

Understanding

# Prostate Cancer

Caring for people with cancer

### Understanding

### Prostate cancer

This booklet has information on:

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

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## Fast facts

### Can my cancer be treated?

### Page 27

Yes, all stages of prostate cancer can be treated. Your doctor will discuss with you what treatments will be of most benefit to you.

### Will I be OK?

### Page 25

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things, and every man's prognosis is different. The prognosis for prostate cancer is very good for most men, but your doctor will advise you on what is likely to happen in your situation.

### What treatment might I have?

### Page 45

Active surveillance: Monitoring your cancer with regular blood tests, digital rectal examinations, biopsies and MRI scans. If these show changes in your cancer, you will be offered treatment.

**Brachytherapy (internal radiotherapy):** Tiny radioactive sources put into your prostate to kill cancer cells.

**External beam radiotherapy:** High-energy rays to kill cancer cells.

Surgery: An operation to remove your prostate gland.

Hormone therapy: Injections or tablets to control the cancer. Watchful waiting: Having no treatment until there are signs that the disease is changing.

### How will my cancer and treatment affect me?

### Page 27

Some men with prostate cancer will have side-effects and symptoms. For example, fatigue, loss of libido (sex drive), urinary incontinence (leaking urine) and erectile dysfunction (ED). Some men may have few or no symptoms.

You can read about the treatments to learn more about their side-effects. For advice on coping with side-effects, see page 87.

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

### We're here for you

### **Page 128**

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

#### Ways to get in touch

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

See page 128 for more about our services.

### **Reading this booklet**

This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference. If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

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

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.

We use the term 'man / men' in this booklet, but we understand that not everyone who has a prostate gland identifies as a man.

It doesn't matter who you are or where you come from, we are here for you. For confidential advice, information and support, contact our Support Line on Freephone 1800 200 700.

## About prostate cancer

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### 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.



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



Support Line Freephone 1800 200 700

### What is the prostate?

The prostate is a gland found only in men. It is about the size of a walnut and lies below your bladder, just in front of your rectum (back passage).



A tube that carries urine runs through your prostate and into your penis. This tube is known as your urethra or water pipe. If the prostate gland is enlarged it can cause trouble passing urine because it presses on the urethra.

The prostate makes a thick white fluid that mixes with sperm (semen). It also makes a protein called prostate specific antigen (PSA), which turns semen into liquid.

### What is prostate cancer?

Prostate cancer is when the cells of your prostate gland grow in an abnormal way to form a lump (tumour). In some men prostate cancer grows slowly, while in others it grows more quickly and spreads to other parts of your body.

**Early (localised) prostate cancer:** This is prostate cancer found only within the prostate gland. It has not spread outside your prostate gland. With early prostate cancer there may be no symptoms. Your doctor may only suspect it after doing a prostate specific antigen (PSA) test (see page 18).

**Locally advanced prostate cancer:** This is when the cancer has broken through the capsule (covering) of the prostate or has spread outside the gland to nearby tissues. Places the cancer might spread to include tissues such as your seminal vesicles, lymph nodes, neck of your bladder or your back passage (rectum). The seminal vesicles are two glands that sit just behind your prostate gland and store seminal fluid.

Some treatments for locally advanced prostate cancer hope to cure it, while others aim to control the disease or stop it from growing.

**Metastatic (advanced) prostate cancer:** This is when prostate cancer cells have spread and are affecting other parts of your body, away from the prostate gland. For example, your bones.

If you want information about metastatic prostate cancer, please read our booklet *Understanding metastatic prostate cancer*. It's available free from Daffodil Centres or by calling our Support Line. You can also download it from our website www.cancer.ie



### What caused my cancer?

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

### How common is prostate cancer?

In Ireland, prostate cancer is the second most common cancer in men, after skin cancer. Each year over 3,900 men are diagnosed with prostate cancer here. This means that 1 in 7 men will be diagnosed with prostate cancer during their lifetime. Although there are many men with this disease, most men do not die from it.



## Diagnosis and tests

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### Being diagnosed with prostate cancer

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

- Upset and overwhelmed by your emotions
- Confused by all the information being given to you
- · Worried about what will happen next
- Angry that this is happening to you

### However you feel, you are not alone.

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

- Ask to speak to the cancer (oncology) liaison nurse or the medical social worker at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters.
- Talk to one of our cancer nurses in confidence visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie.
- Speak to an Irish Cancer Society 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 something similar. Join our online community at www.cancer.ie/community.
- Go to your local cancer support centre. For more information, see page 134.

### 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 other people will react. For example, they may fuss over you or be upset.

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





### What tests will I have?

- You may need to have tests such as a CT scan, PET scan, MRI scan or bone scan.
- These tests can help to stage the cancer.
- Staging cancer means finding out its size and how far it has spread.
- Your cancer will be given a grade. The grade describes how fast the cancer is likely to grow.

After your diagnosis, your doctor may want to do more tests to find out more about your cancer and your general health. Whether you need any tests or not depends on the results of your PSA, Gleason score (see page 24) and how your prostate gland feels to touch. Your doctor will let you know which tests you need to have, if any. Some tests may also be used to see how well you are responding to treatment.



Tests you may have include:

### **PSA test**

When doctors check the prostate gland, they often do a PSA test. The PSA test measures levels of the PSA protein in your blood. This can show how well you're responding to treatment.

### **Biopsy**

Taking samples of prostate cells with a needle. Tissue samples taken during biopsies are examined under a microscope to see how abnormal the cells are.

### Trans-rectal ultrasound (TRUS) biopsy

Your urologist inserts an ultrasound probe with a needle into your rectum. Tissue samples of the prostate and surrounding area are taken.

### CT scan (CAT scan)

This is a special type of X-ray that gives a detailed 3D picture of the tissues inside your body. You might be asked to fast (not eat) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. The injection may make you feel hot all over for a few minutes. During the scan



you will lie on a table which passes through a large doughnutshaped 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 tunnellike machine for 40-60 minutes. Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiation therapist if you're feeling anxious. 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.

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. Usually you can go home soon after the scan. You shouldn't need to stay in hospital.

### PET scan

This scan uses a low dose of radioactive sugar to measure the activity of your cells. This sugar is first injected into your arm and travels to all the cells in your body. Because cancer cells absorb more sugar, there will be more radioactivity where the cancer cells are found.

### Bone scan

Bone scans are very sensitive and can detect any cancer cells in the bone before they show up on a plain X-ray.

For this test a very small amount of mildly radioactive substance is injected into a vein, usually in your arm. After the injection you must wait for up to 3 hours before the scan can be taken. You may want to take a book or magazine with you or a friend to keep you company. A scan is taken of all the bones in your body.



Because abnormal bone absorbs more of the radioactive substance than normal bone, it can show up on the scan. The level of radioactivity used in these scans is very low and safe. It disappears from the body within a few hours. But it is best to avoid contact with pregnant women and very close contact with babies or young children for 24 hours (such as holding them or letting them sit on your lap). You may be advised to drink plenty of water after the scan to flush the radioactive substance from your body.

### Plain X-rays

You may need bone X-rays if the bone scan shows doubtful areas in certain bones. These plain X-rays will help to confirm whether you have benign (non-cancerous) or malignant (cancerous) bone disease.

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

### Waiting for results

It usually takes a week or two 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 prostate 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.
- Staging helps your doctor to plan the best treatment for you.
- Your prognosis is what your doctor expects to happen with your cancer.

The tests you have after diagnosis are usually done to help the doctor to stage your cancer. Staging means finding out the size of the cancer and if it has spread to other parts of your body.



### How is prostate cancer staged?

There are different ways to describe the stages of cancer. The staging system used is TNM:

(T) How big is the tumour?

(N) Is there is cancer in your lymph nodes?

**(M) Metastasis** – has the cancer spread from where it started to a different part of your body?

### What are the stages of prostate cancer?

### Tumour - how big is the tumour?

**T1** The tumour is within your prostate gland. It is too small to be felt during a rectal exam.

**T2** The tumour is still within your prostate gland. It is large enough to be felt during a rectal exam.

**T3** The tumour can be felt throughout your prostate, and may have broken through the outer layer of the prostate.

**T4** The tumour has spread to organs outside your prostate gland.

Node (N) - are the lymph nodes affected or not?

**N** Cancer is present in the lymph nodes.

NO No cancer in the lymph nodes.

N1 Cancer has spread to 1 or more of the lymph nodes.

If you have been diagnosed with early prostate cancer you will see **N0**, meaning the cancer has not spread outside of the prostate.

Metastasis (M) - has it spread outside the prostate?

**M** The cancer has spread to lymph nodes and/or other organs, commonly bones.

M0 The cancer has not spread.

If you have been diagnosed with early prostate cancer you will see **M0**, as the cancer has not spread outside the prostate.

Staging allows your doctor to decide the best treatment for you.

### Grading prostate cancer

Grading helps your doctor to predict how the cancer will behave. This will help them to plan the best treatment for you.

### How is prostate cancer graded?

A doctor called a pathologist will look at samples of your prostate cells under a microscope. The pathologist will give the cells a grade.

The grade is a number from 3 to 5 which describes how normal or abnormal the cells look. A lower number means the cells look more like normal cells. A higher number means they look less like normal cells.

Lower grades are slower growing.

Higher grades are faster growing.



### What is the Gleason score?

The Gleason score will be described using a number from 6 to 10. The pathologist will add the two most common grades together to make the Gleason score. So if the most common grade in the sample is 3, and the second most common grade in the sample is 4, then your Gleason score will be 7 (3+4). However, if only one grade is found, then this grade is added to itself. So if all the sample is only grade 3, then the Gleason score will be 6 (3+3).



If you have any questions about the stage or grade of your cancer, or you find it hard to understand, tell your doctor or nurse. You can also ask one of our cancer nurses. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre.

### **Risk groups**

Your doctor may use your Gleason score, the stage of your cancer (i.e. from X-rays) and your PSA level to describe your cancer as low, intermediate, high or very high risk. These risk groups reflect the level of risk to your future health from this prostate cancer.

### Prognostic grade groups

Some doctors describe prostate cancer as a prognostic grade group, using numbers 1 to 5.

Grades go from grade 1, which has the best outlook, up to grade 5, which describes cancers which grow more quickly. The prognostic grade group is worked out from the Gleason score by the pathologist.

### 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.

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 support services that can help you.

## Treating prostate cancer

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### How is prostate cancer treated?

Prostate cancer can be treated in a number of ways. You may be given a choice of treatments. Sometimes the treatment is to get rid of the prostate cancer completely. If this is not considered likely, the treatment aims to control the cancer or slow its growth. Which treatment options are suitable for you will depend on:

- **The stage of your cancer**, for example, if it has spread outside the prostate gland
- The grade of your cancer (see page 23)
- Your PSA level
- The size of your prostate gland
- If you have urinary symptoms or not
- Your general health



### **Types of treatment**

#### Active surveillance

Active surveillance means you don't start treatment straight away. Instead you have regular tests like blood tests, digital rectal examinations, MRIs and sometimes repeat biopsies to spot any changes or activity in your cancer. This way you can avoid treatment side-effects for as long as possible and still start treatment to cure your cancer as soon as you need it.

This is a treatment option for low-risk prostate cancer, which can be very slow growing and often does not cause symptoms or problems. Active surveillance can carry on for many years if your cancer shows no signs of changing or progressing.

Active surveillance is not suitable for locally advanced prostate cancer.

See page 47 for more details.

#### Watchful waiting

Prostate cancer often grows slowly and does not cause symptoms. Watchful waiting can be a treatment option if you have health problems that make other treatments unsuitable. You will have regular tests to check your PSA levels and sometimes digital rectal examinations done by your hospital or GP. You will also be monitored for new symptoms such as difficulty passing urine or bone pain. If your PSA level rises or if you develop symptoms you will be referred back to your cancer specialist. If there are no signs of the cancer growing it's safe to continue with watchful waiting.

#### Radiotherapy

Radiotherapy uses radiation to treat prostate cancer. The radiation can be delivered in 2 different ways:

**Brachytherapy (internal radiotherapy):** This involves putting a radioactive source into your prostate to kill cancer cells (see page 51).

**External beam radiotherapy:** External beam radiotherapy uses X-rays to kill cancer cells. You may have radiotherapy together with hormone therapy (see page 64).

#### Surgery

The operation to remove your entire prostate gland is called a radical prostatectomy. There are several ways of doing it. For example, traditional open surgery, keyhole surgery, and robotic keyhole surgery. See page 74 for more details.

If prostate cancer is found outside your prostate gland during the operation or when the prostate is examined under the microscope, you may need to have radiotherapy after the surgery as well. Your doctor and specialist nurse will explain this to you in more detail.

#### Hormone therapy

Prostate cancer depends, in part, on the male hormone testosterone to grow and spread. Reducing the amount of testosterone in your body can slow down or stop the growth of cancer cells. In certain circumstances hormone therapy is used together with radiotherapy for early or locally advanced prostate cancer. See page 72 for more details on hormone therapy.

#### Chemotherapy

Chemotherapy drugs may be given to some patients with localised high-grade cancer.

### **Specialist cancer centres**



Prostate cancer is treated in specialist cancer centres in Ireland. The staff at these centres have a lot of experience in managing patients with prostate cancer. As a result, you may be transferred to another hospital from the one where you received your diagnosis.

### Deciding on treatment

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



**Understanding your treatment options:** Your doctor and nurse will explain your treatment options. Your doctor will try to tell you if one treatment is better than another at getting rid of your cancer, but often the treatment options are all thought to be equally good at treating prostate cancer.

Ask as many questions as you like. You could write down any questions you have in advance, so you don't forget anything. If you do forget something or need more explanations, ask your specialist nurse or talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

**Time to think:** You may feel under pressure to make a decision. It may feel as if everything is happening too fast. You can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you. **Second opinion:** You might also find it reassuring to have another medical opinion to help you make a decision about your treatment. Your treating doctor or GP can refer you to another specialist for a second opinion if you feel this would be helpful.



### Making a treatment decision

Many men may find it stressful having to choose between treatment options and worry that they will choose the wrong one. It's important to take enough time to think through the pros and cons of each treatment, in particular the side-effects, and then decide which suits you best. You can ask to talk to a urologist and a radiation oncologist before you make up your mind. You may also find it helpful to fill in the decision aid tool on page 37, once you have read about the different treatments.

### Why am I being asked to make a decision?

Very often there are several different treatments for prostate cancer that are all equally good. There is no right or wrong treatment, so it's up to you to decide which treatment suits you and your lifestyle the best.

### Hints & Tips – making a decision



#### Things to think about when deciding:

- How do I feel about monitoring my prostate cancer?
- How long does the treatment take?
- How do I feel about staying in hospital?
- What is the recovery period for each treatment?
- What are the side-effects of each treatment?
- How will those side-effects change my daily life?
- How many times will I need to visit the hospital?
- Which hospital will I have to travel to for treatment?
- How long will I need to take off work?

#### It may be helpful to:

- Know your results and write down your PSA and Gleason score and the stage of your cancer
- List each option that is available to you
- Write down what you like and don't like about each option
- Ask yourself how important these points are to you (individually) and to your family. The decision tool on page 37 can help you
- Write down the most important goal from treatment
- Talk to other men who had these treatments and find out about their experiences and how they managed any side-effects

The Irish Cancer Society can put you in touch with a trained Survivor Support volunteer who has been through a prostate cancer diagnosis. For more information contact our Support Line on 1800 200 700 or visit a Daffodil Centre.

### Accepting treatment

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

### Giving consent for treatment

Before you start any treatment, you 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.

### Individual treatment

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

### Support Line Freephone 1800 200 700

### Keeping track of information

You may like to fill in these tables with information about your cancer and treatment. Or if you prefer, ask your doctor or nurse to fill them in for you. Ask them to explain the information again if you are unsure.

Grading the prostate cancer	
PSA level at diagnosis	
Clinical stage at diagnosis	
Number of biopsy samples taken	
Number of biopsy samples with cancer	
Gleason score	

Tick all the treatment options suitable for you:

Treatment options suitable for me	
Active surveillance	
Brachytherapy	
External beam radiotherapy	
Laparoscopic prostatectomy (keyhole surgery)	
Open surgery	
Robot-assisted laparoscopic prostatectomy (robotic surgery)	
Watchful waiting	
Hormone therapy	

### Decision aid tool

Fill in the chart below with the help of your nurse or doctor. This might help you to make a decision about your treatment. For each of the treatment options suitable for you, list the advantages and disadvantages. Rank each advantage and disadvantage between 0 and 4. The higher the number, the more this matters to you.

**0** This does not matter at all to me.

**1** This matters a little to me.

2 This does not matter either way to me.

**3** This matters to me.

4 This matters a lot to me.

Treatment options suitable for me	Advantages	Score	Disadvantages	Score

### Who will be involved in my care?

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

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

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

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

**Medical oncologist** A doctor who specialises in treating patients with chemotherapy and other drugs.

**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.

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

**GP (family doctor)** 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.

**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.



**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. Not all hospitals have a psycho-oncology team. Please speak to your oncology team about this.

**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.

**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.

### Waiting for treatment to start

It may be a few weeks before active treatment starts. You may be worried that the cancer will spread if you wait. But with most prostate cancer there is no need to rush treatment.

Having some time can give you the chance to talk through your feelings and try to come to terms with your diagnosis. If you want to talk to a cancer nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre. The nurses can also put you in touch with someone who has had treatment for prostate cancer, if you think this would be helpful.



You could also try to make healthy changes like stopping smoking or trying to lose any extra weight. It can be hard to make changes during an anxious time like this, but it may help your recovery. For example, leaking urine is common after surgery. Extra weight around your tummy or a cough from smoking can make leaking worse. You could also start pelvic floor exercises (see page 94) to strengthen muscles in the area. This might help with leaking urine and erection problems after treatment.

Speak to your doctor for advice and support on how to make these changes.

### Eat well

Eating as well as possible can help you during your treatment. It can help you to:

- Keep up your energy levels
- Keep your weight stable
- Cope better with the side-effects of treatment
- Recover



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

### 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:

 Non-smokers have fewer or less severe sideeffects during cancer treatment



- 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.



## Types of treatment

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### Active surveillance

- Active surveillance is a way to avoid or delay unnecessary treatment if your cancer is not fast growing.
- You may never need treatment for your prostate cancer, or you may avoid treatment for a number of years.
- Active surveillance involves regular tests to check your cancer. These include PSA blood tests, digital rectal exams, MRI scans and sometimes repeat biopsies.

Active surveillance is a way to delay unnecessary treatment and avoid treatment side-effects. Slow-growing, low-risk prostate cancer may not grow or change for many years. You may never need treatment for your prostate cancer, or you may be able to hold off having treatment for a number of years.

Treatments for prostate cancer often cause side-effects that can affect your quality of life, so you could choose to have active surveillance rather than treatment. If your cancer starts to change or grow, then you can start treatment.

### Who can have active surveillance?

If you have prostate cancer that is seen as low risk (see page 24), you may be suitable for active surveillance. If you have medium-risk prostate cancer, you may be suitable too. It will also depend on your age, the amount of cancer in your biopsy and your general health.

If you have high-risk cancer you will not be suitable for active surveillance, as your doctor will want to start active treatment to get the cancer under control.

### What does active surveillance involve?

Active surveillance involves regular tests to check (monitor) your cancer. These tests aim to find any changes in the cancer. If any changes are noticed, your doctor will talk to you about the need for treatment. The tests usually include:

- **PSA blood tests** every few months at the start, and then every 6 months after a couple of years
- **Regular digital rectal exams** where the doctor examines your prostate gland through your rectum (back passage)
- **Prostate biopsies** (taking samples of prostate tissue). You may require one or more biopsies while on active surveillance
- An MRI scan when you have started active surveillance. You may have several MRIs while you're on active surveillance



### If you feel anxious...

During the surveillance, you may feel anxious or worry about your cancer changing. If this is how you feel, then active surveillance may not be the best choice for you.

Remember that if you change your mind after starting active surveillance you can tell your doctor at any stage that you would like to have treatment.

### What happens if the results of my tests change?

**PSA:** A rise in your PSA level may be a sign that your cancer has started to grow. If this happens, your doctor will look at how quickly your PSA is changing and by how much. If your PSA is rising, your doctor will discuss with you whether you need to have further tests and then treatment, if necessary.

**Biopsy:** If your repeat biopsy shows a change in the amount or the grade of cancer, you may be offered treatment. For example, if the biopsy detects some cancer with a higher Gleason score (see page 24).

**Digital rectal exam:** If your doctor feels any changes during a physical exam, they will discuss with you if you need treatment or more tests.

**MRI:** If your MRI scan shows a change in the size or location of your prostate cancer, you may be offered active treatment or further tests.

### Is active surveillance risky?

There is a chance that your cancer will grow while you are on active surveillance. But your tests will help to pick up any changes at an early stage when you can still have successful treatment. The tests are usually good at picking up changes, but there's a chance that changes in your cancer may not be picked up. There is also a small chance that your cancer will be more fast-growing than first thought. A more fast-growing prostate cancer benefits from earlier treatment.

Discuss all the advantages and disadvantages of active surveillance before you decide on this option.

### Remember your active surveillance appointments

- It is very important to go to all your appointments.
- Write the date and time down on a calendar or have a mobile phone alert to remind yourself closer to the time.
- If you cannot make your appointment then make one for another day by contacting the urology clinic in the hospital and speak with your prostate cancer nurse specialist.



### Advantages of active surveillance

- No treatment-related side-effects, like urinary or sexual side-effects
- Does not interfere with your everyday life
- · You can avoid unnecessary treatment

### Disadvantages of active surveillance

- You may feel anxious or worried about your cancer changing
- Repeat investigations are needed, which can be stressful
- The cancer may grow more quickly than expected

### Brachytherapy

- Brachytherapy is a type of radiotherapy.
- The radiation comes from radioactive sources put into your prostate under general or spinal anaesthetic.
- The most common side-effects include urinary problems, erectile dysfunction, fatigue and bowel problems.
- There are 2 types of brachytherapy— low dose rate (LDR, often referred to as seeds) and high dose rate (HDR).

Brachytherapy is a type of radiotherapy. The doctor who specialises in giving radiotherapy is called a Radiation Oncologist. Depending on your individual cancer, brachytherapy may be given on its own or in combination with external beam radiotherapy and/or hormone therapy.

### Who is suitable for brachytherapy?

Not all men are suitable for brachytherapy. It will depend on the stage and grade of your prostate cancer and the size and shape of your prostate gland.

You may not be suitable if you have trouble passing urine, have a very large prostate gland or have recently had surgery to your prostate gland. Your radiation oncologist will let you know if you are suitable for brachytherapy or not.

If you have a larger prostate gland, you may be given hormone therapy to shrink it before brachytherapy. If you have higher-risk prostate cancer, you may receive brachytherapy along with another treatment. For example, you may need some doses of external beam radiotherapy or hormone therapy as well. The two main types of brachytherapy are LDR and HDR brachytherapy.

### Low dose rate (LDR) brachytherapy

With LDR brachytherapy tiny radioactive seeds are put into your prostate. The seeds release radiation slowly over a number of months. The radiation destroys prostate cancer cells. The seeds stay permanently in the prostate and the radiation remains active for a period of about 10-12 months.

### What happens before LDR brachytherapy?

An ultrasound scan of your prostate is completed first. This happens some weeks before the seeds are put in. The scan lasts about 15 minutes. The scan can take pictures of your prostate. The probe that produces the pictures is put into your back passage. The pictures will show the exact size and shape of your prostate so the doctor knows how many seeds to use and where they should be placed. Your nurse will let you know if your bowels need to be empty for the test.

#### How are the seeds put in?

The day before the seeds are put in (implanted), you may be asked to follow a special diet and take medication to clear your bowels. The hospital staff will explain this to you and let you know about any medication to avoid beforehand as well.





Radioactive seeds implanted

Size of the seeds

You will be taken to an operating theatre to have the seeds put in under a general anaesthetic (which means you are asleep for the procedure). Occasionally a spinal anaesthetic may be used (which means you are awake but can't feel the procedure). A thin tube called a urinary catheter will be inserted into the bladder. This will remain in place for a short period after the procedure. An ultrasound probe is put in your back passage to show up your prostate. Then around 60 to 80 radioactive seeds are put into your prostate through the skin between your scrotum and anus (perineum) using a fine needle. It takes about 90 minutes to put in all the seeds. The seeds are about the size of a grain of rice, and remain permanently in the prostate.

### After LDR brachytherapy

- Usually you will be able to go home the same day as the procedure once you have recovered from the anaesthetic and can pass urine normally.
- You may be given antibiotics to prevent an infection. You should take the full course as instructed. You may also be given a prescription for painkillers and alpha blockers. Alpha blockers are tablets to help relax your bladder and make it easier to pass urine.
- At some stage after treatment you will have a scan of the prostate. This is to check the position of the seeds. A very small number of people may need a few extra seeds added. You will have a follow-up appointment around a month after the procedure.

Email: supportline@irishcancer.ie

### Hínts & Típs – after the seeds are put ín



- Do not drive for 24 hours after having a general anaesthetic.
- Take it easy and avoid heavy lifting and straining for 2 or 3 days.
- It is safe to bathe or shower any time after the seeds are put in.
- Return gradually to your regular diet.
- Avoid cycling for a number of weeks, and then gradually return.
- Avoid foods that may irritate your bowel and avoid getting constipated.

### How safe is the radiation?

The radiation is released into your prostate gland over the first few months. This radiation is then absorbed by your prostate. After about 10-12 months, the seeds are no longer active and can stay in your prostate without doing any harm.

It is safe for you to be around other people and pets during this time. The radiation released by the seeds targets the prostate gland only. But as a precaution it is best to avoid long periods of close physical contact with small children or pregnant women for around 2 months after treatment. This means not allowing children to sit on your lap for more than a few minutes each day. It is safe for them to be in the same room as you. You can hold or cuddle them for a few minutes each day. You should also avoid sitting close to a pregnant woman for more than 30 minutes. If your partner is pregnant, inform your medical team and they will tell you what to do. Your radiology team will give you information about any other safety precautions you need to take.

### How long do the seeds stay in my body?

The seeds stay permanently in your prostate gland. There's a slight chance that a seed could be passed out in your semen or urine, although this is rare. If a seed is passed in urine, it should be flushed down the toilet.

You are advised to wear a condom during sexual intercourse for a period of 2 months after implant. If a seed comes out in your semen it should be flushed down the toilet.

Double wrap used condoms and dispose of them in a dustbin. See page 62 for more about sex after brachytherapy.

### Medical alert card

Because you will have radioactivity in your body for a time after brachytherapy, the radiotherapy unit may give you a medical alert card detailing the treatment you have had. This is to alert other medical professionals if you have a medical emergency. It's important to carry this with you all the time, for the amount of time recommended by the unit. If you need to have a procedure in hospital for another reason during the first year after treatment, speak to your brachytherapy unit about the risk of exposure from radiation.

This card is also necessary for airline travel, as some of the security sensors may be triggered by the weak radiation from the seeds.

### High dose rate (HDR) brachytherapy

HDR brachytherapy uses a high dose of radiation. Instead of using permanent seeds, around 15-20 thin needles are inserted into the prostate gland. A small radioactive source on the end of a wire is fed into each needle in turn and this delivers the treatment to the prostate. This is done under general or spinal anaesthetic. When the treatment has been completed, the needle and radiation source are removed.

HDR brachytherapy is often combined with external beam radiation and/or hormonal therapy, but your doctor will discuss your individual treatment plan with you.

### What happens before HDR brachytherapy?

The day before treatment you may be asked to follow a special diet and take medication to clear your bowels. The hospital staff will explain this to you and let you know about any medication to avoid beforehand as well.

#### How are the tubes/radiation wires inserted?

You may have a general anaesthetic (which means you are asleep for the procedure) or you may have a spinal anaesthetic (which means you are awake but can't feel the procedure).



Picture courtesy of CRUK/Wikimedia Commons

Once you have had the anaesthetic, an ultrasound probe is put in your back passage to show up your prostate. Thin needles are then passed into the prostate and surrounding tissue through the area between your scrotum and anus (perineum). This may take about one hour. A catheter (thin tube inserted into the bladder to drain urine) may also be inserted. Once the needles are in position the brachytherapy team will begin planning your treatment. Depending on which hospital is delivering your treatment you may remain under a general anaesthetic for the planning and treatment, or you may be woken up and the planning / treatment will be delivered later that day in a specific treatment room. If this happens you will have a spinal anaesthetic until the treatment is complete.

In the treatment room, the needles that are placed in your prostate will be attached to the HDR machine. This machine feeds the radioactive source (wires) through the needles and into the prostate. The needles are left in for about 3 hours. The radioactive source is removed after every treatment. Once the treatment is finished, the needles will be disconnected from the treatment machine and removed from the prostate. The catheter will also be removed.

### After HDR brachytherapy

- You will not be able to drive for 24 hours after the anaesthetic.
- You may be given antibiotics to prevent an infection. You should take the full course as instructed. You may also be given a prescription for painkillers and alpha blockers. Alpha blockers are tablets to help relax your bladder and make it easier to pass urine.
- If you are having external beam radiotherapy as part of your treatment, you may have a CT planning scan or simulation scan about 2 weeks after your procedure.
- The external beam treatment will start about 4 weeks after your HDR procedure.
- You are not radioactive at any time. The only time that there is any radioactivity present is during treatment. There is not any radiation exposure to your family.

### Prostate brachytherapy side-effects

It may take a few days before you experience any side-effects. It is important to remember that these side-effects are a general guide and you may not experience all of them. Also the severity of these symptoms can vary.

### Bruising, pain, swelling

You may have bruising, pain or swelling in the area between your scrotum and anus (perineum). This should only last a few days and you may take paracetamol if required.



#### Urinary problems

You may see some blood in your urine afterwards, but most bleeding usually goes within the first few days. If it continues, let your doctor know. To help prevent blood clots and flush out your bladder, drink plenty of fluids (about 1½ to 2 litres a day). The radiation can irritate and inflame the tube through which you pass urine (urethra) and your bladder. This can cause symptoms such as a burning sensation when you pass urine, needing to pass urine more often, having a slow stream, finding it harder to start passing urine, and needing to go more quickly than you used to. If you cannot pass urine afterwards, this is called urinary retention. This doesn't happen very often but if it does, you will need to have a tube (catheter) put in for a short period of time.

Urinary side-effects get worse in the first few weeks after treatment. You may need to go to the toilet more often. This can interfere with your normal daily activities.

If you have urinary problems before brachytherapy, you are at higher risk of having problems passing urine after the treatment. Leaking urine (incontinence) is rare after brachytherapy. If you have had surgery to your prostate gland before brachytherapy, you will have a higher risk of incontinence.

There is more information on urinary problems and how to manage them on page 91. Or look at our **website www.cancer.ie** 



#### **Erectile dysfunction**

Brachytherapy can cause damage to the nerves and blood vessels near your prostate gland. This means that you might not be able to get normal erections after the treatment. This is called erectile dysfunction (ED) or impotence. You may not notice it until years after your treatment. It may also become a longterm problem or be permanent.

How treatment might affect your sexual function depends on many factors including your age, your weight, other medications/illness you may have etc. Your risk of erectile dysfunction will increase if you have had erection problems before your treatment. If you have hormone therapy and/or external beam radiotherapy together with your brachytherapy, you are at a higher risk of erectile dysfunction than men who have brachytherapy alone.

You may find this side-effect of treatment very hard to deal with. It can affect your relationship with your partner and your sex life.

Try not to feel embarrassed to talk to your doctor or nurse about this problem. There are practical ways and several treatments available to help overcome it. See pages 95-97 for more information. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre.



#### Infertility

Brachytherapy for prostate cancer may affect your fertility. This means you might not be able to father a child in the future. If this is important to you, talk to your doctor about this before your treatment. See page 101 for more about fertility. Remember it is not safe to assume you are sterile after radiotherapy, so you will need to use contraception.

#### **Bowel problems**

You may get inflammation of your bowel after brachytherapy. This may cause some bleeding or a change in your bowel habit, such as needing to go to the toilet more often. Avoid foods that may irritate your bowel and avoid getting constipated.

Bowel problems can appear straight away or up to 2 to 3 years after your treatment. If this happens, talk to your doctor. There may be treatments that can help. It's important that any doctor who treats you for bowel problems after brachytherapy is aware that you have had brachytherapy. If you are unsure, contact the hospital where you had treatment for advice. A small area of the rectum overlying the prostate may have received a dose of radiation, so your radiation oncologist is likely to advise that you do not have a biopsy of this area. There is a risk that it will not heal properly after a biopsy.

> If you need a bowel or prostate test after brachytherapy, speak to your radiation oncologist.

#### Fistula

This is a very rare side-effect that involves a tear between your bladder and bowel. If it happens you will need to wear a bag to collect your bowel movements and urine.

#### Fatigue (tiredness)

It usually takes a few months for tiredness to improve after treatment. See page 89 for more on coping with fatigue.

Our booklet *Understanding Radiotherapy* has more information on brachytherapy. For a free copy, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also download it from www.cancer.ie



### What about sex after brachytherapy?

It is safe for you and your partner to sleep in the same bed. If your partner is pregnant, ask your medical team for advice.

You can talk to your doctor or nurse about when you can start having sex again after brachytherapy. They may advise you to wait for a week or two. You may not feel like having sex in the first few weeks after treatment. This can be due to tiredness or side-effects like pain or swelling around the area of the prostate. These symptoms normally ease with time. Sometimes ejaculation may be painful but this tends to settle in time. If you have had seeds then you will need to use a condom for the first 10 ejaculations (or 2 months) after the implant. You may ejaculate less semen or no semen at all after having brachytherapy.

Doctors may advise against receiving anal sex for several months. This is to avoid damage to the area.



### Advantages of brachytherapy

- Treatment time is short: 1-2 days.
- You can return to your normal routine quite quickly.

### **Disadvantages of brachytherapy**

- It can cause urinary, erection and bowel problems.
- You may have some temporary discomfort after the procedure.
- You may need to have a general anaesthetic.
- Rarely, it can cause a tear (fistula) between your bladder and bowel. If this happens, you will need to wear a bag to collect your bowel movements and urine.

### External beam radiotherapy

- External beam radiotherapy uses beams of radiation aimed at your prostate gland.
- The treatment is suitable if your prostate cancer is found only within your prostate gland or has spread just outside it.
- Short-term side-effects of radiotherapy include passing urine more often, diarrhoea, discomfort at back passage and fatigue.

External 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.

The treatment is suitable if the cancer is found within your prostate gland or has spread just outside it to the pelvic lymph nodes. The aim of radiotherapy is to fully get rid of your prostate cancer. Radiotherapy may not be the best option if you have severe urinary symptoms.

### Radiotherapy and hormone therapy

### 

Radiotherapy and hormone therapy (see page 72) are often used together to treat locally advanced prostate cancer. This helps to make the radiotherapy work better at controlling the cancer. Hormone therapy can be given for different lengths of time. Typically it starts some months before radiotherapy and continues during and after treatment for a period of months or years, depending on your individual circumstances. Ask your radiation oncologist for how long you will need to take the treatment.

### 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 nearby cells.

#### Simulation

You will have a CT scan to pinpoint the area to be treated. The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. You might also have gold markers called fiducials put into your prostate to make sure the radiotherapy targets the right area. These are put into your prostate gland under anaesthetic before the treatment starts. The dose of radiation will be decided and tightly controlled for your treatment.

### Special diet and fluids

Your prostate gland must be in the same position every time you have your treatment. The position of your prostate can be affected by how full your bladder or bowel is. To make sure your prostate is in the same position each time, you may have to follow a special diet, drink some water just before your treatment, or have an enema. An enema is a fluid solution gently inserted into your bowel through your back passage, which causes you to clear your bowels.

### **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 or in an arc.

The treatment normally takes several minutes and is painless. Most people receive radiotherapy as outpatients, travelling to the radiotherapy unit each week day.

### How much radiotherapy do I need?

The course can be several treatments over a number of days or weeks (usually 4 to 8 weeks). How much treatment you receive will depend on the extent and exact location of your cancer. External radiotherapy does not make you radioactive. It is completely safe for you to mix with family and friends, including pregnant women and children. Radiotherapy is normally given in special cancer treatment centres, so you may have to attend a different department or hospital from where you had another treatment.

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

### What are the side-effects of radiotherapy?

Most of the side-effects that happen affect the part of your body being treated. How severe any side-effects are will vary from person to person, depending on the amount of treatment received. Most side-effects develop during or shortly after your treatment and get better within a few weeks.

### Short-term (acute) side-effects

**Urinary problems:** Burning sensation when passing urine, needing to go to the toilet more often or blood in your urine. See page 91 for tips to manage urinary problems.



**Bowel problems:** Diarrhoea (loose, semi-solid bowel movements) or constipation (not having a bowel movement often enough), cramping pain in your tummy, passing more wind or mucus, needing to get to the toilet more quickly or mild bleeding when you go to the toilet. Drink lots of fluids if you have diarrhoea. You may also be advised to avoid high-fibre foods such as raw fruit and vegetables, as they may make things worse. The hospital team will help you find ways to manage your bowel symptoms during your treatment. These symptoms usually start to settle down a short time after your treatment has stopped.

**Fatigue:** Feeling very tired, even after rest. See page 89 for more about fatigue.

#### Late, long-term or permanent side-effects

Late side-effects may develop some time after treatment. Some side-effects last for a long time or may even be permanent, but it is rare to have long-term problems.



**Erectile dysfunction:** Radiotherapy to your prostate can damage the nerves and blood vessels that control erections. This can make it difficult for you to get and keep an erection, especially if you are taking hormone therapy as well. This is called erectile dysfunction or impotence. It can take up to 2 years for this side-effect to be noticed.

If you have had problems with erectile dysfunction before radiotherapy, you are more likely to have problems with erections afterwards. Having erectile problems will also depend on your age and general health. There is some evidence that taking tablets or using vacuum therapy for erectile dysfunction soon after radiotherapy may reduce your risk of erectile problems. See pages 95-97 for more information.



You may not be interested in sex at first. But taking the tablets or using a vacuum pump at an early stage may improve your chances of getting erections when you are ready to think about sex again.

Discuss this with your doctor, nurse or GP. There are several treatments available for erectile dysfunction.

For more information see pages 96-97 or visit our website. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre, or email the nurses at supportline@irishcancer.ie **Urinary problems:** A very small number of men find their bladder is permanently affected by radiotherapy. They may develop symptoms like needing to go to the toilet more often or pain when passing urine months or years after radiotherapy. Some men's urethra (water pipe) narrows, which can make it difficult to pass urine. Narrowing of the urethra needs to be treated with surgery.

A few men have blood in their urine after radiation therapy, sometimes many months or years after treatment. This is because the blood vessels in your bladder can become more fragile after radiotherapy. If you notice any bleeding, tell your doctor so that tests can be done to check the cause and decide if any treatment is needed.



Rarely, radiotherapy can cause urgency to pass urine, resulting in leakage of urine. But this is unlikely unless you have had prostate surgery as well. If this happens, discuss it with your doctor or nurse.
**Bowel problems:** In some cases, bowel problems might carry on. Or they might develop years after treatment and you find that your bowel habits change permanently. Bowel motions may be more urgent and frequent after radiotherapy. Tell your doctor about any bowel problems that you have, as there are treatments that can help.

The blood vessels in your bowel can also become more fragile after radiotherapy. This can cause blood to appear in your bowel motions. Other bowel problems are common in older men, so symptoms may be due to something else. You may need to have a few tests to find out the cause of your symptoms. If you have ongoing problems with diarrhoea or rectal bleeding, tell your doctor or nurse.

**'Dry' orgasm:** After radiotherapy, some men find that an orgasm has less semen than usual or they have a 'dry' orgasm, where no semen is ejaculated. Dry orgasm means you won't be able to father a child, as there is no semen.

**Infertility:** Radiotherapy for prostate cancer may cause infertility. If this happens, it means you cannot father a child in the future. If this is important to you, talk to your doctor about this effect before your treatment to see if there are any options open to you, such as sperm-banking before treatment. See page 101 for more about fertility. It is not safe to assume you are sterile after radiotherapy, so you will need to use contraception.

If you feel unwell or have any other side-effects or symptom, tell your doctor, nurse or radiation therapist. For more information on the different types of radiotherapy and the side-effects of radiotherapy or a copy of the booklet *Understanding Radiotherapy*, call our Support Line on 1800 200 700 or visit a Daffodil Centre.



# Advantages of external beam radiotherapy

- You don't need a general anaesthetic and you don't need to stay overnight in hospital.
- You may be able to work and carry on normal activities during the treatment.
- You are not radioactive during or after the treatment so you can be in close contact with others.
- Each treatment is relatively short. It usually takes about 15 minutes, although you may be in the radiotherapy department for up to an hour.

# Disadvantages of external beam radiotherapy

- It may be difficult if you have to travel a long way to the radiotherapy unit.
- It may take some time to see how effective the radiotherapy has been.
- You may not be able to have prostate surgery in the future due to the effects of the radiotherapy.
- You might experience side-effects such as bowel or urinary problems, erectile dysfunction and fatigue. Some of these side-effects may develop or get worse over the longer term.
- You may become infertile.
- Treatment may very slightly increase the risk of getting a second cancer.

# Hormone therapy

- Hormone therapy works by reducing the amount of testosterone in your body, to stop it helping the cancer cells to grow.
- It is given as tablets, injections or implants.
- There are many different types of hormone therapies. Your doctor will explain the best type for you.
- Hormone therapy can be given on its own, or in combination with other treatments.
- Possible side-effects include hot flushes, weight gain, loss of sex drive and tiredness (fatigue).

Hormones in your body control how normal cells grow and work. Prostate cancer depends in part on the male hormone testosterone to grow and spread. By reducing the amount of testosterone in your body, the growth of cancer cells can be slowed down or stopped. Hormone therapy can be used to reduce the amount of testosterone made by your testicles. These drugs can be given as tablets, implants or injections.



# Side-effects of hormone therapy

Different hormone therapies have different side-effects. Ask your oncology team about the side-effects you may expect.

Most side-effects happen because of the changes to the balance of hormones in your body. Possible side-effects include:

### Hot flushes

These affect more than half the men who get hormone therapy. Some men find them difficult to cope with.

### Breast swelling and tenderness

This can vary from mild tenderness, with or without swelling, to more noticeable tissue growth around the breast area.

Osteoporosis or bone thinning Bones can become more brittle and more likely to break (fracture).

# Weight gain and muscle loss

You may gain weight, particularly around your waist. Your muscle tone and strength can also be reduced.

# Fatigue

Extreme tiredness is a common side-effect. Fatigue can affect your energy, mood and concentration. See page 89 for more.

# Mood or concentration problems

Less testosterone can lead to mood changes, poor concentration or memory problems, anxiety and sometimes depression.

# Hormone therapy and sex

Hormone therapy can have a big impact on your sex life. Because hormone therapy reduces the male sex hormone testosterone, it can affect your interest in sex (libido) and your ability to get an erection. Libido can come back once you stop taking hormone therapy, although it can take many months. See page 95 for more about sexual side-effects.

See our website **www.cancer.ie** for more on hormone therapy and advice on managing side-effects like hot flushes and bone thinning.

# Surgery

- The aim of surgery is to remove your entire prostate gland and the cancer within it. The operation is called a radical prostatectomy.
- A nerve-sparing prostatectomy may be possible, to protect the nerves next to your prostate that are responsible for erections.
- A urinary tube (catheter) will stay in place for 1 to 3 weeks after your surgery.
- Problems with urinary incontinence and erections are common side-effects of surgery for prostate cancer. These problems often improve with treatment.

The aim of surgery is to remove the cancer. The operation is called a radical prostatectomy. It involves removing your prostate gland and the seminal vesicles, which are glands near your prostate that produce some of the fluid in semen. Sometimes lymph nodes and nearby tissues may be removed as well. The surgeon who removes your prostate gland is called a urologist.



# Who is suitable for a radical prostatectomy?

Surgery is suitable if the cancer is only in your prostate gland and you are fit and healthy. Surgery may be more risky if you have health problems such as heart disease or if you are very overweight. In this case, your surgeon will advise you to have one of the other treatments for early prostate cancer.

Surgery to remove your prostate gland is a big operation. It has risks such as bleeding, blood clots and infection. The average stay in hospital is 5–7 days but can be shorter or longer. You will need some time to recover at home afterwards as well. Once the prostate gland is removed, it will be examined under a microscope in the laboratory. The doctor will check the grade of the cancer cells again (see page 23). They will also check that the edges of the prostate are clear of cancer – this is known as 'checking the margins'.

Negative margins: No cancer cells

**Positive margins:** Cancer cells found at the edge of the tissue removed

These tests are used to predict your response to the treatment along with PSA checks. Your PSA level should drop within weeks of surgery.

# What are the types of surgery?

Surgery to remove your prostate gland can be done in a number of ways. Not all of the treatments are available in all hospitals in Ireland, so discuss your preference with your surgeon.

### Laparoscopic prostatectomy (keyhole surgery)

Small cuts are made in your abdomen so that special instruments can remove your prostate.

Robot-assisted laparoscopic prostatectomy (robotic surgery) This operation is like laparoscopic surgery but the urologist uses computer and robotic arms to help to remove your prostate.

### **Open prostatectomy**

Open surgery means removing your prostate through a cut in the wall of your abdomen between your belly button and pubic bone or through a cut between your scrotum and back passage.

You will be in hospital for a much shorter time with robotic or keyhole surgery than with open surgery. There is also a lower risk of needing a blood transfusion or getting a wound infection. The longterm side-effects of this type of operation are the same as for open surgery. Specially trained surgeons are needed to do these types of surgery.

# Nerve-sparing surgery

Sometimes having to remove all the cancer cells means that the two bundles of nerves attached to the prostate cannot be preserved. These nerves control erections. If the nerves are not preserved or are damaged during the operation it will cause problems with getting an erection in the future.

If the cancer has spread too close to the nerves, your surgeon may need to remove one or both bundles of nerves. In some cases, it is possible to spare nerves on one side of your prostate. This is called a nerve-sparing prostatectomy. It gives you a better chance of regaining erections than if you had both of the nerves removed, but not as good as if you had both bundles of nerves spared. Ask your surgeon if nerve-sparing surgery is possible for you or not. Very often surgeons can't tell until the operation itself if they can do a nerve-sparing operation or not.

# Having the surgery

### Tests

To make sure you are fit for surgery, you will need some tests. For example, blood tests, heart tracing (ECG), chest X-ray and a physical exam. An anaesthetist may also examine you to make sure you are fit for surgery. They will also discuss pain relief with you.

### Risks

Prostate surgery has the same risks as any big operation. These include bleeding and the need for a blood transfusion, chest infection, blood clots and wound infection. Your doctor will discuss these risks and the side-effects of surgery before you sign a consent form.



### Exercises

Before surgery, a physiotherapist or nurse might show you how to do simple exercises to strengthen the muscles that help control your urinary flow. These are known as pelvic floor exercises (see page 94). You may also be shown how to do deep breathing and leg exercises to prevent a chest infection or blood clot afterwards. You may be given some elastic stockings to wear and an injection of an anti-clotting drug to reduce the chance of blood clots forming in your legs.

### Fasting

You cannot eat or drink anything for a few hours before surgery. The operation takes between 2 and 4 hours but you will also spend some time in the recovery room while recovering from the anaesthetic.

# After surgery

When you wake up, you may have drips and tubes attached to your body. For example:

- A drip into your arm or neck to give you fluids until you can drink again
- A flexible tube (catheter) in your penis to drain urine into a bag
- A tube (drain) near your wound to drain away any fluid

If you have open surgery you may have a tube into your back, which gives you drugs to relieve any pain.

When you begin to drink again, the drip will be removed. All other tubes and drains will be taken out over the first couple of days, except for the urinary catheter. You will go home with this tube. It will be left in for about 1 to 3 weeks. See page 80 for more about catheters.



### Pain

With open surgery you will probably have a special pump for relieving pain. This gives you a supply of painkillers, either into your spine (epidural) or into a vein in your arm. Your nurse will show you how to use it. Often the pump is a patient-controlled pump. This means there is a button on the pump that you can press to release the medication when you need it. Once the pump is stopped, you can have painkilling tablets. Let your nurse know if you are in any pain so that they can adjust the painkillers for you. You may have mild discomfort for several weeks. Your doctor will give you a prescription for painkillers to take home with you if needed.

If you have keyhole / robotic surgery you may receive morphinebased painkillers for a day, but often men are able to manage with paracetamol and anti-inflammatory painkiller tablets.

### Wound

It usually takes a few weeks for wounds to heal. Any swelling or bruising will settle down with time. Healing on the inside of your body will take a bit longer.

Immediately after surgery the area will be covered with a dressing. It is important to keep the area clean and dry until healed. Your nurse will advise you how often this will need to be changed and when it can be removed entirely.

Avoid heavy lifting and manual work for up to 8 weeks after the surgery. Your doctor or nurse will be able to advise you about this and also when you can return to driving.

### Sluggish bowel

The anaesthetic during surgery may slow down your bowels. As a result, it may take a day or two before you can start eating and drinking normally again after open surgery. The risk of sluggish bowel is much less with keyhole or robotic surgery.

# Infection and blood clots

A physiotherapist will show you breathing exercises to help prevent a chest infection. They will also show you how to cough without hurting yourself and how to move in the bed. You might find it helpful to hold a pillow or folded towel over your wound when you cough for the first few days. Even when in bed, you should move your legs and do your deep breathing exercises at least once an hour. This will help to prevent blood clots. On the day after surgery, your nurses 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.

### Urinary catheter

The urinary tube will stay in place for between 1 and 3 weeks after your surgery. The urine you make will pass through the tube into a drainage bag. The catheter drainage bag will be worn inside your trousers and will be secured around your lower leg.

Before you go home, your nurse will show you how to look after the drainage bag. It is important that the urine can drain easily from your bladder and into the drainage bag.

You might experience bladder spasms while the tube is in place. This often feels like a strong urge to pass urine, and may result in urinary leakage around the tube, despite the tube being there. This is normal, but talk to your nurse if this happens to you a lot. It may happen when your bowels move. Your doctor can prescribe medication if this becomes a problem for you.

# Hints & Tips - Catheters

- Try to drink plenty of fluids every day to reduce the risk of getting an infection: between 1½ and 2 litres a day is often best.
- · Avoid drinks with alcohol or caffeine in them.
- Wash your hands before and after handling the catheter. When washing the catheter entry tip, wash in a one-way direction away from your body.
- Speak with your nurse if you notice any leaking around the outside of the catheter or if you notice that the catheter is not draining correctly.

# Leaving hospital

If you have surgery, it's best to plan as much as you can ahead of the discharge date. Ask to speak to a medical social worker about the community services that are available, especially if you live alone.

Usually, the public health nurse in your area will visit you at home. If dressings are needed, make sure you have some supplies at home before the discharge date. Ask for a contact name and telephone number at the hospital so that you can talk to somebody if you have a problem. Talk to your specialist nurse, public health nurse or a pharmacist about getting a supply of incontinence pads. Make sure you have a supply at home before the urinary tube (catheter) is removed.

See page 94 for more about pads.

# Going home

If you have open surgery you may have stiches just under the skin. These don't need to be removed as they are dissolvable. If your wound is closed with clips, these will need to be removed. This may be done before you leave hospital, or your practice nurse, public health nurse or GP might remove them when you go home. Contact your GP or the hospital as soon as possible if your wound becomes swollen, red or painful. This could be a sign of infection.

On the day you go home, you will be given a date to have your urinary tube (catheter) removed and often another appointment to see the surgeon. This is usually about 6 weeks after the operation. If you have a worry or symptom that is causing you concern before your check-up date, contact your doctor, nurse or hospital ward for advice.

# Removing the urinary tube

You will need to go to the hospital or to your GP to have your urinary tube (catheter) removed. This takes just a few seconds. Most likely you will experience some leakage of urine once the tube is removed. This is normal and usually improves with time. Your nurse will give you an incontinence pad to wear, along with a small supply to take home. They can also give you information about how to get a supply of pads for yourself. It is important to keep doing pelvic floor exercises once your catheter has been removed to try and reduce urine leakage. If you need help with pelvic floor exercises, ask your nurse.

# What are the side-effects of surgery?

The main side-effects of surgery are:

- Leakage of urine (urinary incontinence)
- · Problems with erections (erectile dysfunction)

Talking to your doctor and nurse, or to someone who has had surgery for prostate cancer, may help you to understand the impact of these side-effects on your daily life, but remember all patients recover in different ways. Call our Support Line on 1800 200 700 if you would like to be put in contact with a trained volunteer who has had treatment for prostate cancer.

### Urinary incontinence

Urinary incontinence means you cannot control the flow of your urine. Almost all men will have trouble with leakage of urine in the first weeks and often months after surgery. The risk of urinary leakage is the same for open, keyhole and robotic surgery. Talk to your surgeon or nurse about the risk of urinary incontinence before you consent to surgery.

You will probably need to wear an incontinence pad for a time to collect the leaked urine. As time goes on, you are likely to regain control of your urine flow and you won't need to wear pads any more. Or perhaps you will only need one pad a day or just when you exercise. A small number of men do not regain complete control over their urine flow and need to continue wearing pads. Tell your surgeon if this happens.

**How to cope with urinary incontinence:** For tips on coping with urinary incontinence and information on treatments available, see page 94.

### Erectile dysfunction (impotence)

Surgery to your prostate gland often leads to problems having an erection. This is called erectile dysfunction (ED) or impotence. It is caused by damage to blood vessels or nerves near your prostate. Even a small amount of damage can lead to erections failing, especially if you are older and have high blood pressure or diabetes. Nerve-sparing surgery can improve your chance of getting your erections back after surgery. See page 76 for more details.



If you had problems with erectile dysfunction before surgery, you are more likely to have these problems after surgery too. Up to 7 in 10 men have erectile dysfunction after a radical prostatectomy.

At first you might find it difficult to get an erection, and it may not be strong enough for sex. It can take at least a year after surgery to find out if the impotence will get better or not. You may need medication or other treatments to help you get an erection.

If you have problems with erections, talk to your surgeon when you go for check-ups, or talk to your GP or nurse. There's more information on sex and erectile dysfunction on our website **www.cancer.ie**. You can speak to cancer nurse in confidence by calling our Support Line on 1800 200 700 or by visiting a Daffodil Centre. You can also email the nurses at supportline@irishcancer.ie

### Early treatment for erectile dysfunction

Taking medication or using a vacuum pump for erectile dysfunction soon after surgery can improve your chance of having erections again. Even if you're not interested in sex, taking the tablets or using a vacuum pump at an early stage may improve your chances of having erections if you want to have sex again in the future. Discuss this with your surgeon, nurse or your GP.



### Managing erection problems

See pages 95-97 for more information about managing erection problems and how to get the best from treatment.

### 'Dry orgasm'

After prostate surgery, an orgasm will not cause an ejaculation of semen. This is known as a 'dry orgasm'. Many men describe the sensation of orgasm as different to their orgasm before surgery. A few men describe it as lasting longer, others describe some pain after orgasm in the early days, or some simply describe it as different. A dry orgasm means that you cannot father a child in the future. Tell your surgeon if you think you might wish to father children after your surgery, as it may be possible to store your sperm before treatment starts. See page 101 for more on infertility.

### Shortening of your penis

Up to a year after surgery you may notice your penis has shortened. Some treatments for erectile dysfunction that encourage blood flow into your penis, such as tablets or a vacuum pump, may help to prevent it. See page 96 for more information.

# Advantages of prostate surgery

- Surgery will completely remove the cancer if it is only in the prostate gland.
- The prostate can be removed and be fully analysed and staged in the laboratory.
- The success of the treatment can be easily assessed by PSA testing.
- If the PSA were to rise after surgery you would still be able to get other treatments like radiotherapy or hormone treatment.

# Disadvantages of prostate surgery

- It involves a general anaesthetic and the usual risks you would expect with surgery, like the risk of bleeding, infection and blood clots. It involves a short stay in hospital for a few days.
- You may get side-effects afterwards like problems with erections and urinary incontinence.
- You will not be able to father children after the surgery, as the prostate, which normally makes some of the fluid needed for semen to be made, has been removed.
- Recovery takes around 6 weeks.

Email: supportline@irishcancer.ie

# **Clinical trials**

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

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

Because the drugs are still in trial, you'll be very closely monitored and may have extra tests and appointments.

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

# More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For more information, you can read our factsheet *Cancer and Clinical Trials*. It's available to read or download on our website, **www.cancer.ie**. You can also get a free copy by calling our Support Line on 1800 200 700 or by dropping into a Daffodil Centre.

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



Cancer Nurseline 1800 200 700

# Managing side-effects and symptoms

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# Fatigue

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

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

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



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

# 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 like meditation, acupuncture or massage, if your doctor says they're safe for you.



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

# Urinary problems

Different treatments for prostate cancer can cause different urinary symptoms. You can read more about the possible side-effects of each treatment in the treatment sections on pages 45-85.

Some of the symptoms you might experience include:

- Leaking urine (urinary incontinence)
- A slow flow of urine / difficulty emptying your bladder fully
- Passing urine frequently (more than 8 times a day)
- A sudden urge to go to the toilet quickly (urgency)
- Blood in the urine

Urinary symptoms normally improve with time, but if they carry on for a long time, your doctor may recommend surgery or other treatments.

Urinary symptoms are most common after surgery for prostate cancer.

# Leaking urine

Leaking urine is a common side-effect of prostate cancer surgery. You may leak just a few drops of urine when you cough, laugh or exercise or it can be a constant drip or trickle throughout the day. Or you may leak some urine before you get to the toilet or after you have been.

If you need advice about coping with leakage, ask your doctor, public health nurse or see if there's a continence adviser at your local HSE health centre. There are things that can help, so don't suffer in silence. See pages 93-94 for advice.



# A slow flow of urine / difficulty emptying your bladder fully

A slow flow of urine may be caused by a narrowing of your urethra (water pipe) after surgery or radiotherapy. If you have a slow flow of urine let your urologist know, so they can find the cause and see if you need treatment. If you have a slow flow of urine your doctor may give you tablets called alpha blockers to help. These can help to relax the muscle in the prostate and to reduce the narrowing of the water tube that runs through the centre of the prostate. Or you may need a short procedure to widen the tube to help you to pee more easily again.

# Medical need toilet card



The Irish Cancer Society has a card that you can show at shops and other public places to get urgent access to a toilet. Get one from a Daffodil Centre or by calling our Support Line on 1800 200 700.

# Hints & Tips - Managing urinary problems

Your doctor can help you to manage urinary problems, so always tell him or her if you have any symptoms. You could also try the following:

- Cut down on food and drinks with caffeine, like cola, tea, green tea, coffee and dark chocolate, as they may irritate your bladder.
- **Drink less alcohol.** Alcohol can increase the amount of urine you produce, making it more likely you'll have to get up during the night.
- Drink plenty of fluids every day about 2 litres a day (average 6-8 cups). Not drinking enough will make your urine more acidic and this may irritate more.
- If you find your need to pee is usually urgent, make sure you can reach the toilet easily and that your clothing can be easily undone.
- **Eat plenty of fibre to avoid constipation.** Constipation can put pressure on your bladder and make urinary problems worse.
- **Exercise regularly**, as it will help your bowels to work well. Your doctor can advise you about suitable exercises for you.
- Keep the area clean and dry to avoid skin irritation and to stay fresh. Use a mild soap and gently pat the area dry.
- Go to the toilet at regular intervals.
- Wear trousers with an elasticated waist, or use braces rather than a belt. This makes it easier when you want to go to the toilet quickly.
- **Try having a rest in the afternoon.** It may help the muscles around your bladder to tighten up and work better for you.
- Plan ahead keep a bag with wipes and pads with you, and make sure you know where the public toilets are if you're going out.
- **Bed protectors are available** if you're worried about leaking during the night.

# **Incontinence** pads

You may need to wear pads to absorb leaks for some weeks or months. You can get pads from your local pharmacy or online. If you have a medical card your public health nurse may be able to get the pads for you.

Try a few different sizes and absorbencies until you get the right pad to suit you. Using a pad that absorbs more than you need can make your skin sore, so pick a smaller size as your leakage reduces. Wear supportive underpants or special net pants to help keep pads in place.

### **Pelvic floor exercises**

Pelvic floor exercises can help to strengthen the muscles around your bladder and in the pelvic floor and may improve your bladder control. Get advice from your hospital team or a local HSE continence adviser. There are instructions on how to do the exercises on our website, **www.cancer.ie** 

# 'The knack'

'The knack' is a technique to help to reduce leakage. It involves squeezing your pelvic floor muscles before you cough, sneeze or laugh or before or during other activities that can make leakage worse. Go to **www.cancer.ie** for more information.

# Treatments for urinary incontinence

If your incontinence carries on for more than 12-18 months your urologist may talk to you about treatments to deal with the problem. For example, an artificial urinary sphincter, internal sling or bulking agents. For more information see our website **www.cancer.ie**. Or talk to a cancer nurse in confidence by calling our Support Line on 1800 200 700 or by visiting a Daffodil Centre. You can also email the nurses at supportline@irishcancer.ie.

# Sexual side-effects

It is natural for you to be concerned about your sex life. Treatment can affect you physically and mentally when it comes to sex. Fatigue, loss of libido (sex drive), changes to the way you ejaculate, urinary incontinence and erectile dysfunction (ED) can all affect your sex life. Some men with prostate cancer feel that changes to their sex lives and their relationships are some of the biggest issues they face.

For more details on sexual side-effects see the individual treatment sections:

Sex after brachytherapy – page 62 Sex after radiotherapy – page 68 Sex and hormone therapy – page 73 Sex after surgery – page 83

# Treatment for erectile dysfunction

Not everyone wants treatment for erectile problems. Some men accept the changes in their body and don't feel the need to get treatment. For others, finding a way to treat their erectile dysfunction is very important. There is no right or wrong way to react – just the way that feels right for you.



The treatment options for erectile dysfunction include:

### **Tablets**

Sildenafil (Viagra®), Tadalafil (Cialis®) Vardenafil (Levitra®) and Avanafil (Sepdra) are all examples of tablets that can help men to get erections. You need to be interested in sex and have sexual stimulation for them to work. Some of these drugs are available on prescription only.

Tablets are often used as a first treatment for erectile dysfunction after prostate cancer. However, it is quite common for them not to work on their own. Many men go on to use another treatment with more success.

### **Urethral pellets**

A urethral pellet can be put into the opening or 'eye' of your penis. Then the pellet is massaged into the penis to help it melt. Standing or walking around can help your erection develop better.

You should get an erection within 5 to 15 minutes. Some men get some pain, redness or a burning sensation in the penis or testicles after using the pellets.

# Penile injections

The idea of injections is that they cause the penis to fill with blood. You should get an erection within about 15 minutes. The erection lasts from 30 minutes to 2 hours. The first dose is given by your doctor in the hospital so that they can see how well you respond and decide the best dose for you. Then you or your partner will be taught how to give the injection at home. The injection does not hurt, as the needle is very fine. You should not inject more than 2 or 3 times a week.

### Vacuum pump

A plastic tube is placed over the penis and a pump is used to create a vacuum. This causes blood to flow into your penis, creating an erection. A rubber ring is then put around the base of your penis to hold the blood in the penis and keep the erection for up to 30 minutes. Some men prefer the pump because it avoids the use of drugs. Also, the cost of the pump is a once-off payment. Although most men find the vacuum pump effective, some find it awkward to use. It can take practice to get the technique right for you. You can use the pump as often as you like. It can also be used together with tablets or injections.

You may be advised to use to pump to encourage blood flow to your penis after surgery or radiation treatments, even if you are not ready to have sex. There is more information on using a vacuum pump on our website, **www.cancer.ie** 

# Penile implants (surgery)

Penile implants can be an option for men who have had erectile dysfunction for at least a year and have tried all other methods. The implant consists of a pair of tubes attached to a reservoir and a pump. This is placed inside your body during an operation. By pressing on the pump, the fluid in the reservoir moves into the tubes to form an erection or rigid penis. Most men and their partners are very satisfied with these devices. Possible side-effects include infection and pain. Rarely, the device stops working properly.

# Hínts & Típs – getting the best from your treatment

- Don't expect too much the first few times you use a treatment. This pressure can make it difficult for you to relax.
- Talk to your partner. A sense of working together and helping each other can ease tensions.
- Don't give up hope. It can take time to find the right treatment for you.
- Don't be afraid to go back to your doctor to say that a treatment has not worked for you.
- Call our Support Line or visit a Daffodil Centre to speak to a cancer nurse in confidence. Or email the nurses at supportline@irishcancer.ie

# **Feelings and emotions**

Cancer can affect how you feel about sex and your relationships. There is no right or wrong way to feel.

Coming to terms with the fact that you have cancer can take quite a while. It can be hard to relax when you have a lot of worries on your mind. Worrying about whether or not you can get an erection can make you avoid sex or feel less interested in it. Weight gain, tiredness and anxiety can also affect your interest in sex.



If your treatment causes erectile dysfunction, urinary problems or a loss of sex drive, it can have an effect on your sense of yourself as a man, your self-esteem and your ability to feel confident in expressing and talking about the sexual aspects of your relationship with your partner.

Talking about your feelings may ease any worries you have. Try to tell your partner how you feel and find out how your partner feels too.

This can help to make sure neither of you feels rejected by the change in your physical relationship. Even if you do not feel like having sex for a time or you're having sexual problems, cuddling and kissing, touching and holding each other can help you to stay close and keep the intimacy in your relationship.

If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. They may refer you for specialist relationship 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. This isn't true.

# Where to get more information and support

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.

Your medical team can also help you if you are feeling angry, frustrated or low and finding it hard to cope because of any changes to your sex life. Getting support or advice can help to stop these feelings building up too much. Your GP can also support you, or you may find counselling useful. See page 112 for more about counselling and page 111 for more about managing your feelings.

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 and find out about support services. Or email the nurses at supportline@irishcancer.ie

# Contraception

Some chemotherapy and other cancer drugs may harm a developing baby, so it's important to avoid pregnancy during and for a time after treatment.

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

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

# Will treatment affect my fertility?

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

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

It's very important to talk to your doctor if you're thinking of using complementary therapies. 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** 



# Support Line Freephone 1800 200 700

# After treatment

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# What follow-up will I need?

After your cancer treatment has ended you will still need regular check-ups. This is called follow-up. The follow-up will involve PSA tests (see page 18) and maybe a digital rectal exam (DRE). At first you will see your consultant every 3 months but these check-ups will become less frequent over time.

You may have follow-up appointments to check your PSA for many years. Some men have PSA tests at the hospital or you may have them at your local GP surgery.

# What is PSA bounce?

If treatment has been successful you would expect the PSA level to drop. Sometimes your PSA may rise again after radiation treatment, as some prostate cells may still produce PSA. Sometimes the PSA level may rise and then fall again 1 to 2 years after treatment. This is called a PSA bounce. It is not necessarily a sign that the cancer has come back. The PSA should drop to its lowest level after 18 months to 2 years after radiotherapy. This is often called the PSA nadir.



# Getting the most from your appointment

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, so you don't forget what you wanted to say.

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

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

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

# What if the cancer comes back?

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

# 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 and in our booklet *Life after Cancer*. Download the booklet from the website or get a free copy by calling our Support Line or visiting a Daffodil Centre. You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 113 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
- Reduce your risk of cancer

A healthy lifestyle includes:

- Exercising
- Eating well
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun
- Getting any vaccines recommended for you. For example, flu and pneumonia. Some vaccinations may not be suitable if you've had cancer treatment, so check with your doctor which you should have and make sure you get them.

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



# Coping and emotions

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# 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 134 for more about cancer support services.

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

Ask about psycho-oncology services at the hospital: 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.

# **Survivor Support**

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

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# **Positive feelings**

In time, some people say they can find positive things in happy and content ... their cancer experience. even though I have to They say that cancer live with this." 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.

Support Line Freephone 1800 200 700

# You and your family

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

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre.

# **People treating you differently**

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

# Talking to children and teenagers

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

### How to tell your children

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

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



# Advice for carers

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# 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 112.

### Find out about support for carers

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

# How to talk to someone with cancer



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

If you want advice on how to support a friend or loved one with cancer, call our Support Line on 1800 200 700. Ask for a copy of our booklet *Caring for Someone with Cancer*, which has advice on talking to someone who is ill. It 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 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



Email: supportline@irishcancer.ie



# Support resources

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# Money matters

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

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

### **Medical expenses**

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP) Medicines
- Visits to hospital

• Overnight stays in hospital

• 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 (DSP) – 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 131 for more details of our Volunteer Driver Service and the Travel2Care fund.

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



# **More information**

Go to **www.cancer.ie** and see our **money advice** page for information on:

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

Our Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.

# Irish Cancer Society services

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

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

### Support Line Freephone 1800 200 700

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

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



# **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
  End-of-life services
- Chemotherapy group education sessions
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- You can email daffodilcentreinfo@irishcancer.ie or visit **www.cancer.ie** to find your local Daffodil Centre.

- Lifestyle and cancer
  - prevention
  - Local cancer support groups and centres

# **Survivor Support**



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

# Support in your area

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

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

# Patient travel and financial support services



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

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

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

# Irish Cancer Society Night Nursing



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

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

# Publications and website information



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

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

# Local cancer support services

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

• **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free one-to-one counselling through 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 and reflexology
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- · Mind and body sessions, for example, yoga and tai chi
- Expressive therapies such as creative writing and art
- Free Irish Cancer Society publications and other high-quality, trustworthy information on a range of topics



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

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at www.cancer.ie/cancer-information-and-support/cancersupport/find-support

# What does that word mean?

Benign Not cancer. A tumour that does not spread.

**Biopsy** Removing a small amount of tissue from your body to find out if cancer cells are present.

**Brachytherapy** A type of internal radiotherapy. Solid radioactive seeds are placed inside your body on or near your tumour.

**Catheter** A long thin flexible tube that is passed into your bladder. It drains urine into a bag.

**Enema** A fluid solution inserted in through your back passage which causes you to clear your bowels.

**Erectile dysfunction** When you cannot get or keep an erection.

Fatigue Ongoing tiredness often not helped by rest.

**Fiducials** Small gold objects that are implanted in your prostate to mark where the radiation will be aimed during each treatment.

**Grading** Checking how normal or abnormal the prostate cells look under a microscope.

**Incontinence (urinary)** When you cannot control the leakage of urine from your body.

**Metastasis** When cancer spreads from one part of your body to another.

Prognosis The expected outcome of a disease.

**Prostate specific antigen (PSA)** This is a protein made by your prostate gland. It can be measured in your bloodstream.

**Radical prostatectomy** An operation that removes your entire prostate gland and seminal vesicles.

Rectum The lower part of your bowel. Also called your back passage.

**Staging** Tests that measure the size and extent of cancer.

# Questions to ask your doctor

Here is a list of questions that you may wish to ask. Never be shy about asking questions. It is always better to ask than to worry. What tests do I need?

How long will I have to wait before the tests?

Do I need treatment straight away? If not, how will you know when I should have treatment?

If I need treatment, what are my treatment choices?

How successful is this treatment for my cancer?

If my treatment is not successful, can I still have other treatments?

Do some treatments have more side-effects than others?

Will I need hormone therapy and radiotherapy? If yes, for how long?

Are the side-effects of treatment short or long term?

Will I have problems with urinary incontinence after my treatment?

Will treatment affect my fertility? Will I develop erectile dysfunction?

Why is follow-up so important? Why do I need regular blood tests?

# 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. We especially thank the people who generously shared their personal experiences of cancer throughout this booklet. We also acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet

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# Join the Irish Cancer Society team

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

# Support people affected by cancer

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

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our 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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