Understanding Early Prostate Cancer
Caring for people with cancer
This booklet has been written to help you to 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 prostate cancer, its treatment and how it may affect you.

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

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<th>Specialist nurse</th>
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This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave their time and expertise to previous editions of this booklet.

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Contents

4 Introduction

About early prostate cancer

5 What is cancer?
6 What is the prostate?
7 What is early prostate cancer?
7 How common is prostate cancer?
8 What increases my risk of prostate cancer?
9 Being diagnosed with prostate cancer
10 What tests will I have?
12 Staging prostate cancer
14 Grading prostate cancer?
15 Asking about your prognosis

Treatment and side-effects

17 How is early prostate cancer treated?
22 Keeping track of information
23 Decision aid tool
26 Active surveillance
29 Brachytherapy
37 External beam radiotherapy
44 Surgery
55 Watchful waiting
55 Clinical trials
56 How can I cope with fatigue?
57 Will treatment affect my sex life and fertility?
62 What follow-up do I need?
64 Cancer and complementary therapies

Coping and emotions

65 How can I cope with my feelings?
69 How can my family and friends help?
71 Talking to children and teenagers
72 Life after cancer

Support resources

73 Coping with the financial impact of cancer
75 Irish Cancer Society services
77 Local cancer support services
78 Helpful books
79 What does that word mean?
81 Questions to ask your doctor
82 Your own questions
Introduction

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

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

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

Reading this booklet

Remember you do not need to know everything about early prostate cancer straight away. Read a section about a particular item as it happens to you or if you are interested in it. Then when you want to know more, read another section.

If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700 or email the nurses at cancer nurseline@irishcancer.ie. You can also visit a Daffodil Centre. See page 75 for more about Daffodil Centres. You can email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.

Cancer Nurseline Freephone 1800 200 700

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 first grows. For example, prostate cancer starts in cells in the prostate gland, breast cancer starts in cells in the breast.

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

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

What is the lymphatic system?

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

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

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. This 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). The PSA protein turns semen into liquid. Some of this protein can pass into the bloodstream. When doctors check the prostate gland, they often measure levels of this protein in your blood. This is called the PSA test.

If your PSA level is higher than normal, it can sometimes be a sign of prostate cancer. However it can also be a sign of a less serious condition.

The prostate gland can get bigger with age, and may press on the urethra (the tube that drains the bladder). This sometimes causes problems passing urine, otherwise known as prostate urinary symptoms.

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. With early prostate cancer there may be no symptoms and the tumour may be too small to be felt during an examination of your back passage. Your doctor may only suspect it after doing a PSA test. The PSA test is a blood test that measures the level of PSA (prostate specific antigen) in your blood. PSA is often raised in men with prostate cancer.

This booklet only deals with early prostate cancer. If you want information about the later stages of prostate cancer, please read our booklet Understanding locally advanced and advanced prostate cancer. It’s available free from Daffodil Centres or by calling our Cancer Nurseline. You can also download it from our website www.cancer.ie

How common is prostate cancer?

In Ireland, prostate cancer is the second most common cancer in men, after skin cancer. Each year over 3,300 men are diagnosed with prostate cancer here. This means that 1 in 7 men will be diagnosed with prostate cancer during their lifetime. Although there are many men with this disease, most men do not die from it.
Being diagnosed with prostate cancer

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

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

Everyone reacts differently to a cancer diagnosis. However you feel, you are not alone. There are many people who can help and support you at this time.

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

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

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

What increases my risk of prostate cancer?

The exact cause of prostate cancer is unknown. But there are certain things called risk factors that can affect your chances of getting the disease.

Having a risk factor doesn’t mean you will definitely get cancer. And sometimes people without any known risk factors develop cancer.

Some things that can increase your risk of prostate cancer are:

- **Age**: The risk of prostate cancer increases with age. It usually affects men over 50 and is rare in young men. 75% of prostate cancers are diagnosed in men over 65.
- **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.

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.

Email cancernurseline@irishcancer.ie
Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparations for a CT scan can vary but the doctor or nurse in your hospital will tell you what to do. During the scan you will lie on a table which passes through a large doughnut-shaped machine. It does not hurt and takes between 10 and 30 minutes. This test is usually done as an outpatient, so you should not need to stay in hospital.

**MRI scan:** This is a scan that uses magnetic energy to build up a picture of the tissues inside your body. You might get an injection before the scan to show up certain parts of your body. During the test you will lie inside a tunnel-like machine. Some people are afraid they may feel claustrophobic during it. If you are anxious, contact the radiographer the day before. They may be able to give you medication to relax you on the day. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test. You cannot wear metal jewellery. The scan does not hurt but it can be noisy. You will be given earplugs to wear during it. Usually you can go home after the scan.

**Bone scan:** Prostate cancer can sometimes spread to your bones. Bone scans are very sensitive and can detect cancer cells before they show up on an X-ray.

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

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**What tests will I have?**

After being diagnosed with prostate cancer, your doctor may want to do more tests to find out more about your cancer and your general health. Whether you need any tests or not depends on the results of your PSA, Gleason score (see page 14) and how your prostate gland feels to touch. Some men will need no tests after diagnosis while others will need one or more. Your doctor will let you know which ones you need to have.

Tests you may have include:

**CT scan (CAT scan):** This is a special type of X-ray that gives a detailed picture of the tissues inside your body. You might be asked not to eat (fast) for a few hours before the scan. You may also be given an injection or a special drink to help show up parts of your body on the scan.

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**Telling people about your diagnosis**

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

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

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you would like to talk things over with a cancer nurse. You can also ask for a copy of our booklet *Who Can Ever Understand?* This booklet can help to you find ways to talk about your cancer and to ask for the help and support you need.
Because abnormal bone absorbs more of the radioactive substance than normal bone, it can show up on the scan.

The level of radioactivity used in these scans is very low and safe. It disappears from the body within a few hours. But it is best to avoid contact with pregnant women and very close contact with babies or young children for 24 hours (such as holding them or letting them sit on your lap).

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

What are the stages of prostate cancer?

Tumour – How big is the tumour?
T1 The tumour is within your prostate gland. It is too small to be felt during a rectal exam.
T2 The tumour is still within your prostate gland. It is large enough to be felt during a rectal exam.
T3 The tumour can be felt throughout your prostate, very close to nearby tissues.
T4 The tumour has spread to tissues outside your prostate gland.

Node – Are the lymph nodes affected or not?
N Cancer is present in the lymph nodes
N0 No cancer in the lymph nodes
N1 Cancer has spread to 1 or more of the lymph nodes

If you have been diagnosed with early prostate cancer you will see N0 as the cancer has not spread out of the prostate.

Metastasis – has it spread outside the prostate?
M The cancer has spread
M0 The cancer has not spread

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

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

How is prostate cancer staged?
There are different ways to describe the stages of cancer. The staging system normally refers to the size of the tumour (T), if there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis).
Grading prostate cancer

Grading helps your doctor to predict how the cancer will behave and how quickly it might grow.

How is prostate cancer graded?
Grading refers to how the cancer cells look under the microscope. The sample of cells from your prostate will probably be taken to diagnose prostate cancer. This is called a biopsy. A doctor called a pathologist will look at the samples under a microscope to see 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.

In prostate cancer the grades are 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 grades of prostate cancer in each sample and adds them together to give an overall score. This means the Gleason score is usually from 6 to 10.

This table 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.

<table>
<thead>
<tr>
<th>Risk</th>
<th>Gleason score</th>
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<tr>
<td>Low</td>
<td>6 or lower</td>
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<tr>
<td>Medium or intermediate</td>
<td>7</td>
</tr>
<tr>
<td>High</td>
<td>8 or higher</td>
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Knowing the stage and grade of your cancer helps the doctor to plan the best treatment for you.

Asking about your prognosis

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

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

It is not always easy for doctors to answer a question about life expectancy, as the answer is based on a ‘typical’ experience. Experiences can vary a lot from person to person. What happens to you might be quite different from what the doctor expects.

If you decide you want information on your prognosis:

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

How is early prostate cancer treated?

Early prostate cancer can be treated in a number of ways. You may be given a choice of treatments.

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 you prefer. Your doctor and nurse will support and advise you in making your decision. See pages 18–23 for more advice about making a decision.

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 our Cancer Nurseline on 1800 200 700 for a copy of Understanding locally advanced and advanced prostate cancer. Or pick one up at a Daffodil Centre.

Types of treatment

The following treatment options are available:

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 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 potential side-effects of treatment. Active surveillance allows for your prostate cancer to be closely monitored so that any changes can be picked up and treatment can start early.
Treatment options: Your doctor and nurse will explain your treatment options to you. Your doctor will try to tell you if one treatment is better than another at getting rid of your cancer, but often the treatment options are all thought to be equally good at treating early prostate cancer. Often the choice of treatment will be a personal decision, based on your own lifestyle and preferences. Ask as many questions as you like about your options, no matter how small or trivial you think they are. You could use the fill-in page at the back of this booklet for your questions and answers. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

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.

Time to think: When faced with a serious illness, it can be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.

Second opinion: You might also find it reassuring to have another medical opinion to help you make a decision about your treatment. Your doctor will refer you to another specialist for a second opinion if you feel this would be helpful.

Making a treatment decision
Many men may find it stressful having to choose between treatment options, and worry that they will choose the wrong one. Your doctor may suggest the best treatment for you, but in many cases there is no one best option.

It’s important to take enough time to think through the pros and cons of each treatment and then decide which suits you and your lifestyle.
as an individual. 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.

Very often there is no rush for you to decide which treatment you want. Taking time to talk things through with doctors and nurses, family and friends can help you to make the right decision for you. You can ask to talk to a urologist and a radiation oncologist before you make up your mind. You may also find it helpful to read the information on each treatment in this booklet.

Hints & Tips – making a decision

Things to think about when deciding:

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

It may be helpful to:

- Know your results and write down your PSA and Gleason score and the stage of your cancer
- List each of the options that are available to you
- Write down what you like and don’t like about each option
- Ask yourself how important these points are to you (individually) and to your family. The decision tool on page 23 can help you.
- Write down what is the most important goal for your treatment
- Talk to other men who have received these treatments and find out about their experiences and how they managed any side-effects. The Irish Cancer Society can put you in touch with a trained Survivor Support volunteer who has been through a prostate cancer diagnosis. For more information contact our Cancer Nurseline on 1800 200 700.

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

Giving consent for treatment

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

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

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

Individual treatment

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

<table>
<thead>
<tr>
<th>Grading the prostate cancer</th>
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<tbody>
<tr>
<td>PSA level at diagnosis</td>
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<tr>
<td>Clinical stage at diagnosis</td>
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<tr>
<td>Number of biopsy samples taken</td>
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<tr>
<td>Number of biopsy samples with cancer</td>
</tr>
<tr>
<td>Gleason score</td>
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Tick all the treatment options suitable for you:

<table>
<thead>
<tr>
<th>Treatment options suitable for me</th>
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<tbody>
<tr>
<td>Active surveillance</td>
</tr>
<tr>
<td>Brachytherapy</td>
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<tr>
<td>External beam radiotherapy</td>
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<tr>
<td>Surgery</td>
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<tr>
<td>Watchful waiting</td>
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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.

<table>
<thead>
<tr>
<th>Treatment options suitable for me</th>
<th>Advantages</th>
<th>Score</th>
<th>Disadvantages</th>
<th>Score</th>
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Waiting for treatment to start
Planning cancer treatment takes time. Most people want to start treatment right away. You may worry that the cancer will spread during this time.

Cancer treatment should start soon after diagnosis. But for most cancers, it won’t hurt to wait a few weeks to begin treatment. This also gives you time to talk about all your treatment options with your doctors, family, and friends.

If you are worried, tell your doctor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.
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 may be able to defer your treatment for a number of years.

For prostate cancer found at an early stage that is a slow-growing, low-risk type, 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 will not be 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
- An MRI scan when you have started active surveillance. If you have not had one previously your doctor may repeat this after a year

With active surveillance you won’t have any treatment-related side-effects, like feeling very tired or changes to your sex life. Having repeated biopsies can increase the chance of infections and other complications like bleeding and pain.

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

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

What happens if the results of my tests change?

- PSA: A rise in your PSA level may be a sign that your cancer has started to grow. If this happens, your doctor will look at how quickly your PSA is changing and by how much. If your PSA is rising, your doctor will discuss with you 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 the biopsy detects some cancer with a higher Gleason score (see page 14).
- 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.
- MRI: If your MRI scan shows a change in the size or location of your prostate cancer, you may be offered active treatment or further tests.

Is active surveillance risky?

There is a chance that your cancer will grow while you are on active surveillance. But your tests will help to pick up any changes at an early stage when you can still have successful treatment. 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.
Brachytherapy

Brachytherapy is a type of radiotherapy that can be used to treat early prostate cancer. With brachytherapy the radiation source is placed inside your body. The radiation comes from tiny radioactive pellets or seeds. The seeds release radiation slowly over a number of months. The radiation destroys prostate cancer cells. The seeds are not removed and the radiation fades away over time. It is a safe therapy. The radiation does not cause any risk to other people. The aim of brachytherapy is to fully cure your prostate cancer.

The doctor who specialises in giving radiotherapy is called a radiation oncologist. 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 (see page 37) and hormone therapy (see page 43).

Remember your active surveillance appointments

- It is very important to keep any future appointments that are arranged for you as part of your active surveillance programme.
- Write the date and time down on a calendar to remind yourself closer to the time.
- If you cannot make the arranged appointment then make one for another day by contacting the urology clinic in the hospital and speak with your prostate cancer nurse specialist.

Advantages of active surveillance

<table>
<thead>
<tr>
<th>Advantages of active surveillance</th>
<th>Disadvantages of active surveillance</th>
</tr>
</thead>
<tbody>
<tr>
<td>No treatment-related side-effects</td>
<td>You may become anxious or worried about your cancer changing</td>
</tr>
<tr>
<td>Does not interfere with your everyday life</td>
<td>Repeat prostate biopsies are needed which can increase the risk of infections and other complications</td>
</tr>
<tr>
<td>You can avoid unnecessary treatment</td>
<td>The cancer may grow more quickly than expected</td>
</tr>
</tbody>
</table>

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 treatment-related 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.

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 surgery to 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 may receive brachytherapy along with another treatment. For example, you may need some doses of external beam radiotherapy or hormone therapy as well.

**HDR brachytherapy**

In a small number of situations you may be offered a different type of brachytherapy using a temporary source of radiation. This is called HDR brachytherapy.

HDR brachytherapy uses a high-dose of radiation. Instead of using permanent seeds, a temporary source of radiation is inserted into the prostate gland for a few minutes.

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

**What happens before brachytherapy treatment can be given?**

An ultrasound scan of your prostate is done first. This happens some weeks before the seeds are put in. 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. An enema is a fluid solution gently put into your bowel through your back passage. 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 a general or spinal anaesthetic. 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. The seed are then guided into your prostate gland using a fine needle. You will not be cut. It takes about 90 minutes to put in all the seeds.

**After brachytherapy**

You prostate may get swollen after brachytherapy, so a tube (catheter) will be put into your bladder during operation to put the seeds in. The tube will drain any urine. It may be left in for a couple of hours or overnight.

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 usually goes 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).

You will be given antibiotics to prevent an infection. You may also be given a prescription for painkillers and alpha blockers. Alpha blockers are tablets to help relax your bladder and make it easier to pass urine. Usually you will be able to go home the day of the implant once you have recovered from the anaesthetic and can pass urine normally.
What about sex after brachytherapy?

It is safe for you and your partner to sleep in the same bed (if your partner is not pregnant). You can talk to your doctor or nurse about when you can start having sex again after brachytherapy. They can give you an advice sheet about this.

You may not feel like having sex in the first few weeks after treatment. This can be due to tiredness or side-effects like pain or swelling around the area of the prostate. These symptoms normally ease with time.

There is a small risk that a seed may come out in your semen when you are having sex. You should use a condom to catch the semen the first 4-5 times you have sex. 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.

Medical alert card

Because you will have radioactivity in your body for a time after brachytherapy, the radiotherapy unit may give you a medical alert card detailing the treatment you have had. This is to alert other medical professionals if you have a medical emergency. It will direct the staff to contact your radiotherapy unit for specific advice. It is important to carry this with you all the time, for the amount of time recommended by the unit. This card is also necessary for airline travel, as some of the security sensors may be triggered by the weak radiation emitted from the seeds.

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 safe is the radiation?

The radiation is released into your prostate gland over the first few months. This radiation is then absorbed by your prostate. After about 12 months, the seeds are no longer active and 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 an 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.

How long do the seeds stay in my body?

The seeds remain permanently in your prostate gland. There is a slight chance that a seed could be passed out in your semen or urine, although this is rare. If you do pass a seed, tell the radiotherapy unit. Do not handle the seed with your fingers and flush it down the toilet.

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.

Hints & Tips – brachytherapy

- Wait 2 weeks after treatment before having sex.
- 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 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

Urinary problems: The radiation can make your urethra inflamed. The urethra is the tube through which you pass urine. The radiation might also irritate your bladder. This can cause symptoms such as a burning sensation when you pass urine, needing to pass urine more often, having a slow stream, finding it harder to start passing urine, and needing to go more quickly than you used to. If you cannot pass urine afterwards, this is called urinary retention. This 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, when the radiation is strongest. You may 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. Urinary side-effects usually improve over time as the seeds lose some of their radiation.

Drinking plenty of fluids can help to ease urinary side-effects. Try to drink 1½ to 2 litres of fluids a day, but avoid drinks with alcohol or caffeine, such as tea, coffee and cola.

You might also need to take medication to help with urinary side-effects. Tablets called alpha blockers can help to relax the muscle within the prostate and to reduce the narrowing of the water tube that runs through the centre of the prostate.

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 have a higher risk of incontinence.
External beam radiotherapy

Radiotherapy is a treatment that uses high-energy rays to kill cancer cells. The aim of radiotherapy is to destroy the cancer cells with as little damage as possible to normal cells. With 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. The aim of radiotherapy is to fully get rid of your prostate cancer.

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.

Planning your treatment

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

In external radiotherapy an important part of the planning process is simulation. This involves using a CT scanner to pinpoint the area to be treated. You may have extra scans or X-rays taken, but this is to plan your treatment only. The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. You might also have gold markers called fiducials put into your prostate to make sure the radiotherapy targets the right area. These are put into your prostate gland under anaesthetic before the treatment starts.
Short-term side-effects

- Urinary problems, such as a burning sensation when passing urine, needing to go to the toilet more often or blood in your urine
- Diarrhoea (loose, semi-solid bowel movements) or constipation (not having a bowel movement often enough)
- Discomfort at your back passage, including soreness and bleeding when you go to the toilet
- Sore or discoloured skin on your bottom or between your legs
- Fatigue (tiredness). See page 56 for more about fatigue

Late, long-term or permanent side-effects

Late side-effects may develop some time after treatment. Some side-effects last for a long time or may even be permanent.

Erectile dysfunction: Radiotherapy to your prostate can damage 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 see our website, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also email the nurses at cancernurseline@irishcancer.ie
‘Dry’ orgasm: After radiotherapy, some men find that an orgasm has less semen than usual or they have a ‘dry’ orgasm, where no semen is ejaculated. See page 53 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 like needing to go to the toilet more often or pain when you pass urine, you might develop a narrowing of your urethra (water pipe). This can make it difficult to pass urine. Narrowing of your urethra 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 urgency to pass urine, resulting in leakage of urine. But this is unlikely unless you have had prostate surgery as well. If this happens, discuss it with your doctor or nurse.

Bowel problems: In some cases bowel problems might carry on. Or they might develop years after treatment and you find that your bowel habits change permanently. Bowel motions may be more urgent and frequent after radiotherapy. 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 to see if there are any options open to you. See page 62 for more about fertility. It is not safe to assume you are sterile after radiotherapy.

If you feel unwell or have any other side-effects or symptom, tell your doctor, nurse or radiation therapist.

For more information on the different types of radiotherapy and the side-effects of radiotherapy or a copy of the booklet Understanding Radiotherapy, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

<table>
<thead>
<tr>
<th>Advantages of external beam radiotherapy</th>
<th>Disadvantages of external beam radiotherapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>You don’t need a general anaesthetic and you don’t need to stay overnight in hospital.</td>
<td>It may be difficult if you have far to travel to the radiotherapy unit.</td>
</tr>
<tr>
<td>You may be able to work and carry on normal activities during the treatment.</td>
<td>It may take some time to see how effective the radiotherapy has been.</td>
</tr>
<tr>
<td>You are not radioactive during or after the treatment so you can be in close contact with others.</td>
<td>You may not be able to have prostate surgery in the future due to the effects of the radiotherapy.</td>
</tr>
<tr>
<td>Each treatment is relatively short. It usually takes about 15 minutes, although you may be in the radiotherapy department for up to an hour.</td>
<td>You might experience side-effects such as bowel or urinary problems, erectile dysfunction and fatigue. Some of these side-effects may get worse over the longer term.</td>
</tr>
<tr>
<td></td>
<td>You may become infertile.</td>
</tr>
<tr>
<td></td>
<td>Treatment may very slightly increase the risk of getting a second cancer.</td>
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</tbody>
</table>
Radiotherapy and hormone therapy

For some types of prostate cancer, giving hormone therapy together with radiotherapy can make the treatment more effective. 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 depending on your own situation. It may last 6 months, 2–3 years or occasionally longer. Do ask your radiation oncologist for how long you will 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

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.

Hormone therapy and sex

Testosterone is the male hormone needed for getting an erection and is responsible for your sex drive. Hormone treatments for prostate cancer lower the level of testosterone in the body. For most patients, this causes a loss of erections and loss of libido (desire for sex).

Libido can come back once you stop taking hormone therapy, although it can take many months.

For more information about hormone therapy and how to manage the side-effects, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read more on our website, www.cancer.ie.

Email cancernurseline@irishcancer.ie
Surgery

The aim of surgery is to remove the prostate cancer. The operation is called a radical prostatectomy. It involves removing your prostate gland and sometimes the 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 is suitable for 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.

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. You can 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.

The main types of prostate surgery are:
- Open prostatectomy (open surgery)
- 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: 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 specialised type of surgery. Surgeons need 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 to 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. As with laparoscopic prostatectomy surgery, specially trained surgeons are needed to do this operation.

Nerve-sparing prostatectomy

Sometimes having to remove all the cancer cells means that the two bundles of nerves attached to the prostate will be damaged. These nerves control erections. If the nerves are damaged during the operation it can cause problems with getting an erection in the future.
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. It will be left in for about 1 to 3 weeks.

Pain:

You will probably 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.

Wound:

Healing of the wounds after surgery usually takes a few weeks. Sometimes they may appear swollen and bruised slightly but this too settles down with time. Healing on the inside of your body will take a bit longer.

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

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

Having the surgery

Tests: To make sure you are fit for surgery, you will need some tests. For example, blood tests, heart tracing (ECG), chest X-ray and a physical exam. An anaesthetist may also examine you to make sure you are fit for surgery. 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 may also be shown how to do deep breathing and leg exercises to prevent a chest infection or blood clot afterwards. You may be given some elastic stockings to wear and an injection of an anti-clotting drug 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 also spend some time in the recovery room while recovering from the anaesthetic.

If the cancer has spread too close to the nerves, your surgeon may need to remove one or both bundles of nerves.

In some cases, it is possible to spare nerves on one side of your prostate. This is called a nerve-sparing prostatectomy. It gives you a better chance of regaining erections than if you had 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.
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. Otherwise, you may have dissolvable stitches which will not need to be removed. Contact your GP or the hospital as soon as possible if your wound becomes swollen, red or painful. This could be a sign of infection. On the day you go home, you will be given a date to have your urinary tube (catheter) removed and often another appointment to see the surgeon. This is usually about 6 weeks after the operation. If you have a worry or symptom that is causing you concern before your check-up date, contact your doctor, nurse or hospital ward for advice.

Removing the urinary tube
You will need to return to the hospital or to your GP to have your urinary tube (catheter) removed. This takes just a few seconds. Most likely you will experience some leakage of urine once the tube is removed. This is not unusual and normally improves with time. 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. It is important to continue performing pelvic floor exercises once your catheter has been removed to try and reduce urine leakage. If you need help in doing these you should discuss this with your nurse.

Leaving hospital
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.

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. The risk of sluggish bowel 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 without hurting yourself 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 will be able to go for walks on your own.

Urinary catheter: The urinary tube will stay in place for between 1 and 3 weeks after your surgery. The urine you make will pass through the tube into a drainage bag. The catheter drainage bag will be worn inside your trousers and will be secured around your lower leg. Before you go home, your nurse will show you how to look after the drainage bag.

It is important that the urine can drain easily from your bladder and into the drainage bag. Try to drink plenty of fluids every day to reduce the risk of getting an infection: between 1.5 and 2 litres is often best. Avoid drinks with alcohol or caffeine in them.

Wash your hands before and after handling the catheter. When washing the catheter entry tip, wash in a one-way direction away from your body. Speak with your nurse if you notice any leaking around the outside of the catheter or if you the notice that the catheter is not draining correctly.

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. This is normal, but talk to your nurse if this happens to you a lot. It may happen when your bowels move. Your doctor can prescribe medication if this becomes a problem for you.
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. You can get pads from the hospital before you leave, from your public health nurse or from a pharmacy. Your nurse will 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 carry on, your public health nurse can give you advice and help. 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.

There is more information on urinary problems after prostate cancer on our website, including advice on how to do pelvic floor exercises. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. If you prefer to contact a cancer nurse by email, please send your message to cancernurseline@irishcancer.ie

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 everyone is different.

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. Call our Cancer Nurseline on 1800 200 700 if you would like to be put in contact with a trained volunteer who has had treatment for prostate cancer.

Urinary incontinence

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

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

It is rare to need more surgery for problems with incontinence. However, there are certain surgical techniques which may help improve the situation such as sling surgery. Your doctor will discuss with you which surgical technique would be most suited to you if necessary.
Erectile problems
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. After prostate cancer surgery, you may find it is not possible to have a ‘natural’ erection without the help of medication or other treatments.

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.

Tips & Hints – urinary incontinence
- Cut down on tea, coffee, cola and alcohol, as these drinks can irritate your bladder.
- Drink plenty of fluids. Try to drink up to 8 glasses or cups each day.
- If you find it hard to get to the toilet in time, 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.

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 45 for more details.

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

Early treatment for erectile dysfunction
Taking medication or using a vacuum pump for erectile dysfunction soon after surgery can improve your chance of having erections again. 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 our Cancer Nurseline on 1800 200 700 or email the nurses at cancernurseline@irishcancer.ie See pages 57-59 for more information about treatments for erectile dysfunction and how to get the best from treatment.

‘Dry orgasm’: After prostate surgery, an orgasm will not cause an ejaculation of semen. This is known as a ‘dry orgasm’. Many men describe the sensation of orgasm as different to their orgasm before surgery. A few men describe it as lasting longer, others describe some pain after orgasm in the early days, or some simply describe it as different. A dry orgasm means that you cannot father a child in the future. Tell your surgeon if you think you might wish to father children after your surgery, as it may be possible to store your sperm before treatment starts. See page 62 for more on infertility.

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.
Watchful waiting

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

Clinical trials

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

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

More information

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

Advantages of prostate surgery | Disadvantages of prostate surgery
--- | ---
Surgery will completely remove the cancer if it is only in the prostate gland. | It involves a general anaesthetic and the usual risks you would expect with surgery, like the risk of bleeding, infection and blood clots.
The prostate can be removed and be fully analysed and staged in the laboratory. | It involves a short stay in hospital for a few days.
The success of the treatment can be easily assessed by PSA-testing. | You may get side-effects afterwards like problems with erections and urinary incontinence.
If the PSA were to rise after surgery you would still be able to get other treatments like radiotherapy or hormone treatment. | You will not be able to father children after the surgery, as the prostate, which normally makes some of the fluid needed for semen to be made, has been removed.
Recovery takes around 6 weeks.

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.
How can I cope with fatigue?

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

Fatigue when you have cancer can be caused by many things, including:
- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Symptoms like pain, breathlessness or fluid retention

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

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

Tips & Hints – fatigue

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

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

Will treatment affect my sex life and fertility?

Some men with prostate cancer feel that changes to their sex lives and their relationships are some of the biggest issues they face. It is natural for you to be concerned about your sex life – men often ask about this.

Treatment can affect you physically and mentally when it comes to sex.

Physical effects of treatment

Many of the treatments for early prostate cancer can have an impact on your sex life. Fatigue, loss of libido, changes to the way you ejaculate, urinary incontinence and erectile dysfunction (ED) after treatment for prostate cancer can all affect the way you feel about having sex.

For more details on sexual side-effects see the individual treatment sections:
- Sex after brachytherapy – page 35
- Sex after radiotherapy – page 39
- Sex after surgery – page 52
- Sex and hormone therapy – page 43

You can also see our website [www.cancer.ie](http://www.cancer.ie) for more information.

Treatment for sexual problems

Not every man wants treatment for erectile problems. Some men accept the changes in their body and do not feel the need to get treatment. For other men, finding a way to treat their erectile dysfunction is very important. There is no right or wrong way to react – just the way that feels right for you.
The treatment options for erectile dysfunction include:

- Tablets
- Urethral pellets
- Penile injections
- Penile implants
- Vacuum pump

**Tablets:** Sildenafil (Viagra®), tadalafil (Cialis®) and vardenafil (Levitra®) are all examples of tablets that can help men to get erections. You need to have an interest in sex and need sexual stimulation for them to work.

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

For more information on taking tablets for ED, see our website www.cancer.ie. You can also speak to a cancer nurse in confidence by calling our Cancer Nurseline on 1800 200 700 or dropping into a Daffodil Centre. You can email the nurses at www.cancer.ie

**Urethral pellets:** A urethral pellet can be put into the opening or ‘eye’ of your penis. Then the pellet is massaged into the penis to help it melt. Standing or walking around can help your erection develop better. You should get an erection within 5 to 15 minutes. Some men get some pain, redness or a burning sensation in the penis or testicles after using the pellets.

**Penile injections:** Injections into the penis such as alprostadil (Caverject®) can work well for men with erectile dysfunction. The idea of injections is that they cause the penis to fill with blood and you should get an erection within about 15 minutes. The erection lasts from 30 minutes to 2 hours.

The first dose is given by your doctor in the hospital so that they can see how well you respond and decide the best dose for you. Then you or your partner will be taught how to give the injection at home. The injection does not hurt, as the needle is very fine. You should not inject more than 2 or 3 times a week.

**Vacuum pump:** A plastic tube is placed over the penis and a pump is used to create a vacuum. This causes blood to flow into your penis, creating an erection. A rubber ring is then put around the base of your penis to hold the blood in the penis and keep the erection for up to 30 minutes.

Some men prefer the pump because it avoids the use of drugs. Another advantage is that the cost of the pump is a once-off payment.

Although most men find the vacuum pump effective, some men find it awkward to use. It can take some practice to get the technique just right for you. You can use the pump as often as you like. It can also be used together with tablets or injections.

You may be advised to use to pump to encourage blood flow to your penis after surgery or radiation treatments, even if you are not ready to have sex.

There is more information and hints and tips on using a vacuum pump on our website, www.cancer.ie

**Penile implants (surgery):** Penile implants can be an option for men who have had erectile dysfunction for at least a year and tried all other methods. The implant consists of a pair of tubes attached to a reservoir and a pump.

This is placed inside your body during an operation. By pressing on the pump, the fluid in the reservoir moves into the cylinders to form an erection or rigid penis. Most men and their partners are very satisfied with these devices. Side-effects include infection and pain. Rarely, the device stops working properly.

**Tips & Hints – getting the best from treatment**

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

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

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

Sexual relationships are built on many things, such as love, trust, common experiences and open communication. Talking about your feelings may ease any worries you have. Try to tell your partner how you feel and find out how your partner feels too. This can help to make sure neither of you feels rejected by the change in your physical relationship.

There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex for a time or you having sexual problems, you can still enjoy a close and loving relationship with your partner. Ways of maintaining a close physical relationship include cuddling and kissing, touching, caressing and holding each other. This can help to keep the intimacy in your relationship.

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

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

**Help with your emotions**

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

Changes to your sexual nature can have an effect on your mood. For example, you may feel angry or frustrated by these changes. If you are finding it hard to cope, talk to your GP, hospital doctor or nurse.

Getting support or advice can help to stop these feelings building up too much. You may find it useful to get in touch with a cancer support centre. Some centres offer a number of free counselling sessions to help you to deal with your feelings. For more information on cancer support centres and counselling, call the Cancer Nurseline on 1800 200 700 or visit [www.cancer.ie](http://www.cancer.ie).

Many men find that keeping active can help to lift their mood. It can also help to focus on hobbies and other things you enjoy.

**Asking for advice**

If you have any questions about how treatment may affect your sex life, ask your doctor or nurse. Don’t be embarrassed or worry that your question is small or trivial. Your doctor and nurse are well used to taking about these matters and will give you advice.

You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie).

**Contraception**

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

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

Ask your doctor’s advice about contraception or if you are thinking about having children after treatment.
Getting the most from your appointment

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

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

Staying healthy after treatment

Many people want to make positive changes to their lives after their treatment has ended. Having a healthy lifestyle is important as it can help you to:
- Feel better
- Heal and recover faster
- Cope better with the side-effects of treatment
- Keep up your energy and strength

Research suggests that a healthy lifestyle may also lower your risk of the cancer coming back. A healthy lifestyle includes:
- Exercising
- Eating healthy foods
- Staying at a healthy weight
- Not smoking
- Protecting yourself from the sun

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

Fertility

Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. Discuss any worries you have about infertility with your doctor before treatment starts. He or she can tell you if there are any options open to you at this time. For example, it may be possible to freeze your sperm before starting treatment. Rotunda IVF at the Rotunda Hospital in Dublin provides a service where eggs or sperm can be frozen for later use.

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

What follow-up do I need?

After your cancer treatment has ended you will still need to go back to the hospital for regular check-ups. This is called follow-up. The follow-up will involve PSA tests (see page 6) and maybe a digital rectal exam (DRE). DRE is where the doctor feels your prostate gland through your rectum (back passage). At first you will see your consultant every 3 months but these check-ups will become less frequent. You may have follow-up appointments to check your PSA for many years. Some men have PSA tests at the hospital or you may have them at your local GP surgery.

What is PSA bounce?

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

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

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

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

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

If you decide to have complementary or alternative treatments...
Before you decide to change your treatment or add any methods of your own, talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. Others can interfere with standard treatment or cause serious side-effects.

More information
To find out more about the different complementary and alternative therapies read our booklet Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients. To get a copy or for more advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read or download the booklet on our website www.cancer.ie

Coping and emotions

How can I cope with my feelings?

People react in different ways when they find out they have cancer. There is no right or wrong way to feel and there is no set time to have one particular emotion or not.

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

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

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

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

Counselling
Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. A trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support and help you to make decisions and cope better.
Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope with cancer, only your way.

It can take some time to come to terms with your emotions after a cancer diagnosis. Coping with the physical effects of treatment can also add to the burden of dealing with cancer.

While it is true that some treatments can have some unpleasant side-effects, most people are able to adjust to life during treatment.

Ways to get support:

Find out about cancer support services in your area. There are lots of local cancer support services that provide a range of helpful services such as counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 77 for more about cancer support services.

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

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

Get one-to-one support. The Irish Cancer Society can put you in touch with a trained Survivor Support volunteer who has been through a cancer diagnosis and who can give you emotional and practical support.

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

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

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

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

Learning to cope

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope with cancer, only your way.

It can take some time to come to terms with your emotions after a cancer diagnosis. Coping with the physical effects of treatment can also add to the burden of dealing with cancer.

While it is true that some treatments can have some unpleasant side-effects, most people are able to adjust to life during treatment.

How can I help myself?

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

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

Involve your family and close friends. Don’t keep your worries or any physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. If you’re feeling alone, you can also talk in confidence to one of our cancer nurses by calling our Cancer Nurseline or visiting a Daffodil Centre.

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

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

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

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

Advice for carers

Caring for someone who has had treatment for cancer can be difficult at times. Some patients manage well and need little practical support from family and friends. Others may need more support and care.

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

Caring for someone with cancer

Learn about cancer: Learn more about early prostate cancer, any possible side-effects and the emotional effects it can cause. This will help you to understand how you can support your partner, relative or friend. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.
Talking to children and teenagers

Every family deals with cancer in its own way. You may feel that you do not want your illness to upset family life, or feel guilty that you can’t do activities with your children, or that you’re letting them down. You may also worry about the emotional impact your illness will have on your children, especially older children, who may already be struggling with the difficult changes that adolescence can bring. These are all natural feelings to have at this time.

Saying nothing

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

How to tell your children

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

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

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

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

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

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

You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 66 for other ways to get support.

### Support resources

#### Coping with the financial impact of cancer

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

### Medical expenses

Medical expenses that you might have to pay include:
- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Appliances, like wigs

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

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication.

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

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

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

If you have health insurance the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It is important to contact your insurance company before starting treatment.
Benefits and allowances
There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer’s Allowance, Carer’s Benefit, Carer’s Leave.

If you want more information on benefits and allowances, contact:
- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 07 4000
- Department of Social Protection (DSP) – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

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

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also help towards travel costs in certain cases. See page 76 for more details of our Volunteer Driving Service and the Travel2Care fund.

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

More information
For more information please see our booklet, Managing the Financial Impact of Cancer – A Guide for Patients and their Families. This explains:
- Medical costs and help available
- Benefits and allowances that you or your family may qualify for
- Travel services
- Ways to cope with the cost of cancer

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

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

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

- Our Cancer Nurseline Freephone 1800 200 700. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie

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

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

- Our Survivor Support. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.
**Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 77 for more information.

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

- **Travel2Care** is a limited fund, made available by the NCCP, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
- **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

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

**Irish Cancer Society Night Nursing.** We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.

**Our publications and website information.** We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website: [www.cancer.ie](http://www.cancer.ie) or call our Cancer Nurseline for a free copy of our publications.

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

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**Local cancer support services**

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

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

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

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

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, treatments, and ways to cope. For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: [www.cancer.ie](http://www.cancer.ie).

You may find the following helpful:

**Treatment and side-effects**

*Understanding Chemotherapy*
*Understanding Radiotherapy*
*Understanding Cancer and Complementary Therapies*
*Diet and Cancer*
*Coping with Fatigue*

**Coping and emotions**

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

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.

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

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

**Fatigue**
Ongoing tiredness often not helped by rest.

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

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

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

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

**Neo-adjuvant treatment**
Treatment given before the main treatment. For example, hormone therapy given before radiotherapy.

**Oncology**
The study of cancer.
Questions to ask your doctor

Here is a list of questions that you may wish to ask. Never be shy about asking questions. It is always better to ask than to worry.

- What tests do I need?
- How long will I have to wait before the tests?
- Do I need treatment straight away? If not, how will you know when I should have treatment?
- If I need treatment, what are my treatment choices?
- How successful is this treatment for my cancer?
- If my treatment is not successful, can I still have other treatments?
- Do some treatments have more side-effects than others?
- Will I need hormone therapy and radiotherapy? If yes, for how long?
- Are the side-effects of treatment short or long term?
- Will I have problems with urinary incontinence after my treatment?
- Will treatment affect my fertility? Will I develop erectile dysfunction?
- Why is follow-up so important? Why do I need regular blood tests?

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

1
Answer

2
Answer

3
Answer

4
Answer

5
Answer

6
Answer
Join the Irish Cancer Society team

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

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

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

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

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

Raise money
All our services are funded by the public’s generosity:

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

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

Did you like this booklet?
We would love to hear your comments or suggestions. Please email reviewers@irishcancer.ie.

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