline on 1800 200 700.

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

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

Learning to cope

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 with cancer, only your way.

It can take some time to come to terms with your emotions after a cancer diagnosis. 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, most people are able to adjust to life during treatment.

How can I help myself?

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.

Use your support network. Doing things for yourself can help to make you feel more in control, but be realistic about what you can manage by yourself. Don't be afraid to ask for help from those who want to support you or to use the support services available. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Involve your family and close friends. Don't keep your worries or any physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed.

Gather information about your cancer and treatment. Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people.

Eat well. Try to eat as well as you can. Have lots of different types of foods with plenty of fresh fruit and vegetables.

Get some exercise. Exercising is a great way to boost your mood and sense of well-being and it can improve your energy levels if you are feeling very tired. Talk to your doctor or nurse about which activity will suit you best.

Try relaxation and stress management techniques. Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres have groups to help you learn these techniques.

Try complementary therapies. Complementary therapies are treatments like acupuncture, yoga and aromatherapy that are given in addition to your standard treatment. They may help to relieve the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 45 for more information on complementary therapies.

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

Know that there will be ups and downs. Sometimes people feel they have to be brave or positive all the time, but it is normal to have bad days. Get help if you are finding it hard to cope.

Keep busy. Try to keep busy and make plans for the things you would like to do. This can mean taking trips, visiting loved ones or doing certain activities.

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

Express yourself: Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of what you are going through. Other forms of creative expression, such as music and art, may help too.

Practical planning. It's very understandable that you might feel anxious or reluctant to talk to your family or friends about how you might like to be looked after if your cancer progresses, for fear of upsetting yourself or them. However, it might be helpful for you, as it can give you the chance to be able to plan and deal with any practical concerns or worries you may have in your personal life. If your cancer is advanced, you can look at our advanced cancer web pages on our website www.cancer.ie for more help with planning ahead. You can also call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice, information and 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 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.

Advice for carers

Caring for someone with bladder cancer can be difficult at times. Some patients manage well and need little practical support from family and friends. Others may need more support and care. It might take a few months before they are fully recovered and can care for themselves.

Coping with both the practical and emotional issues of being a carer can also hard. Here are some things that can help to make life a little easier.

Looking after your loved one

Learn about cancer: Learn more about bladder cancer, any possible side effects and the emotional effects it can cause. This will help you to understand how you can support your relative or friend.

Plan as much as you can ahead of the discharge date: Ask to speak to a medical social worker about the community services that are available. Tell your GP and the local public health nurse that your loved one is coming home. If dressings or other medical supplies are needed, make sure you have some at home before the discharge date. Ask for a contact name and telephone number at the hospital so that you can talk to somebody if you have a problem.

Talk to the dietitian: If your relative or friend has had major surgery, talk to the dietitian before the discharge date. He or she will give you useful advice on the best foods and how to prepare them.

Encourage your relative or friend: At first your relative or friend may feel very tired after treatment. As soon as they are feeling stronger, encourage them to do things for themselves. The more involved they are in their own care, the quicker they will adapt to a new way of life.

Looking after yourself

Share worries: You may feel tired with all the worry and extra work. It can also be very difficult as you try to adapt to a new way of life. Make sure you share your worries with someone else. Phone our Cancer Nurseline or visit a Daffodil Centre if you would like to chat to a cancer nurse in confidence. Stay in touch with your own friends and get out when you can, even if you sometimes do not feel like it.

Take regular breaks: If your partner or friend is anxious or depressed, try to take a break each day, even if it is just a walk to the shops. Ideally, you should also try to organise a longer break, such as an evening out with friends or a trip to the cinema each week. If you have young children, organise for your family or a babysitter to mind them for an hour or two, if possible.

Have little treats: If you don’t want to take a break, then at least give yourself little treats to keep yourself going. Order your favourite magazine each week and give yourself an hour to sit down with a cup of tea or coffee to read it. Or make sure that you can watch your favourite TV programme, have a long soak in the bath after a difficult day, or an early night with a good book.

If you find it difficult to cope, get help. Talk through your feelings and frustrations with a friend or your GP. Your GP can suggest other services and sources of help.

Look after your own health: See your GP sooner rather than later if you have any health concerns of your own.

Join self-help or support groups: Find out about self-help groups, especially for carers of people with cancer. There are a number of voluntary organisations in the country that may provide help and support for you as a carer. Many local cancer support centres have services for carers too.

How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to say or how best to help. You may find it difficult to talk about their cancer. Or you may be afraid of upsetting your friend or relative by saying or doing the wrong thing.

If you want advice on how to support a friend or loved one with cancer, call our Cancer Nurseline and ask for a copy of our booklet *Lost for Words – How to talk to someone with cancer*. The booklet gives advice on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can also pick up a copy of the booklet at any Daffodil Centre, or download it at **www.cancer.ie**

Talking to children and teenagers

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. You may worry about the emotional impact your illness will have on your children, especially older children, who may already be struggling with the difficult changes that adolescence can bring. These are all natural feelings to have at this time.

Saying nothing

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

How to tell your children

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

The booklet is available free of charge from Daffodil Centres or by calling the Cancer Nurseline. It is also available on our website **www.cancer.ie**.

Further information and support

If you want more advice and support, you can ask your nurse or medical social worker. Or call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence.

Life after cancer

Being told your treatment has been successful is wonderful news. But it can take some time for you to adjust to life after cancer treatment. It isn't unusual to feel quite low and lost after your treatment has ended, especially during the first few months.

Feelings you may have include:

Fear of cancer coming back and worrying about every small symptom

Loneliness without the company and support of your medical team and fellow patients

Stress at having to deal with concerns such as finances, going back to work and family issues that may have been on hold during your treatment

Isolation or guilt if your family and friends expect you to get back to normal before you are ready

Anxiety and self-doubt about sexual and romantic relationships

Anger at what has happened and the effect on you and your loved ones

Depression or sadness

There is more about how to cope with these feelings and adjusting to life after cancer on our website **www.cancer.ie/coping/life-after-cancer-treatment**

You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 50 for other ways to get support.

Support resources

Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like car parking during hospital visits, medication, travel, food, heating, laundry, clothing and childcare costs. If you are not able to work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Appliances like wigs

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

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

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

If you do not have a medical card you will have to pay some of the cost of your care and medication.

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

Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

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

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 07 4000
- Department of Social Protection – Tel: 1850 662 244

Always have your PPS number to hand when you are enquiring about entitlements and benefits. It's also a good idea to keep a photocopy of any forms or correspondence.

If you have financial difficulties

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some help towards travel costs. See page 62 for more details of our Volunteer Driving Service and the Travel2Care fund. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

More information

For more information please see our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:

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

The booklet also has lots of other information to help you manage the cost of cancer. For example, disability and mobility supports, help for people in financial difficulty, help for carers, living at home and nursing home supports.

For a free copy of the booklet, contact our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. The booklet is also available on our website: **www.cancer.ie**

Irish Cancer Society Services

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

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

- Our **Cancer Nurseline Freephone 1800 200 700**. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at **www.cancer.ie**
  For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: **remote@slis.ie**
- Our **Daffodil Centres.** Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.
- Our **Survivor Support.** Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 63 for more information
- **Patient travel and financial support services.** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
  - **Travel2Care** is a limited fund, made available by the NCCP, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
  - **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

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

- Irish Cancer Society **Night Nursing.** We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.
- Our **publications and website information.** We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer and financial concerns. Visit our website **www.cancer.ie** or call our Cancer Nurseline for a free copy of our publications.

If you would like more information on any of the above services, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Local cancer support services

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

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society's Strides for Life walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

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

You can call our Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at **http://www.cancer.ie/support/support-in-your-area/directory**

Helpful books

The Irish Cancer Society has a wide range of information on preventing cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: **www.cancer.ie.**

You may find the following helpful:

Treatment and side-effects

Understanding Chemotherapy

Understanding Radiotherapy

Understanding Cancer and Complementary Therapies

Diet and Cancer

Coping with Fatigue

Coping and emotions

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

Managing the Financial Impact of Cancer. A Guide for Patients and their Families.

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.

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?

Join the Irish Cancer Society team

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

There are lots of ways to help:

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

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

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

We would love to hear your comments and suggestions.
Email reviewers@irishcancer.ie

More information and support

If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700.

Acknowledgements

We would like to extend a special word of thanks to: Sheila Kiely, Urology Clinical Nurse Manager, Sonya Bowen, Clinical Nurse Specialist in Urology and Antoinette Walker, Editor

Irish Cancer Society
43/45 Northumberland Road, Dublin 4

T: 01 231 0500
E: info@irishcancer.ie
W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

Find us on Facebook
Follow us on Twitter: @IrishCancerSoc

The National Cancer Charity

Irish
Cancer
Society