

Understanding

Early Prostate Cancer

Caring for people with cancer

Understanding

Early Prostate Cancer

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

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



Specialist nurse	Tel:
Family doctor (GP)	Tel:
Surgeon/Urologist	Tel:
Surgeon	Tel:
Radiation oncologist	Tel:
Radiation therapist	Tel:
Medical social worker	Tel:
Emergency number	Tel:
Treatments	Review dates



If you like, you can also add:

Your name _____

Address _____

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

PROSTATE CANCER ADVISERS

Mr David Galvin, Consultant Urologist
 Prof John Armstrong, Consultant Radiation Oncologist
 Helen Forristal, Clinical Nurse Specialist in Urology
 Ger O'Boyle, Clinical Nurse Manager, Radiotherapy

CONTRIBUTOR

Karen Flynn, Cancer Information Service Nurse

EDITORS

Antoinette Walker and Tara Droog

SERIES EDITOR

Joan Kelly, Nursing Services Manager

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

- *Cancer in Ireland 2013*. National Cancer Registry Ireland, 2013.
- *Recent Trends in Prostate Cancer*, National Cancer Registry Ireland, May 2010.
- *Surgical Outcomes Following Open, Laparoscopic or Robotic Prostatectomy*. European Society of Oncological Urology, 2011.
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First published by the Irish Cancer Society in 2012.

© Irish Cancer Society 2012, revised 2013

Next revision: 2015

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ISBN 0-95323-690-1

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Introduction

This booklet has been written to help you understand more about early prostate cancer. It is aimed at men diagnosed with early stage prostate cancer. By reading it, you can learn what it means and about its diagnosis and treatment. If your prostate cancer is diagnosed at a later stage, call the National Cancer Helpline on 1800 200 700 for a copy of the booklet *Understanding Prostate Cancer beyond the Prostate Gland*.

We hope this booklet answers some of your questions and encourages you to discuss them with your doctors and nurses too. We cannot advise you about which treatment to choose. You can only make this decision along with your doctors when all your test results are ready. But we can tell you about ways to treat this cancer and side-effects that may happen after treatment is given.

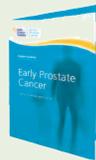
The booklet also discusses some of the feelings you and those close to you may have when a diagnosis of cancer is made. At the end of the booklet you will find a list of books that are useful to read. There is also a list of websites and special groups to help and support you at this time.



Reading this booklet

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

If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the freefone National Cancer Helpline on 1800 200 700. It is open Monday to Thursday 9am–7pm and Friday 9am–5pm. You can also visit a Daffodil Centre if one is located in your hospital. See page 76 for more about Daffodil Centres.



National Cancer Helpline Freefone 1800 200 700

My experience of prostate cancer

When I heard the words you have cancer, I was shocked and dismayed. I thought I was healthy and that there must be a mistake here. I could hear the consultant talking about options but I did not fully comprehend anything he said. I contacted the Irish Cancer Society and read the booklet available from the Society.

After much deliberation, I decided prostatectomy was the correct choice for me. Please read this booklet and weigh up the options. Do not let anyone influence you unduly. Whatever decision you make will be the correct one for you.

Stephen AGED 60

When I was diagnosed, it was hard to know what to do. I wrote to my GP for an appointment to discuss the options. He met me, and my wife, and gave us plenty of time. He went through the options in detail. It was a great help. When I was diagnosed, it was, strangely, a relief to find something. Then I knew what I was dealing with.

John AGED 55

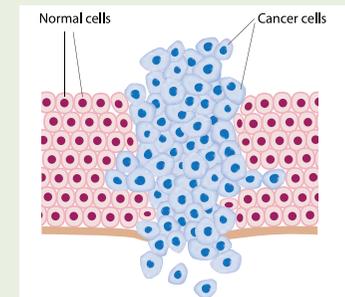


About early prostate cancer

>>> What is cancer?

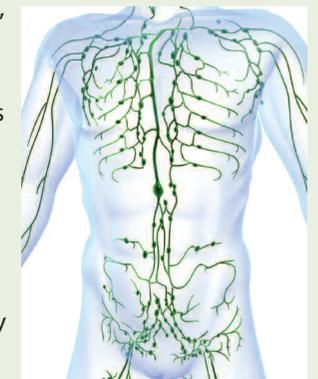
Cancer is a word used to describe a group of diseases, not just one. There are more than 200 different types of cancer. Each is named after the organ or type of cell in which the cancer starts growing. For example, prostate cancer, breast cancer and leukaemia. All cancers are a disease of the body's cells, which are the building blocks of your body. Normally, cells grow and divide in a controlled way and replace old cells to keep your body healthy. But with cancer, the abnormal cells grow without control. Groups of abnormal cells can form a growth or tumour.

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



What are lymph vessels?

Lymph vessels are part of your lymphatic system, which helps your body defend itself against infection. Like your bloodstream, it carries waste material around your body from your tissues. It is made up a network of tiny tubes that pass through most of the tissues in your body. These tubes carry lymph, a clear watery fluid that is leaked into your tissues and returned to your body. Along the network are hundreds of small glands and nodes which remove the lymph. They are mainly found in your neck, armpit and groin. Lymph nodes can trap cancer and as a result grow bigger and hard.



Lymphatic system



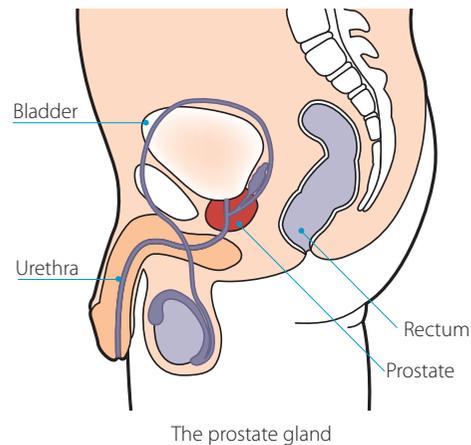
To sum up

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

What is the prostate?

The prostate is a gland found only in men. About the size of a walnut, it lies below your bladder just in front of your rectum (back passage). Running through your prostate is a tube that carries urine through your penis. This tube is known as your urethra or water pipe. It is the reason why some men have trouble passing urine when they have an enlarged prostate gland.

The prostate makes a thick white fluid that mixes with sperm. This fluid is known as semen. It also makes a protein called prostate specific antigen (PSA), which turns the semen into liquid. Prostate cells depend on the male sex hormone, testosterone, to grow. This hormone is made in your testicles. Small groups of lymph nodes are also found near your prostate gland.



What is early prostate cancer?

Prostate cancer occurs when the cells of your prostate gland grow in an abnormal way. Early prostate cancer is also called localised prostate cancer. This means the cancer is found within the prostate only. It has not spread outside your prostate gland. The tumour may be too small to be felt during an exam of your back passage and your doctor may only suspect it after doing a PSA test. Often men with early prostate cancer do not have any symptoms at all.

What causes prostate cancer?

The exact cause of prostate cancer is unknown. Research continues to study possible causes. But there are certain things called risk factors that can increase your chance of getting the disease. These include:

- **Age:** The risk of prostate cancer increases with age. It is rare in men under the age of 50.
- **Family history:** If you have a brother or father with the disease, your risk is higher. The risk is also higher if your relative developed prostate cancer at a younger age or if you have more than one relative with the disease.
- **Race:** Afro-Caribbean men are at a higher risk of developing prostate cancer.

Remember prostate cancer is not infectious and cannot be passed on to other people.

How common is prostate cancer?

In 2010, there were just over 3000 new cases of prostate cancer diagnosed in Ireland. Small areas of cancer cells within the prostate gland are common, especially in older men. Sometimes these cancer cells do not grow very quickly and do not cause any problems or symptoms.

What are the symptoms of prostate cancer?

As you get older your prostate gland can get bigger. This is often due to a condition other than cancer. It is known as benign enlargement of the prostate or benign prostatic hypertrophy (BPH). Some men with prostate cancer may have similar symptoms too. The symptoms may include the following:

- Trouble starting or stopping the flow of urine
- Passing urine more often, especially at night
- Feeling you have not fully emptied your bladder after passing urine
- Pain or difficulty when passing urine

If you have any of the above symptoms, do get them checked out by your doctor. But remember that often symptoms are not due to cancer and they can be treated. Because prostate cancer often grows slowly, symptoms may not occur for many years. It is very common for a man with early prostate cancer to have no symptoms at all.



To sum up

- Prostate cancer is common, especially in older men.
- Early prostate cancer is cancer that is found within your prostate gland and has not spread elsewhere in your body.
- The cause of prostate cancer is unknown in most cases.
- Many men with early prostate cancer have no symptoms.
- The symptoms of prostate cancer include trouble starting or stopping the flow of urine, passing urine more often, feeling you have not emptied your bladder after passing urine, and pain or difficulty when passing urine.

Can I be screened for prostate cancer?

Testing for prostate cancer when you have no symptoms is called screening. There is no national cancer screening programme for prostate cancer in Ireland at present, nor anywhere in the world. If you wish to have a test to understand your risk of prostate cancer,

talk to your GP. You can also find out more about PSA and tests for prostate cancer in our booklet, *Understanding the PSA Test*.

If you have a family history of prostate cancer, especially a family member who was diagnosed with prostate cancer in his 60s or earlier, do talk to your GP about a PSA test for prostate cancer when you reach 40 years of age.

If you do not have a family history of prostate cancer, are aged 50 or over, and are concerned about prostate cancer, do talk to your GP about the advantages and disadvantages of a PSA test.

How is prostate cancer diagnosed?

Visit your GP first if you have any symptoms or worries. If your GP has concerns about you, he or she will refer you to a rapid access prostate cancer clinic. Most early prostate cancers are diagnosed through rapid access clinics. These clinics are found throughout Ireland in hospitals that are specialised cancer centres. There you will be seen by a urologist and specialist nurse. By attending the clinic, you can avoid waiting for outpatient clinics and any tests you might need are speeded up.

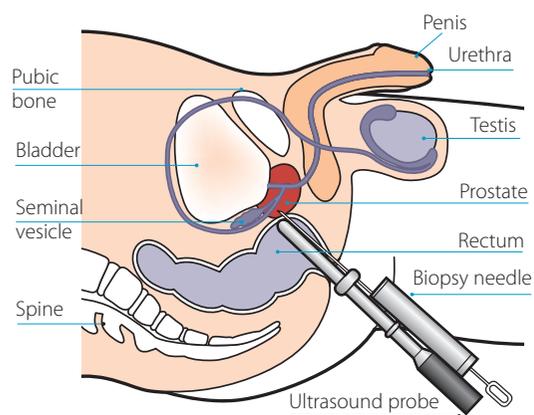
The following tests can usually diagnose prostate cancer:

- PSA blood test
- Digital rectal exam (DRE)
- Transrectal ultrasound (TRUS) and biopsy of prostate
- Template biopsy

PSA blood test: Prostate specific antigen (PSA) is a protein that can rise due to disease in your prostate. PSA can be high in conditions other than cancer too. Remember that not every prostate cancer will cause a rise in the level of PSA. If your PSA is high, your GP will usually repeat the blood test a few weeks later. If it is still high, you will be referred to a urology department, often through a rapid access prostate cancer clinic.

Digital rectal exam: The digital rectal exam (DRE) is where your doctor feels your prostate gland through your back passage (rectum) using a gloved finger. He or she can check if your prostate has enlarged or has abnormal tissue, such as hard or lumpy areas.

Transrectal ultrasound (TRUS) and biopsy: A sample of your prostate tissue can be taken and examined under a microscope. This is called a biopsy. It is the only way to make sure the diagnosis of prostate cancer is correct. The biopsy is taken at the hospital during a test called a transrectal ultrasound. For this test, you will be asked to lie on your side and an ultrasound tube called a probe placed in your back passage. A local anaesthetic will be put onto the area around your prostate gland. The ultrasound builds up a picture of the tissues inside your prostate gland. Using this picture, your doctor can take samples from your prostate gland with a needle. Usually up to 12 samples are taken. These will be looked at under a microscope by a doctor in the laboratory. The test is uncomfortable but only lasts 10–15 minutes.



Transrectal ultrasound biopsy

After a prostate biopsy there is a risk of infection. To help prevent an infection your doctor will give you antibiotics beforehand. These will continue for a day or so after the biopsy. After the test you may notice a small amount of blood in your urine or some bleeding from your rectum. You may

get blood in your semen for up to a month afterwards. These are all very common side-effects. Most go away after a few days. But let your doctor or nurse know if they persist or if you get a high temperature or pain in your back passage. He or she will advise you what to do.

Once prostate cancer is diagnosed by biopsy, your doctors need to know the stage and grade of the cancer so they can choose the best treatment for you.

Template biopsy: A template biopsy takes more samples than a TRUS biopsy and is done through the skin between your testicles and back

passage. It may be done when a TRUS biopsy has not shown any prostate cancer and your doctor feels there is a need for further tests.

Prostate biopsy and infection risk

After a prostate biopsy there is a risk of infection. Follow the instructions of your doctor or nurse carefully and remember:

- Take your antibiotics exactly as instructed.
- If you feel unwell or have a high temperature in the days after a prostate biopsy, go to the emergency department of your local hospital. Tell the staff that you have had a prostate biopsy as you may need antibiotics into your vein.

Waiting for results

It usually takes some time for all your 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 the National Cancer Helpline on 1800 200 700 and speak to one of our specially trained nurses or visit a Daffodil Centre.

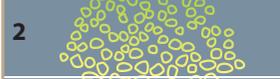
What are the grades of prostate cancer?

After your biopsy a doctor called a pathologist will look at the samples under a microscope.

Grading refers to how the cancer cells look under the microscope.

It describes how normal or abnormal the cells are. The patterns of abnormal cancer cells that are seen are given a grade by the pathologist.

This is known as the Gleason score or grade.

1		Nearly normal cells
2		Some abnormal cells loosely packed
3		Many abnormal cells
4		Very few normal cells left
5		Completely abnormal cells

Gleason score

The grade helps your doctor to predict how quickly the cancer may grow and behave.

In prostate cancer the scores are usually 3, 4 or 5. Lower grades are more slow growing and the higher grades are fast growing or the least-normal looking. Because prostate cancer cells can vary a lot in how they look, your doctor cannot rely on just one sample. Your doctor takes the two most common scores of prostate cancer in each sample and adds them together to give an overall score. This means the Gleason scale is usually from 6 to 10.

Risk	Gleason score
Low	6 or lower
Medium or intermediate	7
High	8 or higher

The table on the left shows the risk of prostate cancer spreading based on the Gleason score. Remember the risk depends on other factors too. For example, if your prostate gland feels normal or not and possibly your PSA level. Your doctor will use all of this information to decide on the best

treatment for you. Do ask your doctor to explain the table if you are unsure about the information.

What are the stages of prostate cancer?

Staging means finding out the size of the tumour and if it has spread to other parts of your body. Tests are used to stage the cancer. Staging allows your doctor to decide the best treatment for you. Knowing the stage also helps your doctor to predict your chance of recovery (prognosis). Staging may not be complete until all the tests are done.

Whether you need any staging tests or not depends on the results of your PSA, Gleason score and how your prostate gland feels to touch. Some men will need no staging tests while others will need one or more. Your doctor will let you know which ones you need to have.

Tests for staging

The following tests may be done to stage prostate cancer:

- MRI scan
- CT scan
- Bone scan

MRI scan: This special scan uses magnetic energy to build up a picture of the tissues inside your body. The scan does not hurt but can be very noisy, so you may be given earplugs to wear during it. During the scan you cannot wear metal jewellery. If you have any medical device implanted, like a pacemaker or pin, you must tell the staff in the X-ray department before your scan. The scan usually takes between 30–40 minutes. You can speak to the staff through an intercom and can listen to music during the scan.



MRI scan

CT scan: This is a special type of X-ray that builds up a detailed picture of the tissues inside your body. It is quick and does not hurt. You may have to fast for 4 hours beforehand. You may also be given a special drink or injection that helps to show up parts of your body on the scan. Before you take the drink or injection, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparation for a CT scan can vary between hospitals. Your doctor or nurse will advise you.

Bone scans: Prostate cancer can sometimes spread to your bones. Bone scans can find cancer spots before they show up on an ordinary X-ray. For this test, a tiny amount of a radioactive liquid is put into one of your veins, usually in your arm. After the injection, you must wait for up to 3 hours. A scan is then taken of all the bones in your body. Abnormal bone takes up more radioactive liquid than normal bone. These areas will show up on the scan and are known as 'hot spots'. It can also show bone changes like arthritis.

Bring a book or magazine to help you pass the time while waiting for the scan. Or you may prefer to bring a friend for company. Don't worry about the amount of radioactivity used in these scans as they are very safe. It disappears from your 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 or sitting on your lap).

Describing the stages

There are different ways to describe different types of cancer. The staging system normally used in prostate cancer is called TNM. This stands for tumour, node, metastasis.

T refers to the size and depth of 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, very close to nearby tissues.
- T4** The tumour has spread to tissues outside your prostate gland.

N refers to cancer present in your lymph nodes or not. **N0** means there are no lymph nodes affected. **M** refers to cancer that has spread (metastasis) or not. **M0** means the cancer has not spread.

TNM for early stage prostate cancer: T stage 1 or 2 N stage 0 M stage 0

The TNM system can be hard to understand, so do ask your doctor and nurse for more information if you wish.

If you would like information about prostate cancer at later stages, call the National Cancer Helpline 1800 200 700 for a copy of the booklet, *Understanding Prostate Cancer beyond the Prostate Gland* or visit a Daffodil Centre.



To sum up

- The following tests are used to diagnose prostate cancer: PSA blood test, rectal exam, transrectal ultrasound, biopsy of prostate and template biopsy.
- Grading refers to how the cancer cells look under the microscope.
- The patterns of abnormal cancer cells are given a grade or score known as the Gleason score.
- Staging means finding out the size of the tumour and if it has spread to other parts of your body.
- The following tests can stage prostate cancer: feeling your prostate gland, MRI scan, CT scan and bone scan.

Treatment and side-effects

How is early prostate cancer treated?

Early prostate cancer can be treated in a number of ways. Both you and your doctor together will decide which treatment suits you best. It is common for you to be asked to make a decision about which treatment suits you best. In making your decision, your doctor and nurse will support and advise you.

The following treatment options are available:

- Active surveillance
- Brachytherapy
- External beam radiotherapy
- Surgery
- Watchful waiting

Sometimes you may have fewer treatment choices than those listed. Many things can affect which treatment options are suitable for you. These include:

- The stage and grade of your cancer
- Your PSA level
- The size of your prostate gland
- If you have urinary symptoms or not
- Your general health

Your doctor will discuss your treatment options with you. If your prostate cancer is diagnosed at a later stage, call the National Cancer Helpline on 1800 200 700 for a copy of *Understanding Prostate Cancer beyond the Prostate Gland*. Or visit a Daffodil Centre.

Types of treatment

Active surveillance: This is a treatment option for low-risk prostate cancer, which can be very slow growing and often does not cause symptoms or cause problems. Active surveillance aims to avoid or delay treatment if your cancer is likely to be slow to change and unlikely to threaten your health. It allows you to avoid the side-effects

of treatment. It also aims to find cancers that change and start to behave more like fast-growing ones, and to offer treatment before the cancer spreads. During active surveillance you will be checked (monitored) with repeat blood tests and biopsies. If there is any sign of activity in your cancer, you will be offered treatment to cure the cancer. Active surveillance can carry on for many years if your cancer shows no signs of changing. See page 25 for more details.

Radiotherapy: Radiotherapy is a treatment that uses X-rays to kill cancer cells. It can be given externally or internally. When given internally, it is called brachytherapy. When given externally, it is called external beam radiotherapy.

Brachytherapy: In this form of internal radiotherapy, radioactive seeds are placed in your prostate gland. They release radiation slowly over the following months. The seeds are very small, about the size of a grain of rice. The number of seeds implanted depends on the shape and size of your prostate gland. Not all men are suitable for brachytherapy. See page 28 for more details.

External beam radiotherapy: This uses high-energy X-ray beams to destroy the cancer cells. Radiotherapy can also be used together with hormone therapy, if needed. It is suitable for most men, although it may not be the best option if you have urinary symptoms. See page 35 for more details.

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 42 for more details.

Watchful waiting: Prostate cancer often grows slowly and does not cause symptoms. For some men with early prostate cancer who have other health issues this may be a reasonable option. Watchful waiting is different from active surveillance. It involves PSA testing but no repeat biopsies. Also, it may suit you if your prostate cancer changed but you were not suitable for either surgery or radiotherapy.

Deciding on treatment

At this time you may be anxious about what is going to happen next. Do not be afraid to ask your doctor or nurse. They will discuss your treatment options with you. Many men find making a decision about which treatment they should have difficult. Do remember that your doctor will tell you if one treatment is better than another at getting rid of your cancer. But often they cannot because the treatment options are all thought to be equally good at treating early prostate cancer.

Very often there is no rush to make up your mind about which treatment to have. It is good to take time to talk to a urologist and a radiation oncologist before you make up your mind. Taking time to talk things through with doctors and nurses, family and friends can help you to reach the right decision for you. You will need to think about what the treatment involves for you, the impact on work or daily activities, and which side-effects you feel you can live with.

Asking questions: Do ask your doctor and nurse as many questions as you like, no matter how small or trivial you think they are. All questions are important. If you forget to ask a question or would like more explanations, call the National Cancer Helpline on 1800 200 700 and talk to one of our specialist nurses or visit a Daffodil Centre.





Why am I being asked to make a decision?

Very often there are several different treatments for early stage prostate cancer. These are all as good as each other at treating the cancer. This means that your doctor cannot guide you to the best treatments because there is not a right or wrong treatment. It is up to you to decide which treatment suits you and your lifestyle the best.



How do I make my decision?

The best way to make a decision is to weigh up the pros and cons of each treatment first. Then talk the decision through with your doctors, nurses and family. Things to think about are:

- 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?
- How far will I have to travel to the hospital for treatment?
- How long will I need to take off work?

It can help to talk to someone who has been in a similar situation. Survivors Supporting Survivors is a one-to-one support programme run by the Irish Cancer Society. You may find it useful to speak with a prostate cancer survivor if you are finding it hard to make a decision. See page 76 for more details. See also the decision aid tool on page 23.

Other opinions: You might find it reassuring to have another medical opinion to help you decide about your treatment. Do not worry that you are offending your doctor by doing this. He or she will gladly refer you to another specialist for their opinion if you feel this would be helpful. If you are suitable for brachytherapy or external beam radiotherapy in particular, it may help to talk to a radiation oncologist before making a decision.

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

Remember...

Ask yourself **Which treatment is best for me?** and not which treatment is best for treating my cancer. Your doctor will answer that question when he or she can. But often there is not one treatment that is better than the others. For some stages of early prostate cancer all treatments are equally good at treating your cancer.

Giving consent for treatment

You may be asked to sign a consent form saying that you give permission for the treatment to take place. No medical treatment can be given without your consent. Before treatment, you should know:

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

Some treatments can be hard to understand and may need to be explained more than once. You can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.



Research – what is a clinical trial?



Research into new ways of treating prostate cancer goes on all the time. By using new drugs or new combinations of drugs and treatments that are already in use, doctors can find new and better ways of treating cancer. Before a drug or treatment is used on patients, it goes through many stages to make sure if it is safe to use. For a factsheet on clinical trials, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre or our website www.cancer.ie

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	
Surgery	
Watchful waiting	

Decision aid tool

To help you make a decision about your prostate cancer treatment, fill in this chart together with your nurse or doctor. 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?

Some of the following health professionals may be involved in your care. Usually a team of cancer care doctors and nurses will help you to decide your treatment.



Surgeon/Urologist	A doctor who specialises in surgery to the prostate, kidneys and bladder.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Liaison oncology nurse or clinical nurse specialist	A specially trained nurse who works with men with prostate cancer. She or he gives information and reassurance to you and your family from diagnosis and throughout treatment.
Radiation therapist	A radiotherapist who specialises in giving radiotherapy and advice to cancer patients.
Physiotherapist	A therapist who treats injury or illness. You may be taught pelvic floor exercises by a physiotherapist if you have surgery for prostate cancer.
Medical social worker	A person specially trained to help you and your family with all your social issues and practical needs. They are skilled at giving emotional support. They can also give advice on benefits, entitlements and services available to you when you go home.
Counsellor	A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness. The Irish Cancer Society provides a counselling service. For details, call the National Cancer Helpline on 1800 200 700.

National Cancer Helpline Freefone 1800 200 700



To sum up

- The treatment of early prostate cancer can include active surveillance, external beam radiotherapy, brachytherapy, surgery, or watchful waiting.
- A team of specialists will help you decide which treatment is best for you.
- You may not be suitable for all treatments. Your doctor will explain which ones will suit you or not.

Active surveillance

Active surveillance is a way to avoid or delay unnecessary treatment if your cancer is slow growing. Prostate cancer may not grow or change for many years. It may not cause any symptoms or threaten you in any way. In other words, you may not need treatment for your prostate cancer ever, or you can defer your treatment for a number of years. For prostate cancer found at an early stage, which is of low risk, active surveillance can avoid or delay treatment without risk to your health. 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.

Who can have active surveillance?

If you have prostate cancer that is seen as low risk, you are suitable for active surveillance. See the chart on page 14 for more information on the type of risk. If you have a medium-risk prostate cancer, you may be suitable too. It will also depend on your age and your general health. If you have high-risk cancer, in general you are not suitable for active surveillance. Your doctor will discuss this with you in more detail.

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
- Digital rectal exams repeated every 3 to 6 months at the start and then perhaps less often after the first 2 years
- Prostate biopsies repeated usually after 1 year and then every couple of years

Because no physical treatment is involved, there are no physical side-effects. So the surveillance does not interfere with your everyday activities.

During the surveillance, you may become anxious or worry about your cancer changing. If this is how you feel, then active surveillance may not be the best choice for you. You can always decide to have treatment at a later stage if this happens to you and you feel active surveillance is no longer for you.

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. If your PSA rises a lot, your doctor will discuss if you need to have treatment or not.
- **Biopsy results:** If your repeat biopsy shows a change in the amount or the grade of cancer, you may be offered treatment. For example, if some cancer with a higher Gleason score is seen.
- **Digital rectal exam:** If your doctor feels any changes during a physical exam, he or she will discuss with you if you need treatment or more tests.

Is active surveillance risky?

There is a chance that your cancer will grow while you are on surveillance. But your tests will help to pick up any changes at an early stage when you can still have treatment. Even though the tests can pick up changes, there is also 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. This is why the biopsy is repeated.

A more fast-growing prostate cancer benefits from earlier treatment. Do discuss all the advantages and disadvantages of active surveillance before you decide on this option.

Advantages of active surveillance	Disadvantages of active surveillance
No physical side-effects	You may become anxious or worried about your cancer changing
Does not interfere with your everyday life	Repeat prostate biopsies are needed
	The cancer may grow more quickly than expected

If you are not happy with this option, you can change your mind and ask to have treatment at any time.



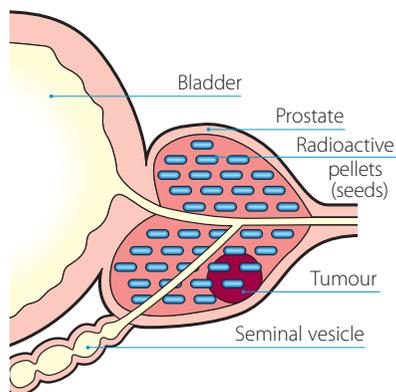
To sum up

- Active surveillance is a way to avoid or delay unnecessary treatment if your cancer is not so fast growing, without any risk to your health.
- You may not need treatment for your prostate cancer ever, or you can defer your treatment for a number of years.
- If your cancer is low risk or perhaps medium risk, you may be suitable for active surveillance.
- Active surveillance involves regular tests to check your cancer. These include PSA blood tests, digital rectal exams, and repeat prostate biopsies.
- The advantages of active surveillance are that there are no physical side-effects and it does not interfere with your everyday life.
- The disadvantages of active surveillance is that you may become anxious or worried about your cancer changing, you need repeat prostate biopsies, and the cancer may grow more quickly than expected.

Brachytherapy

Internal radiotherapy can be used to treat early prostate cancer. When radiotherapy is given internally, it is called brachytherapy. Research shows that brachytherapy is just as good as surgery or external beam radiotherapy at treating certain prostate cancers. The doctor who specialises in giving radiotherapy is called a radiation oncologist.

Brachytherapy is a way of giving radiation directly into your prostate gland. The radiation destroys your prostate cancer. The treatment is usually used on its own. But if there is a higher chance of the cancer spreading, it can be used together with external beam radiotherapy and hormone therapy. In brachytherapy, the radiation comes from small radioactive seeds put into your prostate. The radiation is released slowly over a number of months. The seeds are not removed but the radiation fades away over time. It is a safe therapy with no risk to other people. The aim of brachytherapy is to fully get rid of your prostate cancer.



Radioactive seeds implanted



Size of the seeds

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 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 a resection of your prostate gland. Your doctor 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 will receive brachytherapy along with another treatment. For example, you may need some doses of external beam radiotherapy or hormone therapy as well.

What happens before treatment can be given?

An ultrasound scan of your prostate is done first. This can happen some weeks or days before the seeds are put in or on the same day. The scan lasts about 15 minutes. It uses ultrasound waves to find out the exact size and shape of your prostate gland so your doctor can work out how many seeds need to be put in.

An ultrasound can take pictures of your prostate. This is done through your back passage (transrectal). These pictures will show the number of seeds needed for treatment and where they should be placed. Your nurse will let you know if your bowels need to be empty for the test.

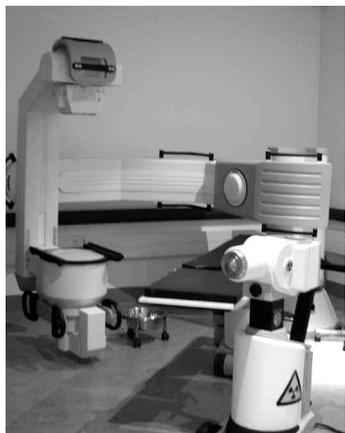
How are the seeds put in?

The day before the seeds are put in (implanted), you may be asked to follow a special diet and have an enema to clear your bowels. The hospital staff will explain this to you beforehand. You will be given advice on any medication to avoid beforehand as well.

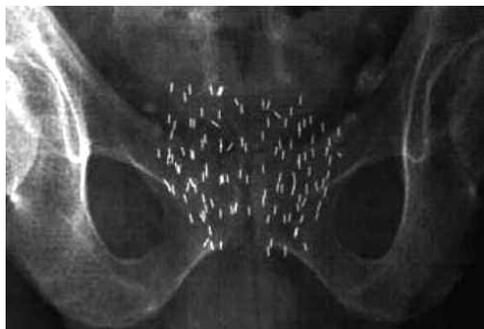
You will be taken to an operating theatre to have the seeds put in under general anaesthetic. It takes about 90 minutes to put in all the seeds. An ultrasound probe is first put in your back passage to show up your prostate. Then around 60 to 120 radioactive seeds are put in through the skin between your prostate and anus. They are then guided into your prostate gland. Some swelling of your prostate may develop, so a tube (catheter) is put into your bladder to drain any urine. It may be left in for a couple of hours or overnight.

What happens when the seeds are put in?

You will be given antibiotics to prevent an infection afterwards. Most likely you can go home the day of the implant once you have recovered from the anaesthetic and can pass urine normally.



A brachytherapy unit



X-ray showing implanted seeds

>>> Hints & Tips – after the seeds are put in

- 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.

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. When the seeds are no longer active they can stay in your prostate without doing any harm. The exact amount of time it takes for the radiation to be released will depend on the type of radioactive substance used. For this reason it is important to follow the guidelines given to you by your hospital.

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 close physical contact (less than arm's length) with small children or pregnant women for the first 2 months after treatment. This means not allowing children to sit on your lap for more than a few minutes each day.

You should also avoid sitting close to a pregnant woman for more than 30 minutes. Your doctor or nurse will give you more detailed information about this beforehand.

>>> Each hospital will do things slightly differently. For this reason it is important to follow the instructions of your doctor and nurse.

If you need to go into hospital and have an operation for another reason during the first year after treatment, speak to your brachytherapy unit about the risk of exposure from radiation.

How long do the seeds remain?

The seeds remain permanently in your prostate gland. There is a slight chance that one seed could be passed out in your semen or urine, although this is rare.

What about sex after brachytherapy?

It is safe for you and your partner to sleep in the same bed. Do talk to your doctor or nurse about when you can resume sex after brachytherapy. They can give you an advice sheet about this.

>>> Hints & Tips – brachytherapy

- Wait 2 weeks after treatment before having sex.
- Use a condom during sex in case a seed becomes dislodged during ejaculation. Your medical team will advise you on the length of time you should use a condom for.
- Don't worry if your semen is black or brown in colour. This is normal and due to bleeding when the seeds are put in.
- If a seed comes out, flush it down the toilet.
- If you need a bowel or prostate test after brachytherapy, speak to your radiation oncologist.
- You may be given a medical alert card, which you should carry at all times. In the event of an emergency, this will let medical staff know that you have had brachytherapy.

What are the side-effects?

It is common to feel mild soreness and some bruising between your legs for a few days after the seeds have been put in. Your doctor can prescribe mild painkillers to relieve this. You may see some blood in your urine afterwards but most bleeding is usually gone within 48 hours. If it goes on beyond that, 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).

It may take a few days before you experience any side-effects. Usually they are at their worst a few weeks after the seeds have been put in. You may get some or all of the side-effects. Each man experiences them differently, so it is hard to predict exactly how you will feel.

The most common side-effects include:

- Urinary problems
- Erectile dysfunction
- Bowel problems
- Fatigue (tiredness)
- Infertility

Urinary problems: The radiation can cause inflammation of your urethra. This is the tube through which you pass urine. It might also irritate your bladder. This can cause symptoms such as burning 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 does not happen very often but if it does, you will need to have a tube (catheter) put in for a time.

Urinary side-effects get worse in the first few weeks after treatment. They usually improve over time as the seeds lose some of their radiation. The urinary side-effects may mean that you need to go to the toilet very often, day and night. This can interfere with your normal daily activities for a while. If you have to get up several times during the night, you can feel quite tired due to disturbed sleep.

Drinking plenty of fluids and avoiding drinks with alcohol or caffeine, such as tea, coffee and coke, may ease these problems. It helps to drink 1½ to 2 litres a day. You might also need medication to help these side-effects for a time.

If you have urinary symptoms 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 also have a higher risk of incontinence.

Erectile dysfunction: Brachytherapy can cause damage to the nerves and blood vessels near your prostate gland. This means that you might be unable to get normal erections after the treatment. This is called erectile dysfunction or impotence. You may not notice it until years after your treatment. It may also become a long-term problem and be permanent. Remember 2 years after brachytherapy 2 out of 10 men have erectile dysfunction. Some 3 years after brachytherapy 5 out of 10 men may have it.

Your risk of erectile dysfunction will increase if you have had erection problems before your treatment. If you have hormone therapy and 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. Naturally, it can affect your relationship with your partner and your sex life. Do not 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 page 40 for more information. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for a free factsheet called *Sex, Erectile Dysfunction and Prostate Cancer*.

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. This side-effect can appear straight away or up to 2 to 3 years after your treatment. If this happens, talk to your doctor as there may be treatments that can help. You will be given advice on what to do if this happens to you. It is 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. For advice on eating, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet *Diet and Cancer*.

Fatigue (tiredness): You may experience tiredness from the radiation or from getting up a lot at night to pass urine. It usually takes a few months for this to improve after treatment. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for a copy of the booklet called *Coping with Fatigue*.

Infertility: Brachytherapy for prostate cancer may affect your fertility. This means you might be unable to father a child in the future. If this is important to you, talk to your doctor about this effect before your treatment. If you have a partner, you may find it helpful to see the doctor together so that you can both talk about your concerns. If your sperm count is normal, it may be possible to store your sperm before radiotherapy for later use. See page 54 for more about infertility. Remember it is not safe to assume you are sterile after radiotherapy.

Side-effects in general

If you would like more information on brachytherapy, call the National Cancer Helpline on 1800 200 700 for a free copy of the booklet *Understanding Radiotherapy*. You can also visit a Daffodil Centre. Any of the booklets mentioned in this section can be downloaded from www.cancer.ie



To sum up

- Brachytherapy is a way of giving radiation directly into your prostate gland.
- The radiation comes from small radioactive seeds put into your prostate under general anaesthetic.
- Having brachytherapy depends on the stage and grade of your prostate cancer and the size of your prostate gland.
- The radiation is released slowly over a number of months.
- After several months, the seeds are no longer active and stay in your prostate without doing any harm.
- The most common side-effects include urinary problems, erectile dysfunction, bowel problems, fatigue and infertility.

External beam radiotherapy

Radiotherapy uses high-energy X-rays to treat cancer cells. When radiotherapy is given externally, it is called external beam radiotherapy. In this case, a beam of radiation is aimed at your prostate gland from a machine called a linear accelerator. These X-rays damage the cancer cells, prevent them from growing, and cause the cells to die. Normal tissue can also be damaged but this repairs itself after treatment has finished.



External radiotherapy

The treatment is suitable if your prostate cancer is found only within your prostate gland or has spread just outside it. The aim of radiotherapy is to fully get rid of your prostate cancer.

Types of external beam radiotherapy

There are two types of external beam radiotherapy available:

- **Conformal radiotherapy:** This is the most common type of radiotherapy. The radiotherapy machine directs the beam to fit the size and shape of your prostate gland.
- **Intensity-modulated radiotherapy (IMRT):** This gives a more precise form of radiation. The beam of radiation is adjusted to give different doses to different parts of your prostate. It is a newer form of radiotherapy available in only some treatment centres in Ireland.

Both types try to reduce the amount of radiation given to normal tissues close to your prostate gland. This helps to reduce the risk of side-effects. Your radiation oncologist will discuss which type of radiotherapy is suitable for you.

Radiotherapy and hormone therapy

Radiotherapy is sometimes used on its own or together with hormone therapy. The hormone therapy is given to reduce the size of your prostate gland and make the cancer easier to treat. It is common to have hormone therapy for some months before radiotherapy and to continue it during treatment and for some time afterwards. The length of time you need to take hormone therapy varies. It will all depend on the degree of risk of your cancer. It may last 6 months, 2–3 years or occasionally lifelong. Do ask your radiation oncologist for how long you need to take the treatment.

Hormone therapy and prostate cancer

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

The common side-effects of hormone therapy include:

- Change in sexual function
- Hot flushes
- Weight gain
- Fatigue
- Mood changes
- Breast swelling and tenderness
- Osteoporosis or bone thinning

Hormone therapy affects different men in different ways. The risk of getting each side-effect also depends on the length of treatment. It is important to understand the side-effects before you start any treatment. Knowing what side-effects to expect can make it easier to cope with them.

For more information about hormone therapy and how to manage the side-effects, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a free factsheet called *Hormone Therapy and Prostate Cancer* or download it from www.cancer.ie.

What does the treatment involve?

For prostate cancer, a course of external beam radiotherapy is needed. It usually lasts 7–9 weeks. This means going to the radiotherapy unit 5 days a week with a break at weekends. The treatment itself only takes a few minutes and does not hurt.

Preparation: Some preparation is needed before the actual radiotherapy can be given. Before treatment, you will visit the hospital for planning scans that use a machine called a simulator. This helps your doctors to work out exactly where to aim the X-rays. Your skin will be marked so that the beam goes to the same area each time you get radiotherapy. 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.

Special diet and fluids: Your prostate gland must be in the same position every time you have your treatment. The exact same position can be affected by having a full bladder or a full bowel. 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 need to have an enema beforehand.

Having the treatment: Before each treatment, the staff will help you into the right position on the radiotherapy table. They will use the marks on your body to make sure that the treatment is given to the right spot each time. Before the treatment starts, the staff will leave the room. They can see and hear you at all times and you can talk to them. During the treatment the machine will move around your body, but it does not touch you and you will not feel anything.

After treatment: The radiation does not stay in your body after the treatment. So it is perfectly safe to be around other people at all times afterwards. Treatment affects people in different ways. You might be able to continue your normal activities, such as work or social activity. Or you might need more rest than you usually have.

What are the side-effects?

Side-effects occur when the normal healthy cells near the treated area are exposed to the beam of radiation. Some side-effects appear during the treatment while others can develop afterwards. Some can become long-term side-effects.

Short-term side-effects

The most common side-effects are those that develop during or shortly after your treatment. Not all men will get all of the side-effects. But there is no way of knowing which of them you will get or how much trouble they will cause you. During your treatment, your radiation therapists can discuss your side-effects and help you manage them.

Short-term side-effects include:

- Urinary problems
- Bowel problems
- Discomfort at your back passage
- Skin changes
- Fatigue (tiredness)

Urinary problems: During radiotherapy your bladder may become irritated. This can make you pass urine more often, during the day and at night. It can also cause a burning feeling when you pass urine. Sometimes drinking too much tea, coffee, coke or alcohol can make these problems worse. If this happens, reduce your intake of these drinks for a time and drink more water, juices or soft drinks.

You may notice a trace of blood in your urine too. If you have problems passing urine or pass blood, discuss it with your doctor, nurse or radiation therapist.

These symptoms usually start to settle down some weeks after your treatment has finished. But for some men they continue long term. On your way home from each treatment you may need to stop off to pass urine, especially if you are asked to drink water before each treatment. For more information, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a factsheet called *Urinary Problems after Prostate Cancer Treatment*. Or you can also download it from www.cancer.ie

Bowel problems: You might develop diarrhoea during treatment. This is because your prostate gland is very close to your back passage (rectum).

Passing watery bowel motions more than three a day is known as diarrhoea. You may also have cramping tummy pain and pass more wind and mucus. If this happens, drink lots of fluids to replace the fluids you are losing. Do let your doctor or radiation therapist know if you have diarrhoea. There is medication that can stop this side-effect. You might also notice that you need to get to the toilet more quickly.

On the other hand, you might have more difficulty opening your bowels and become constipated. Your doctor and nurse will help you find ways to manage your bowel symptoms during your treatment. Again these symptoms usually start to settle down a short time after your treatment has stopped. For advice on eating, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre and ask for a free copy of the booklet *Diet and Cancer*.

Discomfort at your back passage: Radiotherapy to your prostate area may irritate your back passage and cause discomfort. It can also cause soreness around your anus. You may notice some blood on toilet paper after passing a bowel motion. Indeed it may feel as if you have piles. If this happens, tell your doctor or nurse. Your doctor can prescribe medication that will help this problem.

Skin changes: During radiotherapy, the skin on your bottom or between your legs may become sore and a bit darker. It may even look like sunburn. It is best to avoid hot baths and to wear loose cotton clothes at this time. When you wash the area, use warm water and pat it dry with a soft towel. Do not rub the skin while washing and drying. You can use a special cream to treat this problem but be sure to only use creams recommended by your nurse or radiation therapist. Avoid perfumed creams or powders. Check with your radiation therapist or nurse before applying anything to your skin.

Fatigue (tiredness): Tiredness can build up over the course of your treatment. You may feel tired because of the treatment itself or perhaps you have to travel long distances for treatment. Rest as much as you need to and continue to do the things you like. But remember you may have less energy than before treatment. Regular gentle exercise such as walking can help to improve tiredness.

Depending on your job, you might continue to work during treatment or else take time off work. You may feel tired for some time but most men recover from their tiredness within a couple of months of finishing their treatment. If you are having trouble with fatigue, a helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy or visit a Daffodil Centre.

Side-effects in general: These short-term side-effects may continue to get worse for a short time after the treatment has finished. Then they usually start to settle down over the coming weeks and months.

Long-term side-effects

Some side-effects can become long term, while others can appear some time after your treatment has finished.

Long-term side-effects include:

- Erectile dysfunction
- Bowel problems
- Urinary problems
- Infertility

Erectile dysfunction: Radiotherapy to your prostate can cause damage to the nerves and blood vessels that control erections. As the result, it can be difficult to get and keep an erection. This is called erectile dysfunction or impotence. It can take up to 2 years for this side-effect to be noticed, but you might notice it sooner than that.

Erectile dysfunction occurs in about 4 out of 10 men. 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. At this time you may not be even interested in sex. 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. Do discuss this with your doctor, nurse or GP. There are several treatments available for erectile dysfunction. For more information and advice, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of our free factsheet.

After radiotherapy, some men find that an orgasm has less semen than usual and they have a 'dry' orgasm where no semen is ejaculated. See page 52 for more information.

Urinary problems: Your bladder might be permanently affected by radiotherapy. This happens with a very small number of men. As well as the short-term symptoms described on page 38, you might develop a narrowing of your urethra (water pipe). This can make it difficult to pass urine and needs to be treated with surgery.

Sometimes the blood vessels in your bladder can become more fragile after radiotherapy. This can take many months or years to happen and causes some blood to appear in your urine. If you notice any bleeding, tell your doctor so that tests can be done and proper treatment given.

Rarely, radiotherapy can cause leakage of urine due to damage to the nerves that control your bladder muscles. 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 persist. 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. This may mean you open your bowels a little more often than you did before your treatment. Or it may mean a bigger change that affects your everyday life. 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. As other bowel problems are common in older men, it is also possible that symptoms are due to something else. So 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, do tell your doctor or nurse.

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. If you have a partner, it might help to see your doctor

together so that you can both talk about your concerns. If your sperm count is normal, it may be possible to store your sperm before radiotherapy for later use. It is not safe to assume you are sterile after radiotherapy.

Side-effects in general: If you would like more information on radiotherapy and side-effects, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of the booklet *Understanding Radiotherapy* or a DVD called *Radiation Therapy: A Patient Pathway*.



To sum up

- When radiotherapy is given externally, it is called external beam radiotherapy.
- A beam of radiation is aimed at your prostate gland from a machine called a linear accelerator.
- The treatment is suitable if your prostate cancer is found only within your prostate gland or has spread just outside it.
- Some preparation is needed before the actual radiotherapy can be given.
- A course of external beam radiotherapy usually lasts 7–9 weeks.
- The common short-term side-effects of radiotherapy may include passing urine more often, diarrhoea, discomfort at back passage, skin changes and fatigue.
- Long-term side-effects include erectile dysfunction, urinary problems, bowel problems and infertility.

Surgery

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

Who can have a radical prostatectomy?

Surgery is suitable if the cancer is found only in your prostate gland and you are fit and healthy. It might not be suitable if you have health problems such as heart disease or are very overweight. This is because they can increase the risks linked to surgery. 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.

The aim of surgery is to fully get rid of the cancer. 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 and that the edges of the prostate gland are clear of cancer. This is known as checking the margins. Margins are described as negative or positive. Negative margins refer to no cancer cells, while positive margins refer to cancer cells at the edge of the prostate. This is 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. Do discuss with your doctor which way is best for you. Not all of the treatments are available in all hospitals in Ireland, so discuss your preference with your surgeon.

- Open prostatectomy
- Laparoscopic prostatectomy (keyhole surgery)
- Robot-assisted laparoscopic prostatectomy (robotic surgery)

Open prostatectomy: There are two ways of doing open surgery. The most common way is through a cut in the wall of your abdomen between your belly button and pubic bone. A radical prostatectomy can also be done through a cut between your scrotum and back passage. Open surgery is available in hospitals throughout Ireland.

Laparoscopic prostatectomy (keyhole surgery): With keyhole surgery, small cuts are made in your abdomen so that special instruments can remove your prostate. Afterwards, you need less time in hospital and can move around more easily than with open surgery. There is also less risk of needing a blood transfusion or getting a wound infection after keyhole surgery. The long-term side-effects of this type of operation are the same as for open surgery. Keyhole surgery is a fairly new operation for men with early stage prostate cancer. Only a small number of surgeons in Ireland have had special training to do this operation.

Robot-assisted laparoscopic prostatectomy: This operation is like keyhole surgery but with the use of a computer and robotic arms to help remove your prostate. As with keyhole surgery, less time is needed to recover after the operation. There is also a lower risk of needing a blood transfusion or getting a wound infection. Robotic surgery is fairly new to Ireland and so far only a few operations have been done here. At present, it is only available to patients with private health insurance in Ireland and takes place in only a few private hospitals. Only a few surgeons in Ireland are specially trained to do this operation.

Nerve-sparing prostatectomy

Sometimes having to remove all the cancer cells makes it impossible to avoid nerve damage to your prostate gland. In some cases, it is possible to spare nerves on one side of your prostate only. This is called a nerve-sparing prostatectomy. It gives you a better chance of regaining erections than if you had all of the nerves removed, but not as good as if you had both bundles of nerves spared. Discuss with your surgeon if nerve-sparing surgery is possible for you or not. Very often surgeons cannot tell until the operation itself if they can do a nerve-sparing operation or not.

Which type of surgery is best for me?

There is no evidence that one type of operation is better than another at curing prostate cancer. Or that one type of operation is better in terms of side-effects. Two things you might consider are the health cover you have and the skill of the surgeon. While open surgery and keyhole surgery are available to public and private patients, robotic surgery is only available in some private hospitals in Ireland. Only a small number

of surgeons have received training in the skills needed for keyhole surgery. Robotic surgery appears to be as good as open surgery at treating prostate cancer but long-term results are needed to make sure.

If you are interested in keyhole surgery or robotic surgery, talk to your specialist team about the advantages and disadvantages of these types of surgery. Ask them where they are available. For more information on the different types of surgery for prostate cancer, talk to your doctor. You can also contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Surgeons and number of operations

The number of operations that a surgeon has done is important. This can affect the rate of side-effects. In general, the more operations a surgeon does, the less likely you are to get side-effects. Do ask your surgeon how many of the particular type of operations they have done, if you wish.

Before surgery

Tests: To make sure you are fit for surgery, you will need some tests. For example, blood tests, a heart tracing (ECG), chest X-ray and a physical exam. An anaesthetist may also examine you to make sure you are fit for surgery. He or she 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. You will 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 like heparin 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 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 tube (catheter) to drain urine into a bag
- One or two small drains near your wound to drain away any fluid
- 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 in for about 1 to 3 weeks.

Pain: You will likely have a special pump for relieving pain. This gives you a constant 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.

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. But you will quickly be able to take sips of water. The amount of fluids you can take will then be increased. The risk of this is much less with keyhole or robotic surgery.

Infection and blood clots: A physiotherapist will help you with breathing exercises to help prevent a chest infection. He or she will also show you how to cough and 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. Soon you can go for walks on your own.

Urinary catheter: The urinary tube will stay in place for between 1 and 3 weeks after your surgery. Any urine you make will pass through the tube into a drainage bag. Before you go home, your nurse will show you how to look after the drainage bag. It is best to drink about 1½ to 2 litres of fluid a day to reduce the risk of getting an infection.

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

Preparing for discharge



If you have surgery, it is 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. Use whatever help is available. 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. You may also need help getting supplies of incontinence pads. Do talk to the public health nurse or a pharmacist about the special pads for men that are available. Make sure you have a supply at home before the urinary tube (catheter) is removed.

Going home

Your wound clips might be removed 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.

You may notice a change in your bowel habit after surgery. If this happens, you may need to be given some laxatives. If you are constipated, you might need to include more high-fibre foods in your diet. Remember if the problem continues, talk to your doctor or nurse who may give you medication to help.

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.

>>> Hints & Tips – keeping healthy after leaving hospital

- Get a full night's sleep.
- Rest during the day if needed but keep active.
- Exercise every morning and afternoon.
- Drink plenty of fluids.
- Eat a healthy diet.
- Make sure you open your bowels every day or two.



Removing the urinary tube

You will need to return to the hospital or to your GP to have your urinary tube removed. This takes just a few seconds. Most likely you will experience some leakage of urine once the tube is removed. Your nurse will give you an incontinence pad to wear at this time, along with a small supply to take home. She or he can also give you information about how to get a supply of pads for yourself.

What are the side-effects of surgery?

The main side-effects of surgery are:

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

The length of time that these side-effects can trouble you varies. It is impossible to predict how it will be for you, as each individual differs.

Talking to your doctor and nurse, or another man who has had surgery for prostate cancer, may help you to understand the impact of these side-effects on your daily life. Men Against Cancer are trained volunteers who have had treatment for prostate cancer. If you would like to talk to a volunteer, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Urinary incontinence

The risk of urinary leakage is the same for open, keyhole and robotic surgery. Do talk to your surgeon or nurse about the risk of urinary incontinence before you consent to surgery.

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. This means that you most likely will need to wear an incontinence pad to collect the leaked urine. The amount of leakage can vary from some drops when you exercise, cough, sneeze or laugh to a much larger amount. As a result, you need to wear pads to cope with the amount of leakage.

As time goes on, you are likely to regain control of your urine flow and no longer need to wear pads. 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. Do report this to your surgeon if it happens.

You might have long-term problems with leakage of urine, or you might experience the occasional leakage of urine or regularly leak urine. Rarely would you need more surgery for problems with incontinence.

>>> Urinary incontinence usually improves with time.

How to cope with urinary incontinence

Remember that urinary incontinence usually improves with time. It helps to be prepared in a practical way to cope with the leakage of urine in the first weeks after surgery. For example, make sure you have a supply of incontinence pads at home. These can be got from the hospital before you leave, from your public health nurse or bought

from a pharmacy. Your nurse will also give you information about pads made specifically for men.

Doing pelvic floor exercises can improve the problem. Your doctor may refer you to a physiotherapist to make sure you can do the exercises properly. She or he can also support you and help you build up some muscle strength.

If you have a medical card, your public health nurse can assess your incontinence and help with a supply of pads. If you have problems that persist, do contact them for advice and help. If your incontinence persists for a long time, they can also refer you to a continence adviser who can show you ways to cope. You can also contact a continence adviser through your local HSE office for more information. See page 74 for more details.

Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for a free copy of our factsheet on urinary problems after prostate cancer. It also includes advice on pelvic floor exercises.



Tips & Hints – urinary incontinence



- Cut down on tea, coffee, coke and alcohol, as these drinks can irritate your bladder.
- Don't reduce the amount of fluids you take. Try to drink up to 8 glasses or cups each day.
- If you cannot get to the toilet soon enough, make sure you can reach it easily and that your clothing can be easily undone.
- Keep a healthy weight for your height.
- Eat a healthy balanced diet. It should be rich in fibre to avoid constipation, as this can put pressure on your bladder and make urinary problems worse.
- Exercise regularly, as it will help your bowels to work well.
- Do pelvic floor exercises regularly. These exercises can help to strengthen the muscles around your bladder and in the pelvic floor.
- Avoid skin irritation or odour with regular hygiene. Use a mild soap and gently pat the area dry.

Erectile problems

The erectile problems can include:

- Erectile dysfunction (impotence)
- 'Dry orgasm'
- Shortening of your penis

Erectile dysfunction (impotence): Surgery to your prostate gland often leads to problems having an erection. This is called erectile dysfunction 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 and diabetes.

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. Remember it can take at least a year after surgery to find out if the impotence will get better or not.

At first you might find it difficult to get an erection strong enough for sex. Erections are often not as good as they were before surgery and you may never get back the ability to have an erection without treatment. Nerve-sparing surgery can improve your chance of getting your erections back after surgery. See page 44 for more details.

Problems with erections can be discussed with your surgeon when you go for check-ups, or with your GP or nurse. A useful factsheet on sex and erectile dysfunction is also available from the Irish Cancer Society. Call 1800 200 700 for a free copy or visit a Daffodil Centre. You can also download a copy from www.cancer.ie

Early treatment for erectile dysfunction:

Taking medication or using vacuum therapy for erectile dysfunction soon after surgery can improve your chance of having erections again. At this time you may not be even interested in sex. But taking the tablets or using a vacuum pump at an early stage may improve your chances of having erections when you are ready to think about sex again. Do discuss this with your surgeon, nurse or your GP. For more information, call the National Cancer Helpline on 1800 200 700.

‘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. If you are planning to have children, it may be possible to store your sperm before surgery. These can then be used later in fertility treatments. In Ireland, this is done at the HARI Unit at the Rotunda Hospital in Dublin. Discuss this with your surgeon if you think you might wish to father children after your surgery.

Shortening of your penis: Up to a year after surgery you may notice the length of your penis has shortened. It is not clear what causes this shortening. Some treatments for erectile dysfunction that encourage blood flow into your penis, such as tablets or the vacuum pump, may help to prevent it.

For information on how to get a vacuum pump, contact the National Cancer Helpline on 1800 200 700 and ask for a free copy of our factsheet *Sex, Erectile Dysfunction and Prostate Cancer*.



To sum up

- The aim of surgery is to remove your entire prostate gland and the cancer within it. The operation is called a radical prostatectomy.
- There are different types of surgery. They include open prostatectomy, keyhole surgery and robotic surgery.
- A nerve-sparing prostatectomy may be done to protect the nerves next to your prostate that are responsible for erections.
- A urinary tube (catheter) will stay in place for between 1 and 3 weeks after your surgery.
- Many men have trouble with control of urine flow straight after a radical prostatectomy. Usually this improves over the weeks and months after the operation.
- Problems with urinary incontinence and erections are common side-effects of surgery for prostate cancer. These problems can often be improved with treatment.

New treatments

Research into new ways of treating prostate cancer goes on all the time. Some new treatments are available in medical centres in Europe and America. At present these new treatments do not mean a better standard of care than treatments used currently. For this reason, many doctors advise that they should only be used as part of a clinical trial. For a copy of our factsheet on clinical trials, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre or our website www.cancer.ie

Some new treatments include:

- High-intensity focused ultrasound (HIFU)
- Cryotherapy
- Proton beam radiation therapy
- Multiparametric MRI scans

High-intensity focused ultrasound (HIFU) uses ultrasound waves to treat the prostate gland. So far, research shows that HIFU is no better at treating prostate cancer than current treatments.

Cryotherapy is a way of killing prostate cancer cells by freezing them. So far, research shows that cryotherapy is no better at treating prostate cancer than current treatments.

Proton beam radiation therapy is an advanced type of radiotherapy. It uses proton beams to target the prostate gland. It has not been shown to be better than other types of radiotherapy for prostate cancer.

Multiparametric MRI scan is a special type of MRI scan that can be used to help diagnose prostate cancer in some men. Research is looking at who should have a multiparametric MRI and how it can diagnose prostate cancer.

Researchers are also looking at treating parts of the prostate gland rather than the whole gland. This is known as focal therapy. Research into focal therapy is at a very early stage. It will be a number of years before we know who will benefit from this type of treatment.

Will treatment affect my sex life and fertility?

Physical side-effects of treatment

Many of the treatments for early prostate cancer will have an impact on your sex life. For the sexual side-effects of brachytherapy, see page 33. For the sexual side-effects of external beam radiotherapy, see page 40. For the sexual side-effects of surgery, see page 51.

Sex and relationships

Treatment can often affect your sex life. The changes can sometimes be difficult for you and your partner to talk about. Needing treatment to get an erection can also change your relationship with your partner or how you see that relationship. In that case, relationship counselling or sex therapy can help you and your partner overcome this problem.

Coming to terms with the fact that you have cancer can also take quite a while. Your emotions will be turned upside down. It can often be hard to relax as well when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment. As a result, you may lose interest in sex. This is quite normal when you are concerned about your health.

If you have a supportive partner, you may find that talking about your feelings may ease your anxiety. Even if you do not feel like having sex, or cannot get an erection, you can still enjoy a close and loving relationship with your partner. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist counselling if you feel that would be helpful. The National Cancer Helpline 1800 200 700 has a list of psychosexual counsellors who can help you and your partner find a way of being close again. Some organisations offer a sex therapy service to help couples who are experiencing a change in their sexual relationship. See page 79 for contact details.

There is no set time for you to be ready to have sex again. It varies from person to person. Once you return to your usual routine your interest in sex should return too. You may find it will be some weeks before you will feel well enough to have sex again after surgery.

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this. It is quite safe for you to have sex with your partner, both before and after treatment.

Asking for advice

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

Infertility

Your fertility may be affected by some of the treatments. Sadly, you might not be able to father a child in the future. If this is the case, do talk to your partner about your feelings. Also, discuss your worries about infertility with your doctor. He or she can tell you if there are any options open to you at this time. It may be possible to freeze your sperm before treatment begins. The HARI (Human Assisted Reproduction Ireland) Unit at the Rotunda Hospital in Dublin provides a service where sperm can be frozen for later use. Talk to your doctor about this service or call the National Cancer Helpline on 1800 200 700 for more information.

Dealing with infertility may not be easy, depending on your age and if you have had children or not. It can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener.

What follow-up do I need?

No matter what type of treatment you get, you will still need to come back for regular check-ups once it is over. This is called follow-up. The follow-up involves a PSA test and perhaps a digital rectal exam. At first these visits will be quite often, sometimes every 3 months at first and then every 6 months. Some men continue to come back to the hospital for their PSA checks for many years. Others have their PSA checked by their GP. Your doctor will decide which is best for you.

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

Cancer and complementary therapies

Complementary treatments for cancer are very popular today. Many people find them very helpful during their illness. For example, relaxation, meditation, gentle massage and acupuncture. They are treatments that are sometimes given **together with** conventional treatment. Conventional therapies are treatments that doctors use most often to treat people with cancer. For example, surgery, radiotherapy, chemotherapy and hormone therapy.

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include diet therapy, megavitamin therapy and herbalism. Most doctors do not believe that such treatments can cure or control cancer.



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



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

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

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

Coping and emotions

How can I cope with my feelings?

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

Common reactions include:

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

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

Shock and disbelief

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

Shock is often the first reaction to a cancer diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think cancer will never happen to them and are totally shocked when it does. Even if your doctor and nurse discuss the cancer with you, the news may not sink in for a while. You may find yourself confused, asking the same questions over and over again. Or else you may accept the news calmly and say nothing because you cannot really believe what is happening to you.

Fear and uncertainty

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

There is no doubt that cancer is a scary word. Not surprisingly, you may have many fears when first told of your diagnosis. Often the first thing people think about is dying. They think the worst. But nowadays many men with early prostate cancer can be cured with modern

treatments. Another great fear about cancer is pain. The fear of pain can sometimes overwhelm everything else. However, some cancers cause no physical pain at all or else can be controlled with good painkillers.

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

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

Loss of control

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

After a cancer diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom. Because you don't know enough about your

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

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

Sorrow and sadness

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

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

Denial

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

Sometimes after being told their diagnosis, people deny they have cancer. While this may seem unusual, it is a valid way of coping. As a result, you may not wish to mention or discuss your illness. Or else you may talk as if your illness is nothing serious. Denial may last for a short or longer time, depending on how long it takes for you to adjust to your illness. Tell your family and close friends that you would prefer not to talk about your illness, at least for the time being. Your doctors and nurses will also understand if you don't want to hear any information about your cancer until you're ready.

Anger

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

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

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

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

Resentment

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

It is natural that you might be resentful and unhappy – even jealous – because you have cancer while other people are well. During the course of your illness similar feelings of resentment may occur for many reasons. You may resent that

another patient receiving the same treatment as you has responded quicker than you have. You may resent your healthy relatives or having to change your lifestyle in some way.

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

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

Blame and guilt

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

When diagnosed with a serious illness such as cancer, it is natural to want to know what caused it. Sometimes people blame themselves or others for their illness. As cancer experts rarely know

exactly what has caused cancer, there is no good in blaming yourself. Other times, people feel guilty because they delayed going to the doctor with their symptoms, fearing the worst. No matter what the reason, don't torture yourself at this time.

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

Withdrawal and isolation

'I just need to be on my own.'

It is true that a cancer diagnosis is stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may want to be left alone and withdraw from people. It is normal to want to be alone to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope.

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

If you would like more information on how to talk about your cancer, there is a useful booklet available called *Who Can Ever Understand? Talking about Your Cancer*. If you would like a copy, call the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre or download it from www.cancer.ie



How can my family and friends help?

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



How can I talk to someone with cancer?

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



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

Be patient

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

Lost for Words: How to Talk to Someone with Cancer is a useful booklet written for relatives and friends of people with cancer. Available from the Irish Cancer Society, you can call the National Cancer Helpline on 1800 200 700 for a free copy or visit a Daffodil Centre.

How can I talk to my children?

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

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

Be honest

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

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

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

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

Coping with children's emotions

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

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

How can I help myself?

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope, only your way. During your illness there are many things that you can learn, not only about cancer itself but also about you as a person.

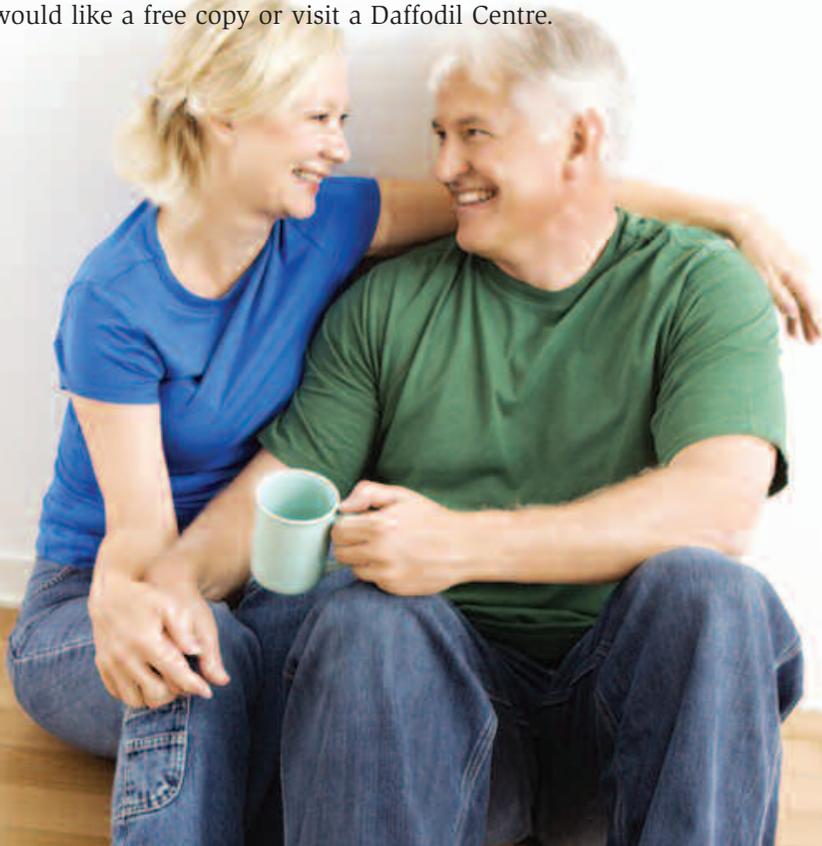
Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

- **Communicate with your family and close friends:** Do not keep your worries or symptoms secret from the people closest to you. This includes physical or emotional problems. Ask the person closest to you to come with you when visiting the doctor and when treatments will be discussed.
- **Live one day at a time:** Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.
- **Live well:** Try to eat as well as you can. Eat little and often, using lots of different types of foods with plenty of fresh fruit and vegetables. Do some regular exercise that you enjoy. Take it easy at first, building up the amount you do as you feel stronger.

- **Expect change in your life:** Even though you may want to stick to your old routines, sometimes this may not be possible. It may take a while for you to adjust to your new routine. Remember that change may bring new opportunities and blessings.
- **Keep an open mind:** Don't feel you have to be positive all the time. Expect ups and downs during your cancer journey. There will be times when you feel low but don't feel guilty about it, as it will pass.
- **Seek information:** Be sure to ask your doctor as many questions as you can and get involved in decisions about your treatment. Always ask for information that is personal to you. Ask what side-effects you can expect so you can prepare for them. Build up as much information about your cancer and treatment as possible. Follow your doctor's instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor or nurse. Keep a notebook of all your dates for blood tests, X-rays, scans, treatments, symptoms, side-effects, medications, and your general health. Keep a record of any emotions you are feeling too, especially strong ones. Call 1800 200 700 for a free copy of *Journey Journal* to help you keep track of your cancer treatment.
- **Find what works for you:** It can help to use whatever way of coping that has helped you solve problems in the past. Some people are comfortable taking about their illness, others are not. You may prefer relaxation, meditation, walking, listening to music, or other approaches helpful. Do whatever suits you. But if it's not working, be open to finding a new way to cope.
- **Build a support network:** Be realistic about what you can manage by yourself. No man is an island, so seek help from those who want to support you. Talk to your family, friends, nurses or doctors. Meet with other patients in support groups and self-help groups as they can understand what you are going through. If the group does not suit you and is not helping, leave it.
- **Seek professional help:** If you have any low moods or strong emotions, talk to your close friends and family – or someone who is a good listener. If they are still getting the better of you, discuss them with your nurse and doctor. They may recommend you talk to a trained counsellor or other specialist.

- **Spiritual care:** When faced with a cancer diagnosis and treatment, you may start thinking about the meaning of life and the afterlife. For some people spiritual and religious beliefs can bring comfort and hope. Prayer or meditation can help you to focus on what has value and meaning in your life. Even if you do not consider yourself a religious or spiritual person, it is still possible to take comfort and support from these practices. Some complementary therapies that have a spiritual dimension may also help you to focus on being positive and hopeful.
- **Express yourself:** Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of your cancer journey and can bring great healing and relief. Other forms of creative expression, such as music and art, may help too.

A useful booklet called *Understanding the Emotional Effects of Cancer* has been written for people with cancer and is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 if you would like a free copy or visit a Daffodil Centre.



Support resources

Who else can help?

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

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

Medical social worker: The medical social worker in your hospital can help in many ways. He or she can give support and counselling to you and your family and give advice on practical and financial supports and services available when you go home.

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

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

GP (family doctor): You may feel comfortable talking to your family doctor (GP) about your prostate cancer too. He or she can discuss any of your queries and offer advice and support.

Community health services: There are various community health services available from your local health centre. These centres have public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far from your hospital, your community

welfare officer can also help with practical issues such as financial problems or exceptional needs. More information on the services is available either from the medical social worker in your hospital before you go home or at your local health centre.

Support groups: Joining a support group can put you in touch with people who have been in a similar situation. For example, Men Against Cancer. They can give you practical advice about living with cancer. Cancer support centres are found in most counties in Ireland and can offer a wide range of services. Some are listed at the back of this booklet. Useful websites, including patient forums, are also listed. You can also download the Irish Cancer Society's *Directory of Cancer Support Services* from www.cancer.ie

Irish Cancer Society: The staff of the Cancer Information Service will be happy to discuss any concerns you or your family may have, at any stage of your illness. This can range from treatment information to practical advice about your financial matters. For example, getting life insurance.

Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for information about any of the services outlined above or for support services in your area.

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

Health cover

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

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



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

Hospital cover

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

Outpatient cover

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

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances. You may have to pay a prescription charge of €2.50 per item up to a limit of €25 per family per month.

To qualify for a medical card depends on a means test regardless of age. If you are over 70 and your weekly income is €500 or less (€900 for couples), you can still apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office.

If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card. But it will depend on your financial circumstances and how long your treatment is expected to last. In this case, your spouse and children will not be covered if your means are over the limit. If you wish to apply for a medical card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 1890 252 919.

GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will have

to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at your hospital or your HSE office to see if you are eligible. If you wish to apply for a GP visit card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 1890 252 919.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €144 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your local pharmacy.

Private healthcare cover

Private health insurance pays for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available through the VHI, Laya Healthcare, AVIVA Health, GloHealth, and other schemes. They provide cover for day care or inpatient treatment and hospital outpatient treatment. Before attending hospital, do check the level of cover provided by your insurer, both for inpatient and outpatient services.

If you have private insurance, your tests might not get done as quickly as you would like. Your health insurer has to approve some tests in advance. For example, MRI and PET scans. Sometimes it might take 24–48 hours to get approval from your health insurer.

Benefits and allowances

Information on the following is given in this section:

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

For a free copy of *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download a copy at www.cancer.ie

Application forms for the benefits below are available from social welfare offices or Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or LoCall 1890 927 770. You can also download the forms from websites such as www.welfare.ie or www.citizensinformation.ie

Illness Benefit

This is a benefit for insured people. Your eligibility will depend on your PRSI contributions. You must be under 66 and unable to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Department of Social Protection, PO Box 1650, Dublin 1. Tel: (01) 704 3300 or LoCall 1890 928 400. These certificates are available from your GP and from the hospital you attend during inpatient care. You should send your claim to the Department within 7 days of becoming ill and unable to attend work. A delay might result in loss of payment. The benefit lasts for 2 years.

Disability Allowance

You might qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least 1 year. Disability allowance is a weekly allowance paid to people with an injury, disease or a disability who are aged between 16 and 65. For this allowance, you must satisfy a means test, live in Ireland and be medically suitable. To be medically suitable, you should have an illness that has continued or may continue for at least 1 year.

You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas and electricity and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme.

Invalidity Pension

This is a pension paid instead of an illness benefit or disability allowance, if you are unable to work permanently. This means if you

have been incapable of work for at least 12 months and likely to be incapable for at least another 12 months because of a serious illness or incapacity.

Your eligibility will also depend on your PRSI contributions. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas and electricity and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme.

Carer's Allowance

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

Carer's Benefit

If you are employed but wish to care for a sick relative full time, you might qualify for a carer's benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. You must be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged between 16 and 66 years, live in Ireland, not be self-employed or employed while caring for the person, and not live in a hospital or nursing home.

Carer's Leave

By law you may be entitled to unpaid temporary leave from your employer. Carer's leave allows you to leave your employment for up to 104 weeks to care for someone in need of full-time care and attention.

The leave will be unpaid, but you will have your job kept open for you while you are on leave. You do not need to be eligible for carer's allowance or carer's benefit to apply for carer's leave. You must have worked for your employer for a continuous period of 12 months to be eligible to apply for carer's leave. The person you are caring for can be a partner or family member, friend or colleague. The family doctor (GP) of the person you are caring for will also need to fill in part of your application form.

You can work while you are on carer's leave for up to 15 hours a week. But you must make sure your income from employment or self-employment is less than a weekly income limit set by the Department of Social Protection.

Appliances

If you have a medical card most appliances are free of charge or subsidised. The subsidy will depend on the HSE area.

Travel to hospital

You can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your medical social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres, usually for patients with medical cards.

See page 78 for information on the Care to Drive and Travel2Care schemes run by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you. Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

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

For social welfare queries, contact:

Dept of Social Protection – Information Service

Oisín House
212–213 Pearse Street
Dublin 2
Tel: 1850 662 244

Leaflet line: 1890 202 325
Email: info@welfare.ie
Website: www.welfare.ie

If you have queries about health and social services, contact the HSE office in your area.

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

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

Citizens Information

Tel: 0761 07 4000 **Email:** information@citizensinformation.ie
Website: www.citizensinformation.ie



If you have financial worries...



A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, like medication, travel, food, heating, laundry, clothing and childcare costs. If you are unable to work or unemployed, this may cause even more stress. It may be hard for you to deal with cancer if you are worried about providing for your family and keeping a roof over your head.

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 77 for more details. You can also call the National Cancer Helpline on 1800 200 700 and the nurse will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 0761 07 2000. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 79 for contact details. A useful book for preparing low-budget nutritious meals is *101+ Square Meals*. See page 85 for more information.

Irish Cancer Society services

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

- Cancer Information Service (CIS)
- Daffodil Centres
- Cancer support groups
- Survivors Supporting Survivors
- Counselling
- Night nursing
- Oncology liaison nurses
- Cancer information booklets and factsheets
- Financial support
- Care to Drive transport project

Cancer Information Service (CIS)

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

- The website www.cancer.ie provides information on all aspects of cancer.
- All queries or concerns about cancer can be emailed to the CIS at helpline@irishcancer.ie
- **Message Board** is a discussion space on our website to share your stories and experiences with others.
- The **CancerChat** service is a live chatroom with a link to a CIS nurse.
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- Find us on **Facebook** and follow us on **Twitter** ([@IrishCancerSoc](https://twitter.com/IrishCancerSoc)).

Daffodil Centres

Daffodil Centres are located in a number of Irish hospitals. They have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give you a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. For example, Men Against Cancer. See pages 80–83 for more details.

Survivors Supporting Survivors

Being diagnosed with cancer can be one of the hardest situations to face in your lifetime. Survivors Supporting Survivors is a one-to-one support programme run by the Irish Cancer Society. It provides emotional and practical support to newly diagnosed patients. It can provide you and your relatives with information, advice and emotional support from time of diagnosis and for as long as is needed. All the volunteers have had a personal experience of cancer and understand the emotional and physical impacts of the disease. They are carefully selected after recovery and are trained to provide information and reassurance on the phone. The service is provided on a one-to-one basis and is confidential. If you would like to make contact with a volunteer, call the National Cancer Helpline on 1800 200 700.

Counselling

Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms with your illness. You might also find it difficult to talk to a close friend

or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the National Cancer Helpline on 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Night nursing

The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of-life care at home. The night nurse can also give practical support and reassurance to your family. You can find out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

Oncology liaison nurses

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

Cancer information booklets and factsheets

These booklets provide information on all aspects of cancer and its treatment, while the factsheets deal with very specific topics. The booklets also offer practical advice on learning how to cope with your illness. These booklets and factsheets are available free of charge from the Irish Cancer Society by calling 1800 200 700. They can also be downloaded from www.cancer.ie or picked up at a Daffodil Centre.



Financial support

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society may be able to provide limited financial help to patients in great need. You may be suitable for schemes such as Travel2Care or Financial Aid.

Travel2Care is funded by the National Cancer Control Programme (NCCP) and managed by the Irish Cancer Society. The scheme can help with your travel costs if you have genuine financial hardship due to travelling to a designated cancer centre or approved satellite centre. It will help with the costs of public transport, such as trains or buses, private transport costs, or petrol and parking. If you are travelling to a Rapid Access Diagnostic Clinic, you may qualify for the Travel2Care scheme.

Travel2Care: If you would like to request this kind of help, contact your oncology nurse or the Irish Cancer Society at (01) 231 6643 / 231 6619 or email: travel2care@irishcancer.ie

Financial Aid: A special fund has been created to help families in financial hardship when faced with a cancer diagnosis. If this applies to you, contact the medical social work department in your hospital. You can also speak to your oncology nurse or contact the Irish Cancer Society at (01) 231 6619.

Care to Drive transport project

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their chemotherapy using volunteer drivers. All of the volunteers are carefully selected, vetted and trained. You are collected from your home, driven to your appointment and brought back home again. Call (01) 231 0522 for more information.



If you would like more information on any of the above services, call the National Cancer Helpline on 1800 200 700. You can also visit the website www.cancer.ie or a Daffodil Centre.

National Cancer Helpline Freefone 1800 200 700

Useful organisations

Irish Cancer Society

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

Citizens Information

Tel: 0761 07 4000
Email: information@citizensinformation.ie
Website: www.citizensinformation.ie

HARI: The National Fertility Centre

Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Email: info@hari.ie
Website: www.hari.ie

Irish Oncology and Haematology Social Workers Group

Website: <http://socialworkandcancer.com>

Men Against Cancer

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

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Helpline 0761 07 2000
Email: helpline@mabs.ie
Website: www.mabs.ie

Relationships Ireland

[Relationship counselling charity]
38 Upper Fitzwilliam Street
Dublin 2
LoCall: 1890 380 380
Email: info@relationshipsireland.com
Website: www.relationshipsireland.com

ACCORD (Catholic Marriage Care Service)

ACCORD Central Office
Columba Centre
Maynooth
Co Kildare
Tel: 01 505 3112
Email: admin@accord.ie
Website: www.accord.ie

Health insurers

AVIVA Health (formerly VIVAS Health)

PO Box 764
Togher
Cork
Tel: 1850 717 717
Email: info@avivahealth.ie
Website: www.avivahealth.ie

GloHealth

PO Box 12218
Dublin 18
Tel: 1890 781 781
Email: findoutmore@glohealth.ie
Website: www.glohealth.ie

Laya Healthcare (formerly Quinn)

Eastgate Road
Eastgate Business Park
Little Island
Co Cork
Tel: 021 202 2000
LoCall: 1890 700 890
Email: info@layahealthcare.ie
Website: www.layahealthcare.ie

Voluntary Health Insurance (VHI)

IDA Business Park
Purcellsinch
Dublin Road
Kilkenny
CallSave: 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support groups

ARC Cancer Support Centres
Dublin and Cork (see pages 81 and 82).

Lakelands Area Retreat & Cancer Centre

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

Men Against Cancer

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

Connaught support groups & centres**Athenry Cancer Care**

Social Service Centre
New Line
Athenry
Co Galway
Tel: 091 844 319 / 087 412 8080

Ballinasloe Cancer Support Centre

Society Street
Ballinasloe
Co Galway
Tel: 090 964 5574 / 087 945 2300
Email: ballinasloecancer@yahoo.co.uk

Cara Iorrais Cancer Support Centre

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

East Galway Cancer Support Centre

The Family Centre
John Dunne Avenue
Ballinasloe
Co Galway
Tel: 087 984 5574 / 087 945 2300
Website:
www.eastgalwaycancersupport.com

Gort Cancer Support Group

The Hawthorn
Ennis Road
Gort
Co Galway
Tel: 086 312 4220
Email: gcsupport@eircom.net
Website: www.gortcs.ie

Mayo Cancer Support Association

Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407
Email: info@mayocancer.ie
Website: www.mayocancer.ie

Roscommon Cancer Support Group

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

Sligo Cancer Support Centre

44 Wine Street
Sligo
Tel: 071 917 0399
Email: scsc@eircom.net
Website:
www.sligocancersupportcentre.ie

Tuam Cancer Care Centre

Cricket Court
Dunmore Road
Tuam
Co Galway
Tel: 093 28522
Email: support@tuamcancercare.ie
Website: www.tuamcancercare.ie

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

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

ARC Cancer Support Centre

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

Arklow Cancer Support Group

25 Kingshill
Arklow
Co Wicklow
Tel: 085 110 0066
Email: arklowcancersupport@gmail.com

Balbriggan Cancer Support Group

Unit 23, Balbriggan Business Park
Balbriggan
Co Dublin
Tel: 087 353 2872

Bray Cancer Support & Information Centre

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

Cara Cancer Support Centre

Mullavalley
Louth Village
Dundalk
Co Louth
Tel: 042 937 4905
Mobile: 087 395 5335
Email: info@ccscdundalk.ie
Website: http://ccscdundalk.ie

Cuisle Centre

Cancer Support Group
Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: info@cuislecentre.com
Website: www.cuislecentre.com

Dóchas: Offaly Cancer Support

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

Éist Cancer Support Centre Carlow

The Waterfront
Mill Lane
Carlow
Tel: 059 913 9684
Mobile: 085 144 0510
Email: info@eistcarlowcancersupport.ie
Website: www.eistcarlowcancersupport.ie

Gary Kelly Support Centre

George's Street
Drogheda
Co Louth
Tel: 041 980 5100 / 086 817 2473
Email: services@gkcancersupport.com
Website: www.gkcancersupport.com

Greystones Cancer Support

La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email: info@greystonescancersupport.com
Website: www.greystonescancersupport.com

Haven Cancer Support and Therapy Group

Haven House
68 Hazelwood
Gorey
Co Wexford
Tel: 053 942 0707 / 086 250 1452
Email: info@thehavengroup.ie
Website: www.thehavengroup.ie

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

Kilkenny Cancer Support Services
Walkin Street
Kilkenny City
Tel: 085 721 9280
Email: info@kilkennycancersupport.com
Website: www.kilkennycancersupport.com

Lakelands Area Retreat & Cancer Centre
Ballinalack
Mullingar
Co Westmeath
Tel: 044 937 1971
Callsave 1850 719 719
Email: info@larcc.ie
Website: www.larcc.ie

Newbridge Cancer Support Group
144 Allenvue Heights
Newbridge
Co Kildare
Tel: 083 360 9898
Email:
newbridgescancerhealinghelp@gmail.com

Rathdrum Cancer Support Centre
34 Main Street
Rathdrum
Co Wicklow
Tel: 087 292 8660
Email: rathcan@gmail.com

Tallaght Cancer Support Group
Millbrook Lawns
Tallaght
Dublin 24
Tel: 087 217 6486
Email: ctallaght@yahoo.ie

Wicklow Cancer Support Centre
1 Morton's Lane
Wicklow
Tel: 0404 32696
Email: wicklowcancersupport@gmail.com

Munster support groups & centres

Cancer Information & Support Centre
Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 485 163
Website:
www.midwesterncancercentre.ie

CARE Cancer Support Centre
14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 618 2667
Email: cancersupport@eircom.net
Website: www.cancercaire.ie

Cork ARC Cancer Support House
Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: info@corkcancersupport.ie
Website: www.corkcancersupport.ie

Kerry Cancer Support Group
124 Tralee Town House Apartments
Maine Street
Tralee
Co Kerry
Tel: 066 719 5560 / 087 230 8734
Email: kerrycancersupport@eircom.net
Website: www.kerrycancersupport.com

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

Sláinte an Chláir: Clare Cancer Support
Tír Mhuire
Kilnamona
Ennis
Co Clare
Tel: 1850 211 630 / 087 691 2396
Email: admin@clarecancersupport.com
Website: www.clarecancersupport.com

South Eastern Cancer Foundation
Solas Centre
7 Sealy Close
Earlscourt
Waterford
Tel: 051 876 629
Email: infosecf@eircom.net
Website: www.secf.ie

Suimhneas Cancer Support Centre
2 Clonaslee
Gortland Roe
Nenagh
Co Tipperary
Tel: 067 37403
Email: suaimhneascancersupport@eircom.net

Suir Haven Cancer Support Centre
Clongour Road
Thurles
Co Tipperary
Tel: 0504 21197
Email: suirhaven@gmail.com

Youghal Cancer Support Group
161 North Main Street
Youghal
Co Cork
Tel: 024 92353 / 087 273 1121

Ulster support groups & centres

Cancer Support and Social Club
Tiernaleague
Carndonagh
Co Donegal
Tel: 086 602 8993 / 087 763 4596

Coiste Scaoil Saor ó Ailse
Knockastoller
Gweedore
Letterkenny
Co Donegal
Tel: 087 121 7857
Email: scaoilsaor@hotmail.com

Crocus: Monaghan Cancer Support Centre
The Wellness Centre
19 The Grange
Plantation Walk
Monaghan
Tel: 087 368 0965

Cuan Cancer Social Support and Wellness Group
2nd Floor, Cootehill Credit Union
22-24 Market Street
Cootehill
Co Cavan
Tel: 086 455 6632

The Forge Cancer Support Group
The Forge Family Resource Centre
Pettigo
Co Donegal
Tel: 071 986 1924

Living Beyond Cancer
Oncology Day Services
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 912 5888 (Bleep 674/734) / 074 910 4477

For other support groups or centres in your area, call 1800 200 700.

Support groups & centres unaffiliated to Irish Cancer Society

Cancer Care West
Inis Aoi bhinn
University Hospital Galway
Costello Road
Galway
Tel: 091 545 000
Email: info@cancercairewest.ie
Website: www.cancercairewest.ie

Cúnamh: Bons Secours Cancer Support Group
Bon Secours Hospital
College Road
Cork
Tel: 021 480 1676
Website: www.cunamh.ie

Dundalk Cancer Support Group
Philipstown
Hackballscross
Dundalk
Co Louth
Tel: 086 107 4257

Good and New Cancer Drop In Centre

Unit 1, Portlink Business Park
Port Road
Letterkenny
Co Donegal
Tel: 074 911 3437

Killybegs Cancer Support Group

Kille
Kilcar
Co Donegal
Tel: 074 973 1292

Solace: Donegal Cancer Support Centre

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

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

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

American Cancer Society

Website: www.cancer.org

Cancer Focus Northern Ireland

40–44 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 9066 3281
Email: hello@cancerfocusni.org
Website: www.cancerfocusni.org

Cancer Research UK

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

The Continence Foundation (UK)

Tel: 0044 020 7831 9831
Email: continence.foundation@dial.pipex.com
Website: www.continence-foundation.org.uk

Macmillan Cancer Support (UK)

Tel: 0044 20 7840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre

Belfast City Hospital Trust
77–81 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Email: cancerinfo@belfasttrust.hscni.net

National Cancer Institute (US)

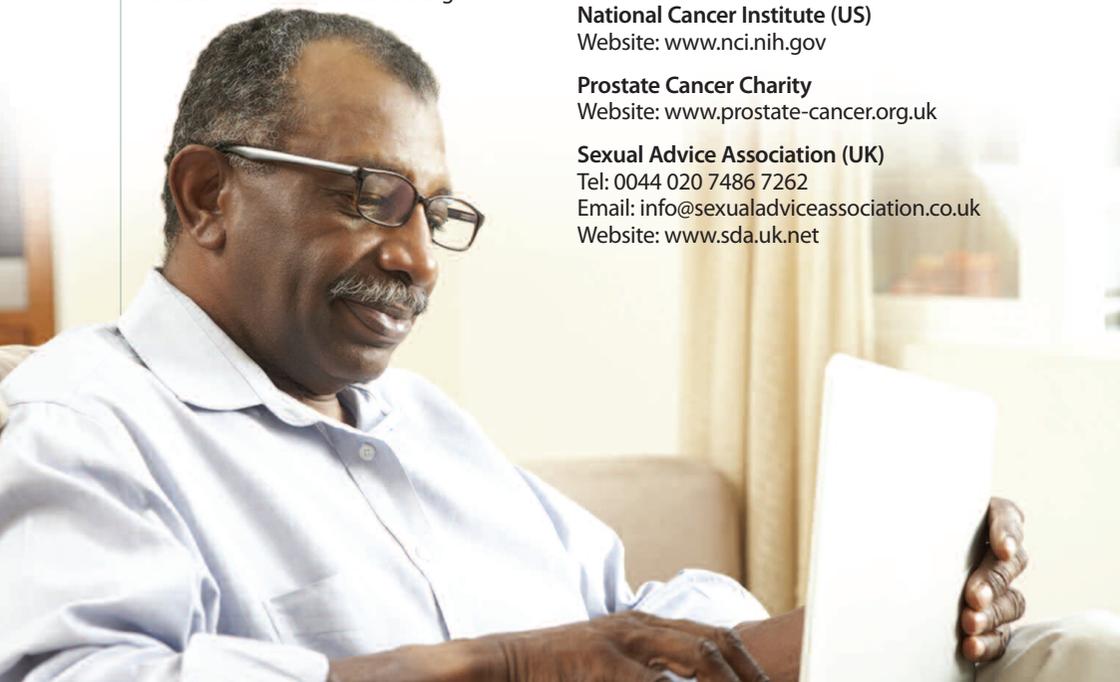
Website: www.nci.nih.gov

Prostate Cancer Charity

Website: www.prostate-cancer.org.uk

Sexual Advice Association (UK)

Tel: 0044 020 7486 7262
Email: info@sexualadviceassociation.co.uk
Website: www.sda.uk.net



Helpful books

Free booklets from the Irish Cancer Society:

- *Understanding Prostate Cancer beyond the Prostate Gland*
- *Understanding Radiotherapy*
- *Understanding Radiation Therapy: A Patient Pathway (DVD)*
- *Understanding Cancer and Complementary Therapies*
- *Diet and Cancer*
- *Coping with Fatigue*
- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Taking About Your Cancer*
- *Talking to Children about Cancer: A Guide for Parents*
- *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*
- *Journey Journal: Keeping Track of Your Cancer Treatment*

***Coping with Prostate Cancer***

Robert H Phillips
Avery Publishing Group, 1994
ISBN 0895295644

Guide to Surviving Prostate Cancer

Patrick Walsh & Janet Farrar Worthington
Time Warner Books, 2001
ISBN 0446679143

Prostate and Cancer: A Family Guide to Diagnosis, Treatment and Survival

Sheldon Marks
Da Capo Press, 2003
ISBN 978-0738208398

Prostate Cancer: A Comprehensive Guide for Patients

Kieran Jefferson
TFM Publishing, 2004
ISBN 1903378109

The Prostate: An Owner's Manual

Dr Peter Scardino
Michael Joseph, 2005
ISBN 0718146948

The Prostate Cancer Book: The Definitive Guide to the Causes, Symptoms and Treatments

Jonathan Waxman
Vermilion, 2002
ISBN 0091857120

101+ Square Meals

[Budget and nutrition]
Norah Bourke et al
MABS/HSE West/Paul
Partnership/Limerick
VEC/Safefood, 1998
ISBN 187407514X
[For more details see www.mabs.ie]

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.
Cells	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
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.
Malignant	Cancer. A tumour that spreads.
Metastasis	When cancer spreads from one part of your body to another.
Neo-adjuvant treatment	Treatment given before the main treatment. For example, hormone therapy given before radiotherapy.

Oncology	The study of cancer.
Prognosis	The expected outcome of a disease.
PSA	Prostate specific antigen. This is a protein made by your prostate gland. It can be measured in your bloodstream.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Radical prostatectomy	An operation that removes your entire prostate gland and seminal vesicles.
Radiotherapy	The treatment of cancer using high-energy X-rays.
Rectum	The lower part of your bowel. Also called your back passage.
Staging	Tests that measure the size and extent of cancer.
Urologist	A surgeon who specialises in treating prostate, kidney and bladder disease.



Questions to ask your doctor

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

- What tests do I need?
- Will the tests definitely show if I have cancer or not?
- How long will I have to wait before the tests?
- How is prostate cancer confirmed?
- 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?
- 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?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

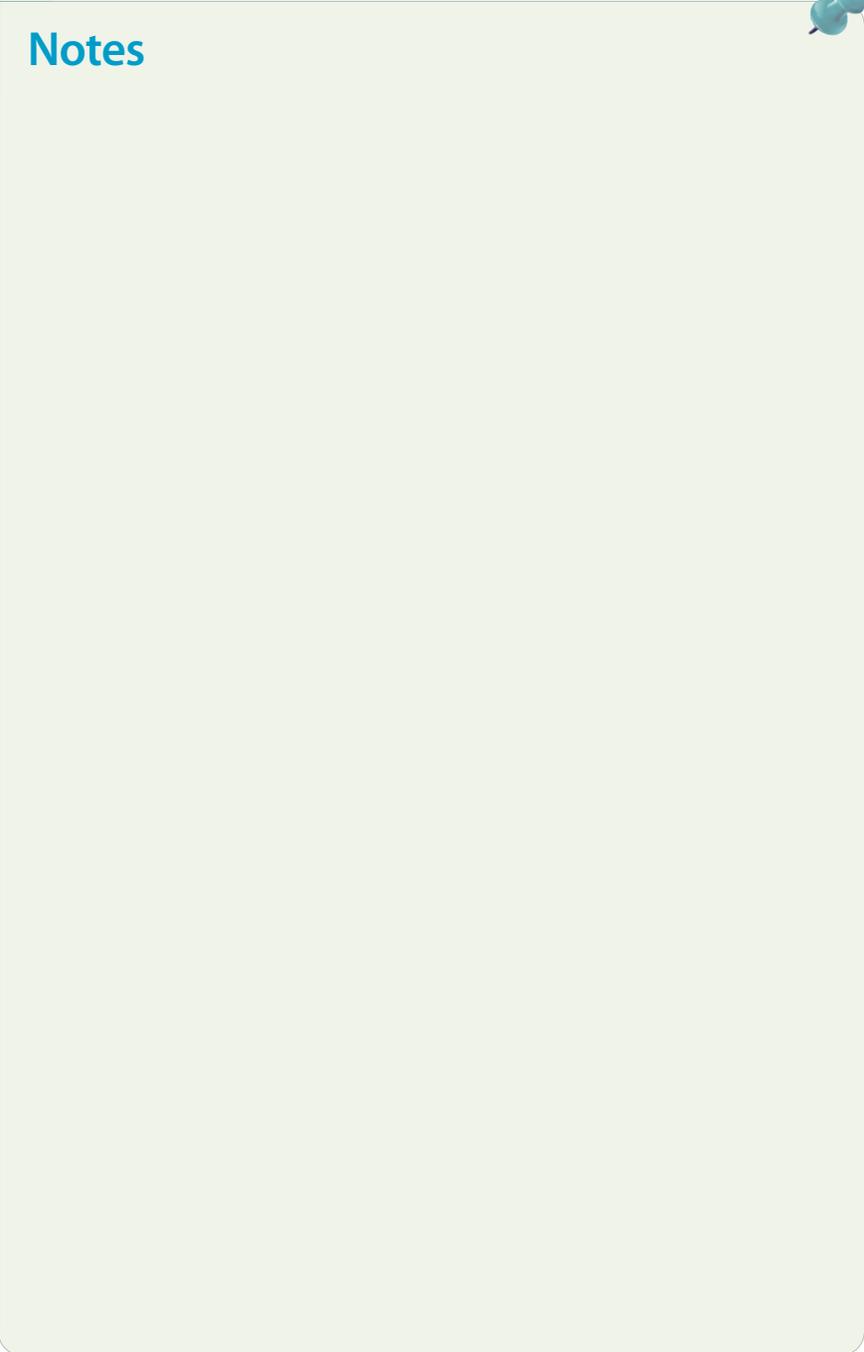
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Answer

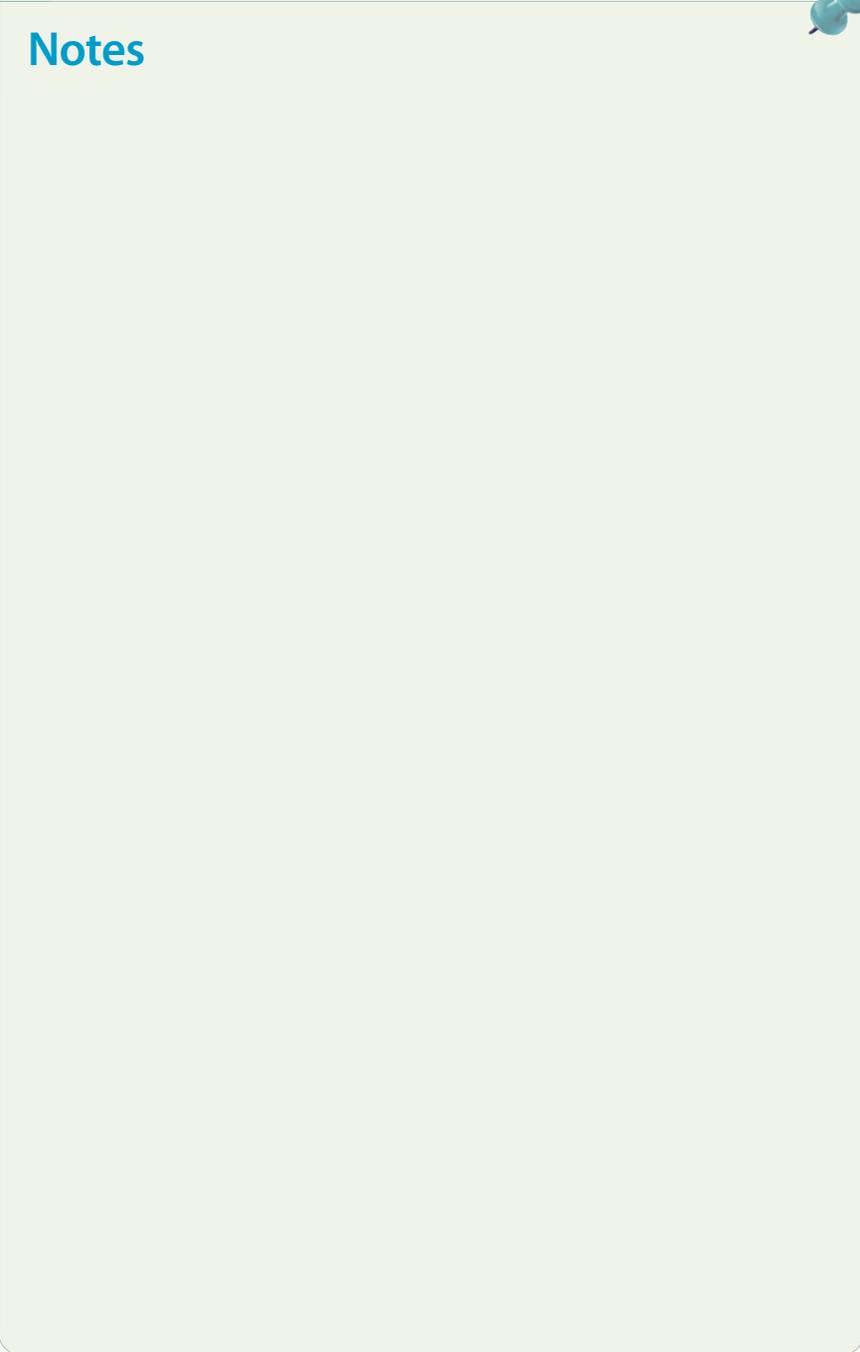
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Answer

>>> **Notes**



>>> **Notes**



Acknowledgements

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

Michael H Phillips, Illustrator
Siemens Ireland

Would you like more information?

We hope this booklet has been of help to you. After reading it or at any time in the future, if you would like more information or someone to talk to, please call the National Cancer Helpline on 1800 200 700.

Would you like to be a patient reviewer?



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

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

If you would prefer to phone or write to us, see contact details below.

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, education and research. This includes patient education booklets. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us at CallSave 1850 60 60 60 or email: **fundraising@irishcancer.ie**

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4

Tel: 01 231 0500 **Email:** info@irishcancer.ie **Website:** www.cancer.ie

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

National Cancer Helpline Freefone 1800 200 700

Open Monday to Thursday 9am to 7pm

Friday 9am to 5pm

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

