Irish
Cancer
Society

Understanding

Bladder cancer

Caring for people with cancer

Understanding

Bladder cancer

This booklet has information on:

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

Useful numbers

Specialist nurse

Urologist

Medical oncologist

Radiation oncologist

Radiation therapist

Medical social worker

Oncology ward

Family doctor (GP)

Emergency

Hospital records number (MRN)

Contents

Fast facts

What kind of treatment will I have? Page 29

Most people have non-muscle-invasive bladder cancer, which is treated with surgery and sometimes drug treatments. Muscle-invasive bladder cancer can be treated with surgery, radiotherapy and cancer drugs.

Are there side-effects from treatment? Page 79

Your doctor and the team caring for you will talk to you about possible side-effects. For example, there is a small risk of bleeding and infection if you have a surgical wound.

Read about each of the treatments to learn more about their side-effects. There are treatments to help with most side-effects, so tell your doctor if you have any – they will want to know. It is important that you don't suffer in silence.

Will I be OK? Page 27

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

Clinical trials Page 78

Clinical trials are when cancer patients get a new type of treatment to see if it works better than existing treatments. Ask your consultant if there are any trials suitable for you.

We're here for you Page 116

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

Ways to get in touch

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

See page 116 for more about our services.

Helplines Partnership
MEMBER

Support Line Freephone 1800 200 700

Reading this booklet

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

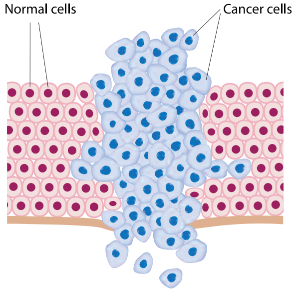
If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

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

We cannot give advice about the best treatment for you. Talk to your hospital team about your treatment and care – they know your medical history and your individual circumstances.

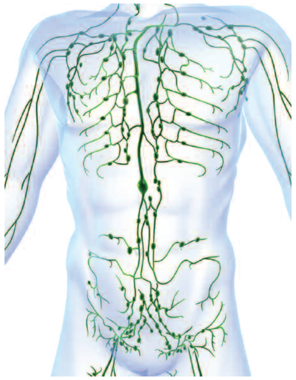
About bladder cancer

What is cancer?



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

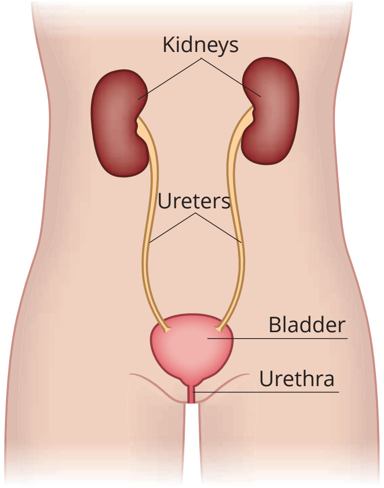
What is the lymphatic system?



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

What is the 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.

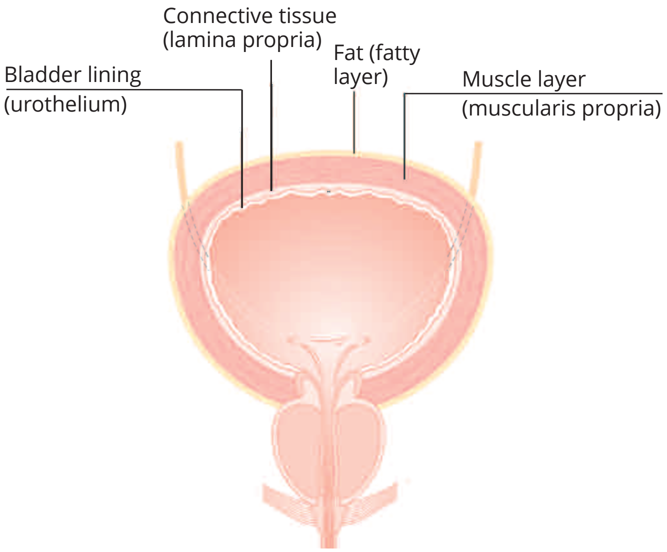


Your bladder stores urine until it is full. Urine is made in your kidneys and contains water and waste products. The urine leaves your kidneys through tubes called ureters and drains into the bladder where it is stored. The inside of the bladder has a special type of lining that stretches as the bladder fills up. This lining is called the urothelium or transitional epithelium. It stops urine from being absorbed into the body. When your bladder is full, nerves send a message to your brain that you need to pass urine.

When you are ready to pass urine, the bladder muscle contracts. This forces the urine out through a tube called the urethra. This is sometimes 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 many layers. The first layer is the urothelium. Below this layer is a thin layer of connective tissue called the lamina propria. Underneath this is muscle tissue called the muscularis propria. Around the muscle tissue is a fatty layer.



Pictures courtesy of Cancer Research UK/Wikimedia Commons

What is bladder cancer?

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.

How your specialist treats your bladder cancer will depend on how far the cancer has grown into the layers described above. This tells your doctor the stage of your bladder cancer (see page 25).

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.

What are the types of bladder cancer?

Transitional cell bladder cancer

The most common type of bladder cancer is transitional cell bladder cancer (TCC), which is also called urothelial cancer. It starts in the transitional cells in the lining of the bladder.

There are 2 types of transitional cell bladder cancer (TCC):

- Non-muscle invasive (superficial)
- Muscle invasive

> Most patients with bladder cancer have non-muscle invasive bladder cancer that will not develop into the muscle-invasive type.

Non-muscle-invasive bladder cancer

This cancer is also known as superficial bladder cancer and is the most common 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, and is called papillary bladder cancer (Ta – see page 25). Your surgeon can remove these growths with a minor operation. However, it isn’t unusual for non-muscle-invasive or superficial bladder cancer to return.

Some types are more likely to come back. These include carcinoma in situ (CIS), T1 tumours and high-grade tumours. See page 25 for more.

Carcinoma in situ (CIS): This type appears as red ulcers inside your bladder. The cells are very abnormal and can grow quickly.

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

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

Muscle-invasive bladder cancer

Muscle-invasive bladder cancer is when 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.

Rarer types of bladder cancer

Squamous cell bladder cancer: This rare type of bladder cancer starts in the squamous cells, which make up the tissues that line our organs. Squamous cell bladder cancer is usually muscle invasive.

Adenocarcinoma: This is a very rare bladder cancer. Adenocarcinoma starts in cells that produce mucus in the lining of our body organs. It is usually muscle invasive.

> You can reduce your chances of the cancer returning if you stop smoking. See page 39 for more about giving up smoking.

Advanced (metastatic) bladder cancer

Bladder cancer can also spread beyond the bladder. If this happens, it is called advanced (metastatic) 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.

How common is bladder cancer?

In Ireland, about 470 people are diagnosed with bladder cancer each year. It is more common in men than women and occurs mostly in people over 65.

What caused my cancer?

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

Diagnosis and tests

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

However you feel, you are not alone.

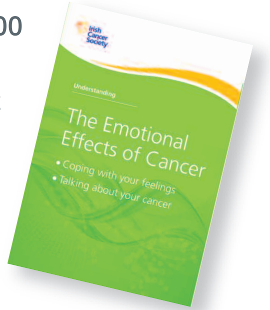
If you need to talk to someone, or if you want support or advice:

- Ask to speak to the cancer (oncology) liaison nurse or the medical social worker at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to one of our cancer nurses in confidence – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- Speak to an Irish Cancer Society Survivor Support volunteer who has had a cancer diagnosis and really knows what you are going through. Our cancer nurses can put you in touch with a volunteer
- Talk to other people going through the same thing. Join our online community at **www.cancer.ie/community**
- Go to your local cancer support centre. For more information, see page 122

Telling people about your diagnosis

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

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



Irish Cancer Society

Understanding

The Emotional Effects of Cancer

- Coping with your feelings
- Talking about your cancer

What tests will I have?

- Tests you may have include a biopsy, cystoscopy, CT scan, MRI scan and possibly a bone scan and PET scan.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

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

Tests you may have include:

Blood tests

Blood tests can help to check your general health. They will be done regularly during your treatment.

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 23). 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.

Cystoscopy

A cystoscopy is usually done to diagnose bladder cancer, but you may have one later or as part of your follow-up care. A cystoscopy uses a small tube to see inside your bladder. The tube is called a cystoscope and is like a telescope with a camera at one end. You may have a general anaesthetic, so you will be asleep during the test.

Or you may have a local anaesthetic. 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.

X-rays

X-rays use high-energy rays to take pictures of the inside of your body. They can check for bone and other joint problems. X-rays can also show changes in tissues and organs, such as the breasts and lungs.

CT scan (CAT scan)/CT urogram (CTU)

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

MRI scan

This is a scan that uses magnetic energy to build up a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine. Some people may feel claustrophobic inside the tunnel. Tell the radiographer if you're feeling anxious at the time of the examination.

An MRI can also be noisy, but you will be given earplugs / headphones to wear. 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 soon after the scan. You shouldn't need to stay in hospital.

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

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

With rare types of bladder cancer, you may need to have a bone scan. The scan 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

A PET scan can show if the cancer has spread to other tissues and organs. A low dose of radioactive sugar is injected into your arm. The radioactivity can highlight cancer cells in your body. An hour or so after the injection you will have a scan. During the scan, you will lie on a table which moves through a scanning ring. The scan can last up to an hour. Before the scan, you may have to fast (not eat) for a few hours.

PET is safe to use and there are no side-effects. You may have to travel to a specialist centre to have a PET scan, as not every hospital has these scanners.

Waiting for test results

It usually takes over 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 Support Line on **1800 200 700** or visit a Daffodil Centre to speak to a cancer nurse.

Staging and grading bladder cancer

- Staging cancer means finding out its size and if it has spread.
- Grading means looking at the cancer cells to see how they might grow.
- This helps your doctor to decide the best treatment for you.
- Your prognosis is what your doctor expects to happen with your cancer.

The tests you have after diagnosis help the doctor to give your cancer a stage 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 helps your doctor to decide the best treatment for you.

What are the grades of bladder cancer?

Cancer can be low grade or high grade. Lower grades are slower growing. Higher grades tend to grow more quickly. Different grades need different treatments. The grade of bladder cancer is important in deciding your treatment plan.

How is bladder cancer staged?

There are different ways to describe the stages of cancer. The staging system normally used in bladder cancer is called TNM. It describes:

Tumour (T)

The size of the tumour

Nodes (N)

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 (M)

M1 means the cancer has spread to other parts of your body and M0 means it hasn't. The organs most likely to be affected are your bones, liver or lungs.

Your doctor often uses this information to give your cancer a number stage. A higher number, such as stage 4, means the cancer has spread to other parts of the body. Some stages are further divided into stage A and B. In general, the lower the number, the less the cancer has spread.

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

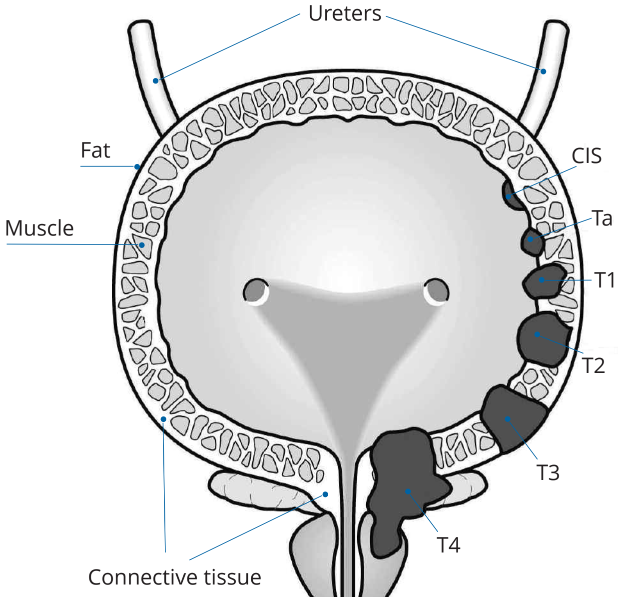
Sometimes you may need surgery to find out the exact stage. This means that your treatment plan may only be decided or may change after you have had surgery.

The most common bladder cancer – **non-muscle-invasive bladder cancer** – will be staged as the following:

Carcinoma in situ (CIS): This appears as flat, red areas in your bladder. This type of bladder cancer is more likely to come back after treatment, often as another non-invasive cancer in the bladder. CIS is always classed as high grade. It 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.



The rarer **muscle-invasive bladder cancer** is staged as:

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 (metastatic) bladder cancer

T4: The cancer has spread outside your bladder to other organs. For example, with locally advanced disease, the cancer may have spread into the pelvic wall, the prostate in men, or the womb or vagina in women.

If there are distant metastases, it means the cancer has spread beyond the surrounding areas, to other parts of your body such as the liver, bones or lungs.

Asking about your prognosis

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

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

Should I ask about my prognosis?

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

If you decide you want information on your prognosis:

- **Think carefully about how you will cope with the information** before asking for your prognosis.
- **Get information on prognosis from your doctor.** They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Ask a friend or family member to go with you**, if you would like some support.
- **Be careful with online information.** It may be hard to understand or even incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.

- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treating bladder cancer

How is bladder cancer treated?

- Surgery, chemotherapy and radiotherapy are the main treatments for bladder cancer.
- A team of healthcare professionals will be looking after you (multidisciplinary team).

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 age and general health

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

In this section we give a brief overview of the treatments used for bladder cancer. See page 41 for non-muscle-invasive cancer treatments and page 51 for muscle-invasive cancer treatments.

Types of treatment

Surgery

Surgery for **non-muscle-invasive cancer** aims to remove the tumour from your bladder. Surgery is the main treatment for this type of bladder cancer (see page 43).

Surgery for **muscle-invasive bladder cancer** usually involves removing the whole bladder. See page 54.

Radiotherapy

Radiotherapy is used to treat **muscle-invasive bladder cancer**. It 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. See page 66.

Chemotherapy

Chemotherapy is the use of drugs to kill or control the cancer cells. **For non-muscle-invasive bladder cancer**, intravesical chemotherapy (chemotherapy into the bladder) may be given after your surgery to reduce the risk of the cancer coming back. See page 47 for more about intravesical chemotherapy.

For muscle-invasive bladder cancer, chemotherapy 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, to make the treatment more effective. This is called chemoradiation
- On its own for advanced (metastatic) bladder cancer
- After surgery if there is a high risk of the cancer coming back (recurrence). This is called adjuvant treatment

See page 70 for more about chemotherapy.

Immunotherapy

Immunotherapy drugs help your immune system to work better to fight cancer cells. These treatments can change special immune cells to help them attack the cancer directly. They also change other parts of the immune system to make it more difficult for cancer cells to grow or spread. See page 48 for more details.

Deciding on treatment

Multidisciplinary team

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

Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance, so you don’t forget anything. You could use the fill-in page at the back of this booklet for your questions and answers. If you do forget something or need more explanations, ask your specialist nurse or talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Time to think

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

Second opinion

You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your treating doctor or GP 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 a particular treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.

Who will be involved in my care?

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

Urologist A doctor who specialises in the urinary system. They are in charge of your treatment. They have a team of doctors working with them.

Surgeon A doctor who specialises in surgery and who can remove a tumour from your body.

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 from diagnosis and throughout treatment.

Uro-oncology clinical nurse specialist A nurse who is specially trained to care for people with cancer of the urinary system.

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 your social issues and practical needs. They can give counselling and emotional support. They can give advice on benefits and financial matters and on practical supports and services available to you when you go home.

GP (family doctor) Your GP can be a great support to you. 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 advice on diet during your illness and use diet to help symptoms.

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.

Pharmacists – in hospital and in your local pharmacy – dispense chemotherapy and other cancer drugs. They can give advice on cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

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

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.

Giving consent for treatment

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

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

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

Waiting for treatment to start

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

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

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

You might like to make some lifestyle changes while you're waiting for treatment. This can help you prepare for your treatment and feel more in control.

How can I help myself?

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

Eat well

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

- Maintain a healthy weight
- Cope better with the side-effects of treatment
- Recover more quickly

Ask to talk to the dietitian at the hospital for advice on the best diet for you. You could also read our booklet ***Diet and Cancer***. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it on our website **www.cancer.ie**

Be active

Being active has many benefits. It can help to:

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

Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you. Be careful not to overdo it at the beginning, but build up gradually.

Quit smoking

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

- Stopping smoking can help prevent non-muscle-invasive bladder cancer from coming back (recurring)
- Non-smokers have fewer or less severe side-effects during cancer treatment. For example, chest problems such as chest infections
- Smoking can reduce how well chemotherapy or radiotherapy work
- Not smoking can help you to heal better after surgery
- Not smoking reduces the risk of other illnesses

If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. Some hospitals have smoking cessation officers who can help and support you.

Other ways to help yourself

Get information about your cancer and treatment

Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. If it makes you anxious, you could ask a friend to do the research for you, and tell you anything important.

Involve your family and close friends

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

Use your support network

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

Try relaxation and stress management techniques

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

Accept change in your life

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

Know that there will be ups and downs

Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. Get help if you are finding it hard to cope.

Try to cope day by day

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

Treatment for non-muscle-invasive bladder cancer

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 47).

Surgery

- Surgery means removing a tumour.
- There are different types of surgery for bladder cancer.
- You may have drug treatment into your bladder after surgery.

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). Special instruments are put through the cystoscope to cut or burn off the tumour. The surgeon may use a mild electrical current to seal the wound and stop any bleeding (cauterisation). After the procedure, the tumour is sent to the laboratory. Here it will be looked at in great detail, and your doctor will use this information to find out more about the tumour and the stage and grade it was at.

Getting ready for surgery

Your surgical team and specialist nurse will tell you about your surgery. It is natural to feel very anxious about having surgery. Talk to your doctor or nurse if you are feeling anxious. If there is anything that you do not understand, ask again. They will be happy to answer your questions. They will tell you what you can expect after the operation and help you find ways to cope. You can also talk to one of our cancer nurses by calling our Support Line on 1800 200 700.

Tests before surgery

You will most likely need some extra tests to make sure you are fit for surgery. These tests may include blood tests and an ECG heart test. Sometimes an ECHO (heart ultrasound) and PFT (lung/breathing) tests will be needed, depending on your age and general health.

Smoking

If you are a smoker, giving up before your operation will improve the quality of your breathing and reduce the risk of a chest infection after surgery. See page 39 for more on giving up.

Before surgery

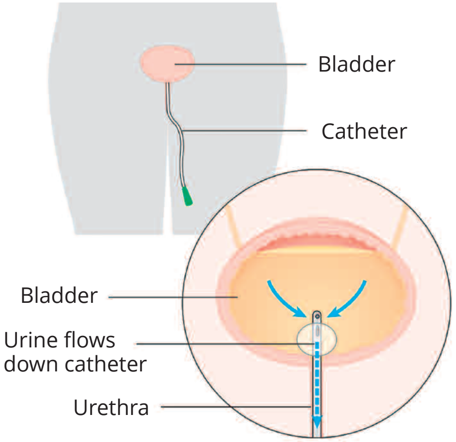
You will not be allowed to eat or drink for a few hours before surgery. You may get an anti-clotting injection like heparin, and elastic stockings may be put on your legs to prevent blood clots. Before you go to theatre, you may be given medication that will make you feel more relaxed and sleepy.

After surgery

You will be encouraged to move about as soon as possible – this is to help prevent problems such as chest infections or blood clots.

Catheter

You will most likely 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.



Picture courtesy of Cancer Research UK/ Wikimedia Commons

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 will usually clear up. However, if the bleeding is heavy, you are having difficulty passing urine or you are passing clots, it is important that you tell your doctor or specialist nurse straight away.

Possible risks of surgery

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

Will I need more treatment?

Superficial bladder tumours can come back after treatment. For this reason, your doctor may decide you need further surgery. You may have regular check-ups for some 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 (see page 51). In this case, your doctor and nurse will give you more details.

Drug treatment after surgery

Intravesical chemotherapy (chemotherapy into your bladder)

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 liquid chemotherapy drug is normally put directly into your bladder, through a catheter tube. This treatment is known as intravesical chemotherapy.

You might have this treatment on the day you have the surgery or in the hospital's outpatient department after you have been discharged.

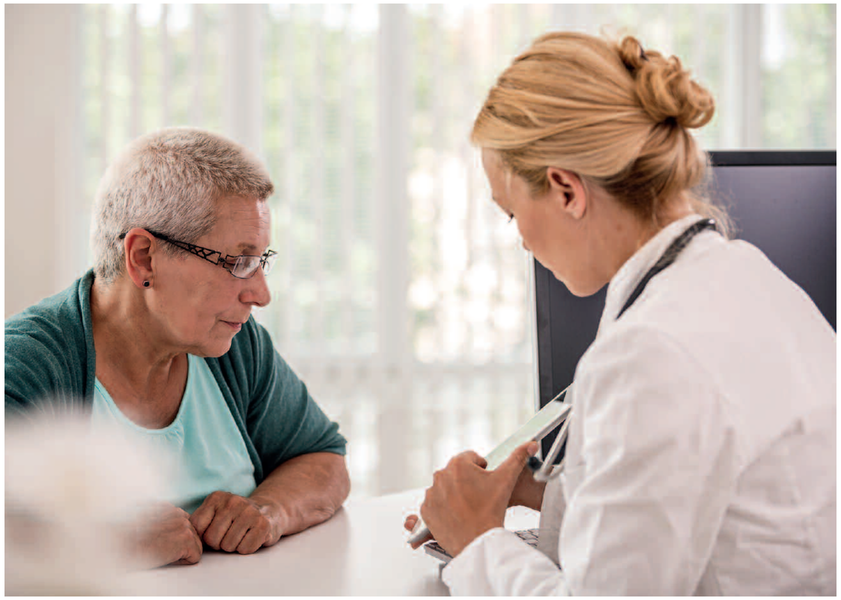
Examples of drugs used in intravesical chemotherapy are mitomycin-C, epirubicin and doxorubicin. For the few hours before the treatment you will be advised to limit the amount of fluid you take, as once you have the chemotherapy in your bladder, you must try not to pass any urine for an hour. This gives 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. After treatment, the doctor or nurse will remove the catheter tube.

You may have a single treatment or a course of treatments, depending on the stage and grade of your cancer. If your doctor feels you have a low risk of the cancer coming back, you may not need any more than one treatment. If they feel you have a greater risk, they may recommend you have more intravesical chemotherapy. This is usually given once a week for 6 consecutive weeks.

It is important to note that hardly any of the drug is absorbed into the bloodstream, so it rarely affects any other part of your body.

Intravesical immunotherapy

Immunotherapy helps your immune system to work better to fight cancer cells. BCG treatment is an intravesical (directly into your bladder) immunotherapy. While BCG is better known to some people as a vaccine used to prevent tuberculosis (TB), it is also used as a form of treatment for bladder cancer.



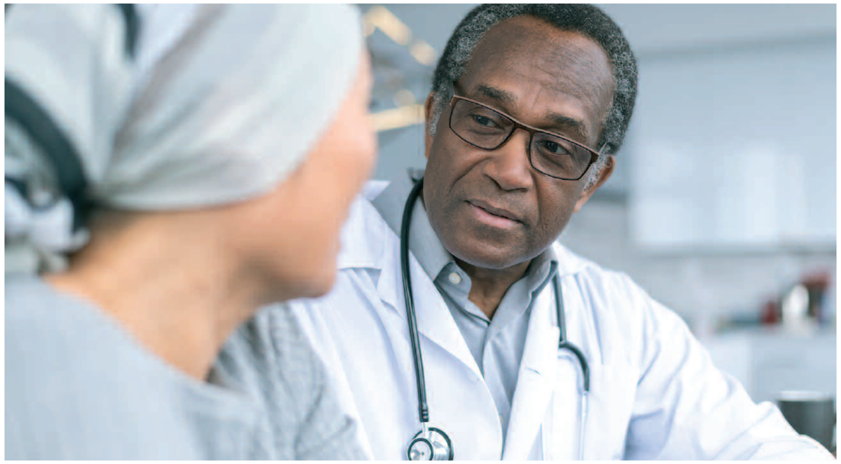
BCG can help to stop bladder cancers coming back or spreading deeper into the bladder. When BCG is in the bladder, it goes to the cancer cells. This in effect turns on the immune system, and the immune system will then attack the bladder cancer cells.

This treatment only works for cancer cells that are in the lining of your bladder (superficial). It does not work for cancer that has spread to your bladder wall. BCG is usually used for carcinoma in situ and higher grade bladder tumours. Your doctor or nurse will give you more information if needed.

As with chemotherapy, the drug is given as a liquid, which is passed into the bladder through a catheter tube, which is placed in your urethra. Once you have the treatment in your bladder you must try not to pass urine for 2 hours. The treatment is usually given once a week for 6 weeks.

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 cystoscopy, with or without a biopsy, and urine tests. These are to make sure the cancer has not come back. Your surgeon will let you know how often you need to visit him or her. See page 91 for more on follow up.

Treatment for muscle-invasive bladder cancer

How is muscle-invasive bladder cancer treated?

The following can be used to treat muscle-invasive bladder cancer:

- Surgery
- Radiotherapy
- 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 Support Line on 1800 200 700 or visit a Daffodil Centre for advice and support from a cancer nurse.

Surgery

Radical or total cystectomy

Surgery to remove your bladder is called a cystectomy. If the surgeon removes just part of your bladder, this is called a partial cystectomy. For most people, the whole bladder will be removed, which is called a radical or total cystectomy. The type of procedure you have will depend on the stage the cancer is at and your general health.

Having all or part of your bladder removed is major surgery. It is only carried out in a small number of hospitals (specialist centres) where specialists are available to do it. You may have to travel to your nearest specialist centre to talk to your surgeon about the operation and to have the surgery done.

In a radical cystectomy, your surgeon may remove nearby tissues, lymph nodes and organs. In men, the prostate, seminal vesicles and part of the vas deferens and urethra may be removed. In women, the uterus, fallopian tubes, ovaries, and part of the vagina may be removed.

If your whole bladder has been removed, your surgeon will need to find a new way to drain your urine. This is done at the same time as the cystectomy.

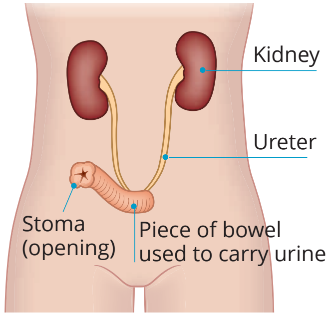
Ways of draining urine

There are three ways in which your surgeon can divert your urine. These will be discussed and explained to you by your surgeon and specialist nurse. Urostomy (ileal conduit) is the most common (see the next page for details). Continent urinary diversion (page 56) and bladder reconstruction (page 57) are less common. You may need to travel to a different hospital for your surgery if your doctor recommends continent urinary diversion or bladder reconstruction.

Urostomy (ileal conduit)

This is the most common type of urinary diversion. Most patients who have a cystectomy will have a urostomy. Your surgeon can use part of your small bowel to bring urine to an opening outside your body. This is known as a urostomy or an ileal conduit.

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

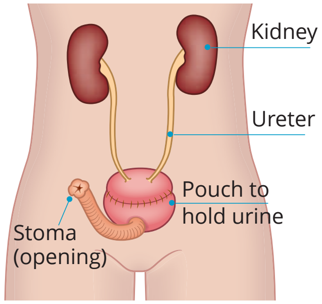


A flat, watertight bag is placed over the stoma to collect your urine. It’s kept in place with a special type of glue. The bag will fill with urine, and you will need to empty it regularly. A stoma nurse will show you how to take care of it.

Advantages	Disadvantages
Simplest of the surgeries	There is an external visible bag to collect urine
Requires less time to recover	The stoma will need regular care
Less disruptions to the bowel than the other urinary diversions	The stoma bag may leak or smell occasionally
No need for a catheter	Urine may travel back up to the kidneys, causing infection
	Body image can be affected

Continent urinary diversion/continent catheterisable pouch

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.

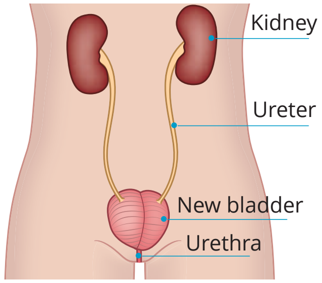


The internal pouch that replaces your bladder is connected to your tummy wall by a stoma. Your surgeon will create a one-way valve to keep the urine inside the pouch. You empty urine from the pouch through the stoma using a thin tube called a catheter. You will need to do it about 5 or 6 times a day.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

Advantages	Disadvantages
There is no smell, and leakage risk is minimal	Longer surgery time
Requires less time to recover	The stoma will need regular care
Urine is stored inside the body until you are ready to empty it	Larger amount of bowel tissue taken, so more of the bowel is disrupted. May have problems absorbing nurtrients
Small bandage over the stoma may cause fewer body image issues than the ileal conduit (page 55)	You will need to empty the pouch every 4-6 hours
Less risk of back-up of urine into the kidneys	Small risk of leakage when pouch is full
	Greater risk of surgical complications
	Greater risk of needing more surgery

Bladder reconstruction

In this type of surgery, instead of making a stoma, the surgeon makes a new pouch out of bowel tissue. The kidneys drain the urine into this pouch. The pouch is then is connected to your urethra. The pouch (known as a neobladder) stores urine like your bladder did, and you pass urine out through your urethra.



You can empty the pouch by holding your breath and pushing down into your tummy. You will need to do this regularly as you won't know when your bladder is full. Your hospital team will give you more information about this.

Advantages	Disadvantages
No stoma	Surgery takes longer than ileal conduit option
Avoids urine back-up into the kidneys	Recovery can be lengthy, and lots of physio is required to get control of the neobladder
Most like your normal urinary flow	Leakage of urine (incontinence) is normal while you learn how to regain control of urination. This can take up to 6 months
	Some patients will always leak a few drops of urine, and will need to continue to wear pads. Some will not be able to empty the neobladder and will need to use a catheter to drain it
	Most patients will need to get up more often at night to empty their bladder. Night time leakage can also be a problem for some
	The bowel is disrupted to provide the tissue to make the neobladder

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.

Preparing for a stoma

The stoma nurse will visit you before surgery to discuss having a stoma (urostomy). She or he will mark on your skin the best place for the new stoma to be located. It is usually placed where it best suits your needs and where you can see it. This will also depend on whether you are left or right handed.

Before surgery

You will not be allowed to eat anything for a few hours before your surgery. You may get an anti-clotting injection like heparin, and advised to put on your elastic stockings (to prevent blood clots). Before you go to theatre, you may be given medication that will make you feel more relaxed and sleepy.

After the surgery

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

Drips, drains and tubes

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

- You will have a drip in a vein in your arm. You will be given fluids through this until you can drink again.
- 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.
- One or more thin tubes called drains may be coming out of your tummy (abdomen) near your wound. These help to drain blood, bile and fluid from the operation site to let your wound heal.

Pain

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

Wound

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.

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.

Getting up and about

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

Side-effects of surgery

Bleeding and infection

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.

Blood clots

There is a risk of blood clots in the lungs or legs. Doing your breathing and leg exercises (see page 60) can reduce this risk.

Urine leakage

There is a risk of urine leakage from the newly formed pouch in the first few days after surgery.

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. Women may have shorter vaginas, which can make vaginal penetration more difficult. Woman may also notice changes in sensation. There are also emotional issues relating to a change in body image and loss of libido (sex drive). See page 79 for more about the side-effects of treatment and your sex life.

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.

They 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 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 information and support from a cancer nurse, you can call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre.

Going home

Most patients are ready to go home 7-14 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.

Help 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.

Hints & Tips – living with a urostomy

- **The urostomy bag will usually last 3 to 5 days.** Do not change it earlier unless needed. If you remove the adhesive flange more frequently, it may irritate and damage the skin around your stoma, causing soreness.
- **If the bag leaks, change it as soon as you can.** The longer your skin is exposed to urine, the more your skin might suffer.
- **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.**

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 91.

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

Radiotherapy

- Radiotherapy uses high-energy rays to kill cancer cells.
- You normally have treatment every weekday for a number of weeks.
- Side-effects affect the area of the body where the radiotherapy is aimed.
- Side-effects normally go once your treatment is over, but some can last a long time or develop later on.

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 such as pain, discomfort, bleeding or blockage if the cancer is advanced or has come back.
- 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 19) 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 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 week 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 you receive.

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
- Your bladder or bowel may be permanently affected
- Narrowing of the vagina
- Effects on ability to have erections (erectile dysfunction)
- Infertility

For more on side-effects and ways to cope, see page 79, or go to **www.cancer.ie** for information and advice.

For more information on radiotherapy and its side-effects, call our Support Line on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet ***Understanding Radiotherapy*** or download it from our website **www.cancer.ie**

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.

Chemotherapy

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

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:

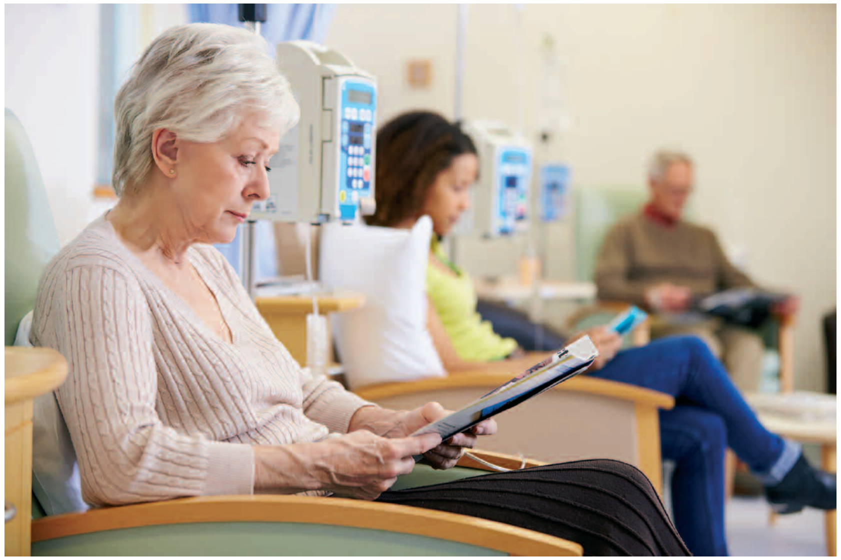
- Before surgery or radiotherapy to shrink the cancer and reduce the risk of it coming back. This is called neo-adjuvant treatment.
- At the same time as radiotherapy to make the treatment work better (chemoradiation).
- After surgery to reduce the risk of the cancer coming back. This is called adjuvant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

This type of chemotherapy is different to intravesical chemotherapy, which is used to treat non-muscle-invasive bladder cancer (see page 47).

A combination of 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 and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. See our *Understanding Chemotherapy* video series on **www.cancer.ie** which also has valuable information on chemotherapy.

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. Usually your treatment will be given in the chemotherapy day care unit.



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. You may have a central venous access device fitted. This is a thin tube (line) which goes directly into a vein and stays in place until your treatment is over. This saves you having repeated injections. There are different types of central venous access devices, such as ports, Hickman lines and PICC lines. There's more about ports and lines on our website **www.cancer.ie**

Understanding your drug treatment

It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you.

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Support Line on 1800 200 700.

What are the side-effects of chemotherapy?

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

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

Fatigue

Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 81.

Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting.

Infection

Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection at all times. If you have any of the signs of infection, contact your hospital immediately to get advice. Symptoms include feeling shivery and unwell (even without a high temperature), having a high or low temperature, having a cough, pain passing urine or increased frequency in going to the toilet to pass urine.

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.

Bleeding and bruising

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

Mouth and throat problems

Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.

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. Hair will grow back after you stop chemo.

Constipation and diarrhoea

Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).

Skin and nail changes

Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle.

Peripheral neuropathy

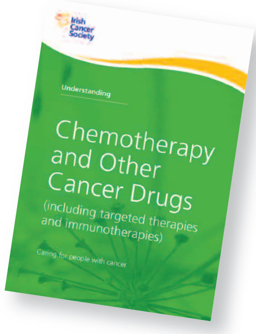
Some drugs can affect your nerve endings. They may cause numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.

Changes in kidney function

Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination, swelling of the hands or feet (oedema) or headaches, as these can be a sign of kidney damage.

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

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



Irish Cancer Society

Understanding

Chemotherapy and Other Cancer Drugs

(including targeted therapies and immunotherapies)

Caring for people with cancer

Treatment for cancer that has spread (metastatic cancer)

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

If your cancer has spread it can still be treated. Treatment is usually to try to control the cancer rather than to cure it. There are a range of treatment options for metastatic bladder cancer and new treatments are being developed all the time.

Often metastatic cancer is treated with chemotherapy or other cancer drugs. There may also be treatments that you can have as part of a clinical trial (see page 78).

Immunotherapy

Immunotherapy drugs encourage the immune system to recognise and help destroy cancer cells. A new group of drugs called Checkpoint inhibitors can be used when the cancer is locally advanced or advanced. Your oncologist will advise you if they think immunotherapy drugs are suitable for you.

Other types of Checkpoint immunotherapy drugs may become available soon. Clinical trials are testing whether combining newer Checkpoint immunotherapy drugs with chemotherapy and radiation therapy will benefit people with bladder cancer.

Common side-effects include:

- Feeling tired
- Skin changes
- Feeling sick
- Diarrhoea
- Feeling short of breath

Because of the way immunotherapy drugs work, they can cause the immune system to attack other parts of the body. This is not common, but it can cause serious side-effects in the lungs, other organs or glands that make certain hormones. Sometimes, the treatment needs to be stopped. It is important to tell your doctor or nurse about any side-effects you have, even after you have stopped having treatment.

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

Palliative care

Palliative care helps you to manage your symptoms and improve your quality of life. Palliative care includes end-of-life care, but your doctor may also recommend palliative care to relieve symptoms earlier in your illness.

The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors. Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with metastatic cancer. You don't need medical insurance.

Clinical trials

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

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, a different dose of a drug or using two treatments together.

Drugs that are used in a clinical trial have been through years of testing before they are given to patients. Because the drugs are still in trial, patients taking part will be monitored even more closely than normal and may have extra tests and appointments.

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

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. Read more about cancer and clinical trials on our website **www.cancer.ie**. Talk to a cancer nurse on our Support Line on 1800 200 700 or drop into a Daffodil Centre.

You can see a list of current cancer trials at **www.cancertrials.ie**

Managing side-effects and symptoms

How can I cope with fatigue?

- Fatigue means feeling extremely tired.
- There are things that can improve fatigue, depending on what’s causing it.

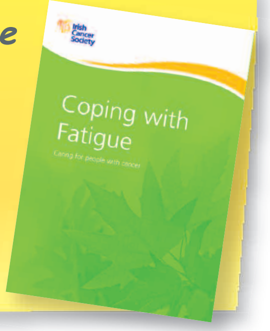
It’s common to feel fatigue when you have cancer. This extreme tiredness can be caused by many things, including:

- 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. 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.

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



Hints & Tips – 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, if your doctor says they're safe for you. For example, meditation, acupuncture or massage.

Will treatment affect my sex life?

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take quite a while. 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 your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. Touching, caressing and holding each other can help you to stay physically close.

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

There is no set time for you to be ready to have sex again. It varies from person to person. Your doctor will advise if you can have sex while on radiotherapy. But you may find it will be some weeks before you will feel well enough to have sex again after surgery.

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

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.

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 Support Line on 1800 200 700. You can also email the nurses: supportline@irishcancer.ie

After cystectomy you will be unable to father a child naturally. See page 87 for more about fertility and bladder cancer.

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.

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 and some targeted therapies.

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

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

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor and nurse are well used to talking about these matters, so there's no need to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at supportline@irishcancer.ie

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments for bladder cancer and you may not be able to have a child in the future. Discuss any worries you have about infertility with your doctor before treatment starts. He or she can tell you if there are any options open to you. For example, it may be possible to freeze your eggs or sperm before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this is an option for you.

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

Cancer and complementary therapies

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

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

It's very important to talk to your doctor if you're thinking of using complementary therapies. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

Integrative care

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

What’s the difference between complementary and alternative therapies?

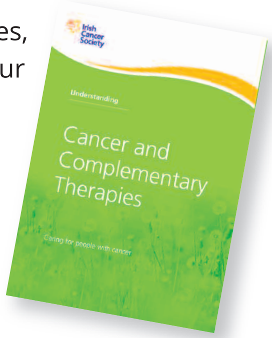
Complementary therapies are used **together with** standard medical treatment.

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

Modern medical treatments are very effective at curing cancer and keeping it under control. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

More information

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


Understanding

Cancer and Complementary Therapies

After treatment

What follow-up will 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 19). 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 anything.

It's important to go to your follow-up appointments. They give your doctor the chance to:

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

It is better to be aware of these as early as possible so that suitable treatment can be given.

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

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

What if the cancer comes back?

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

Life after treatment

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

Feelings you may have include:

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

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

You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 101 for other ways to get emotional support.

Living a healthy lifestyle

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

- Feel better
- Heal and recover faster
- Keep up your energy and strength

A healthy lifestyle includes:

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

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

Planning ahead

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

Planning ahead might include:

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

Who can help me plan?

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

Coping and emotions

How can I cope with my feelings?

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

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

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

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

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

Anxiety and depression

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

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

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

Counselling

If you're feeling very distressed or finding it hard to cope, a trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support, help you to make decisions and learn ways to cope better.

Free one-to-one counselling is available at some local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline@irishcancer.ie

A list of counsellors funded by the Irish Cancer Society is available at **www.cancer.ie**

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

Ways to get emotional support

Find out about cancer support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 122 for more about cancer support services.

> 'Counselling has helped me with every part of my life.'

Join a support or educational group: You might find it 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

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

Get online support: Special websites called online communities let you write questions, share stories, and give and receive advice and support. Visit **www.cancer.ie/community** to join the Irish Cancer Society online community.

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

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

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

Positive feelings

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

In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships.

Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

You and your family

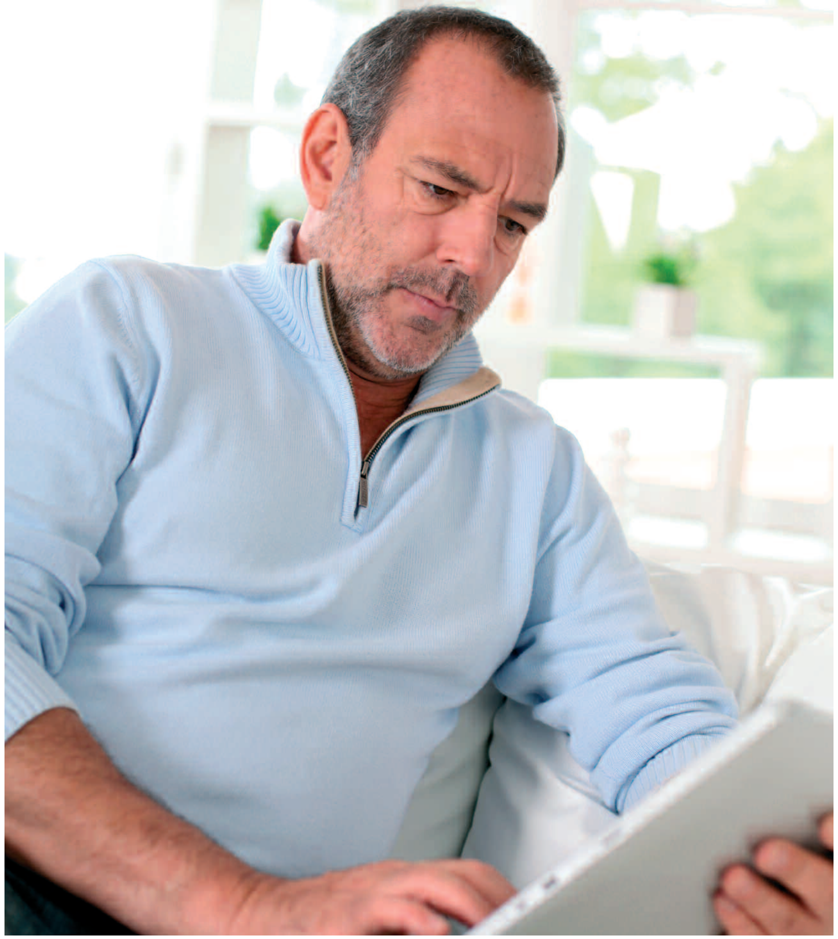
Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved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

Changing relationships

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

Further information and support

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet ***Talking to Children about Cancer***, which has practical advice about how to talk to children of different ages.



Supporting someone with cancer

Supporting someone with cancer

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

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

Learn about cancer

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

Share worries

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

Be kind to yourself

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

Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members at our affiliated cancer support centres. Talk to your GP or see page 100.

Find out about support for carers

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

How to talk to someone with cancer

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

If you want advice on how to support a friend or loved one with cancer, call our Support Line on 1800 200 700. Ask for a copy of our booklet ***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**

Support for you

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

Our booklet, ***Caring for Someone with Cancer*** has lots of information on:

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

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

Support resources

Coping with the financial impact of cancer

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

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

Medical expenses

Medical expenses that you might have to pay include:

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

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

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

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

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

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

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

Benefits and allowances

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

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

- **The medical social worker** in the hospital you are attending
- **Citizens Information** – Tel: 0761 074 000
- **Department of Employment Affairs and Social Protection** – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to photocopy completed forms before posting them.

If you have money problems

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 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 give some help towards travel costs in certain cases. See page 119 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

More information

Go to **www.cancer.ie/publications** and check out our booklet, ***Managing the Financial Impact of Cancer***. This explains:

The Financial Impact of Cancer

- 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. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living-at-home and nursing home supports.

Irish Cancer Society services

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

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

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information.

Our Support Line is open Monday–Friday, 9am to 5pm.

You can email us at any time on **supportline@irishcancer.ie** or visit our Online Community at **www.cancer.ie**

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

Daffodil Centres

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

Who can use the Daffodil Centres?

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

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

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

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 and the National Cancer Control Programme to ensure cancer patients and their families have access to high-quality confidential support in a location that's convenient to them. The Society funds professional one-to-one counselling (including telephone and video-call counselling) and group survivorship programmes in communities across the country. For information about what's available near you, call our Support Line on 1800 200 700 or go to **www.cancer.ie** and search 'Find Support'.

Patient travel and financial support services

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

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

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

Irish Cancer Society Night Nursing

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

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

Publications and website information

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

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

Local cancer support services

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

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free one-to-one 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 Support Line 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**

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?

Your own questions

Acknowledgments

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

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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.
- *National Cancer Strategy 2017-2026,* National Cancer Control Programme
- *Cancer in Ireland 1994-2017 with estimates for 2017-2019:* Annual report of the National Cancer Registry (2019)
- *Cancer Nursing: Principles and Practice,* CH Yarbro, MH Frogge, M Goodman & SL Groenwald. Jones and Bartlett, 7th Ed (2011).
- *The Chemotherapy Source Book,* M Perry, Lippincott Williams and Wilkins, 2012.

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Product or brand names that appear in this booklet are for example only. The Irish Cancer Society does not endorse any specific product or brand.

Join the Irish Cancer Society team

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

Support people affected by cancer

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

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our 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's like to organise or take part in a fundraising event

Raise money

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

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

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

Did you like this booklet?

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

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E: info@irishcancer.ie
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