Understanding Cancer of the Cervix

Caring for people with cancer
Understanding cancer of the cervix

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

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

Specialist nurse       Tel:
Family doctor (GP)    Tel:
Gynaecologist         Tel:
Radiation oncologist  Tel:
Radiation therapist   Tel:
Medical oncologist    Tel:
Emergency number      Tel:

Treatments Review dates


If you like, you can also add:
Your name
Address
The Irish Cancer Society is the national charity for cancer care, dedicated to eliminating cancer as a major health problem and to improving the lives of those living with cancer. This booklet has been produced by Nursing Services of the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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Next revise: 2012

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ISBN 0-95323-690-1
Introduction

This booklet has been written to help you understand more about cancer of the cervix. By reading it, you can learn what it means and about its diagnosis and treatment. We hope that it answers some of the questions you may have.

We cannot advise you about which treatment to choose. You can only make this decision, along with your doctors, when all your test results are ready. However, we can tell you about some of the methods used to treat this cancer and the side-effects that may occur when treatment is given. Remember too that each patient is an individual. Even if patients have a similar diagnosis, the treatments may be different.

This booklet also discusses some of the feelings you and those close to you may have after a cancer diagnosis. At the end of the booklet you will find a list of books that are useful to read. There is also a list of websites and special groups to help and support you at this time. You can also call the freephone National Cancer Helpline 1800 200 700 to discuss any queries or concerns you have.

Reading this booklet

When first diagnosed with cervical cancer you may be overwhelmed with all the information to take in. Instead of wanting to know everything about it, you may prefer to know as little as possible. This can happen to patients at this time and is quite normal. You may find it hard to concentrate on reading too, especially if you are feeling anxious or worried.

As things happen to you, it can help to read the relevant section or what interests you. Take it slowly at first and read when you feel relaxed and want to know more. Some of the information may not be relevant to you. If you find the booklet useful, you could pass it on to a family member or friend, as they might find it helpful too.

What does that word mean?

Benign
- Not cancer.

Biopsy
- The removal of a small amount of tissue from your cervix to find out if abnormal cells are present.

Cervical intraepithelial neoplasia (CIN)
- The cell abnormality in the cervix that smear tests try to find. It is graded from 1 to 3 to describe where the cells are found. It can also be called low or high grade changes. Some of these abnormal changes return to normal by themselves, while others need treatment.

Cervix
- The top of your vagina that opens into your womb. It is also known as the neck of the womb.

Chemotherapy
- A treatment that uses drugs to cure or control cancer.

Colposcope
- A large magnifying glass or microscope with a bright light that helps the doctor or nurse to look closely at the surface of your cervix. It does not go inside your vagina.

Colposcopist
- A doctor or nurse who has been specially trained in colposcopy.

Colposcopy
- A test where your cervix and vagina are examined more closely using a light and a microscope called a colposcope.

Cone biopsy
- A treatment that removes a small cone-shaped piece of your cervix containing abnormal cells.

Cytology
- The study of cells under a microscope. In this case, cervical cells.
Dyskaryosis  
Cervical cells that look abnormal.

Gynaecologist  
A doctor who specialises in treating diseases of the female reproductive system (womb, vagina and ovaries).

Gynaecological oncologist  
A doctor who specialises in or has an interest in cancers of the female reproductive system.

Human papilloma virus (HPV)  
A virus that can cause abnormal changes in the cells of the cervix or warts in the genital area. Most papilloma viruses are spread by direct skin contact.

Hysterectomy  
An operation to remove your womb (uterus).

LLETZ / LEEP  
This stands for large loop excision of the transformation zone. It is a treatment that uses a thin wire loop with an electric current to remove the abnormal cells in your cervix. It is done in the outpatient clinic. LLETZ is also known as LEEP – loop electrosurgical excision procedure.

Lymphadenectomy  
An operation to remove lymph nodes and so prevent cancer cells from spreading.

Malignant  
Cancer.

Metastasis  
The spread of cancer from one part of the body to other tissues and organs.

PAP smear  
A test where cells are taken from your cervix and put into a bottle or liquid and sent to a laboratory to be examined.

Pelvis  
The lower part of your abdomen, found between your hip bones. It contains your womb, ovaries, bladder and bowels as well as lymph nodes.

Precancerous  
Abnormal changes which are not cancer. But if left untreated they may become cancerous over time.

Radical hysterectomy  
An operation to remove your womb, upper part of your vagina and soft tissue beside your womb.

Radioactive source  
A radioactive material that gives off high-energy rays. These rays can kill cancer cells.

Radiotherapy  
A treatment that uses high-energy X-rays to cure or control cancer and other diseases.

Smeartaker  
The person who takes the smear. For example, your GP or nurse.

Speculum  
An instrument used by a doctor or nurse to keep your vagina open so that it is easier to examine your cervix.

Tracheectomy  
An operation where your cervix, top part of your vagina and nearby soft tissues are removed. The rest of your womb is left in place.

Transformation zone  
A small area of skin at the end of your cervix where two types of cells meet and overlap. This is the area from which a smear is taken.

Uterus  
The womb.
Understanding cancer of the cervix

What is the cervix?
The cervix forms part of the female reproductive system together with the womb (uterus), ovaries and vagina. It is found deep inside your vagina at the lower part of your womb. It is often called the neck of the womb, as it is the opening to the womb from the vagina. It is shaped like a cone and is about 2.5 cm long. Usually your cervix is closed and only opens during labour to allow the baby be born.

The cervix is always changing in response to a woman’s hormones. The area of your cervix that changes most is called the transformation zone. In young women this area is on the outside of the cervix, but in older women it can be found on the inside. In the cervix, cells that divide are active and as a result can be prone to virus infections.

What is cancer of the cervix?
Cancer of the cervix is a cancer of the cells lining the cervix. It is also called cervical cancer. Cervical cancer develops slowly over a number of years, first becoming precancerous and then leading to cancer itself. The precancerous cells may also be called cervical intraepithelial neoplasia (CIN). These cells are not cancerous, but if left untreated may develop into cancer. A regular smear test every 3–5 years can show abnormal changes in the cells. After more tests, it can be treated and so reduce the chance of developing cancer.

When cancer occurs, the cells in the cervix form a tumour. These cells may then break away and spread to other areas. They can involve tissues outside the pelvis, including organs in the pelvis such as the bladder and bowel, and lymph nodes around the hips.

Before diagnosis

What is cancer?
Cancer is a word used to describe a group of diseases. Each one has its own name. For example: skin cancer, lung cancer and breast cancer. Each has an individual type of treatment and chance of being cured.

In the body, the organs and tissues are made up of tiny building blocks called cells. All cancers are a disease of the body’s cells. In healthy tissue these cells replace or repair themselves when they get worn out or injured. With cancer, the cells do not behave as normal and keep on growing, even when there is no need.

These groups of abnormal cells can form a lump or tumour. Tumours can either be benign or malignant. Benign tumours are less likely to spread to other parts of the body and so are not called cancer. Malignant tumours are made up of cancer cells that can spread from where they first started to grow. This happens when a cell or group of cells breaks away and is carried by the bloodstream or lymph glands to form a new tumour somewhere else in the body. This is called a metastasis or secondary tumour.

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 somewhere else. This is called a metastasis or secondary tumour.
There are over 100 types of HPV and most do not cause any problems. The high-risk ones that can cause cervical cancer are types 16 and 18. The low-risk ones that can also cause genital warts are types 6 and 11.

Some women can be upset when told that cervical cancer is caused by a virus passed on by sexual contact. This may give rise to many feelings and emotions. See page 55 for more about blame and guilt.

Smoking

Smoking also increases your risk of getting precancerous changes in your cervix. If you smoke, the chemicals in cigarettes can remain in your cervical mucus. High levels of these chemicals in the mucus can interfere with how your cervix fights infection. As a result, you may have trouble getting rid of the virus and are more likely to develop abnormal cells.

Other risks

One of the biggest risks is not having regular smear tests (see page 12 for more about cervical screening). Regular smear tests can find abnormal cells early and treat them, and so prevent cervical cancer. Your risk of cervical cancer is also increased if you have sex from an early age and if have had many sexual partners. If you are concerned that you may be at high risk, talk to your doctor. You can also contact the National Cancer Helpline 1800 200 7000 for advice in confidence.

How can I reduce my risk of getting cervical cancer?

- Have regular smear tests to pick up early problems. This should be every 3 years if you are aged 25–44 and every 5 years if aged 45–60.
- Quit smoking.
- Be vaccinated against HPV before you have been exposed to the virus during sexual contact. For this reason it best that young girls are vaccinated. You must also continue with regular smear tests because it is not yet known for how long vaccination gives protection and not all types of HPV are covered by the vaccination.

Make sure to visit your doctor if you have irregular bleeding, vaginal discharge, painful sex, bleeding after sex or after the menopause. He or she can examine your cervix with a speculum to see if it is healthy.
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The smear test itself takes about 5 minutes. You lie on a couch with your knees drawn up and spread apart. The doctor or nurse gently puts an instrument called a speculum into your vagina, which is then opened to show your cervix. Next some cells are gently removed from the surface of your cervix using a small brush. These cells are then put in a liquid and sent to the laboratory to check for any abnormal changes.

National screening programme

In Ireland, a national cervical screening programme called CervicalCheck began in 2008. This means that CervicalCheck provides free smear tests to women aged 25 to 60. Women are called/recalled every 3 or 5 years for a free smear test, depending on their age. For women aged 25 to 44, it is every 3 years and for those aged 45 to 60, it is every 5 years. For more details about this service in your area, see the CervicalCheck website www.cervicalcheck.ie or freephone 1800 45 45 55.

Diagnosing early changes to the cervix

When abnormal cells are found on the surface of the cervix, it is called cervical intraepithelial neoplasia (CIN). These abnormal changes can be low grade or high grade.

Low grade changes means there are some minor changes in the cells of your cervix. These are early changes in the size, shape and number of cells on the surface of your cervix. It can also be called mild dyskaryosis. These cells will often return to normal by themselves and it does not mean you have cancer. You will have a free repeat smear test in 6 months to check the cells again. If the low grade changes persist, you may be referred to a colposcopy clinic.

High grade changes means there are a larger number of abnormal cells in your cervix. This can also be called moderate to severe dyskaryosis. These changes are less likely to return to normal by themselves. This does not mean you have cancer but you will be referred to a colposcopy clinic.

Sometimes the grades are called CIN 1, 2 or 3. If left untreated or not rechecked, these changes might develop into cancer cells over time.

Being vaccinated against HPV

Two vaccines to prevent HPV infection have been licensed for use in the EU. These vaccines are called Gardasil® and Cervarix®. The vaccines target the high-risk HPV types that cause cervical cancer. These include types 16 and 18. The vaccine has been proven to work best for girls or women who have not been exposed to the virus. It involves a course of three doses given over 6 months and is injected into a deep muscle. If you are vaccinated, it does not mean that you no longer need smear tests.

You must continue with regular cervical smear tests because the vaccine does not cover all the HPV types that cause cervical cancer and it is not known for how long the vaccine gives protection.

A national cervical vaccination programme has started in Ireland. This programme recommends that all girls in the first year of secondary school should receive the HPV vaccine.

What is cervical screening?

Because the cervix is always changing, it is important that all women, even if they do not have sex, get their cervix checked regularly. The best way to do this is by cervical screening. Cervical screening is a check-up involving a smear test to see if there are early changes in the cells of the cervix. Some of these changes are known as precancerous because they might become cancer cells if not found and treated. These early changes have no symptoms so you may be unaware of them.

The earlier a change is found, the easier it is to treat. For most women the test results show that everything is fine, but for 1 in 40/50 there may be changes that need to be checked again or treated.

Women should have regular cervical smears. This should be every 3 years for those aged 25–44 and every 5 years for those aged 45–60.
Treating early changes to the cervix

If your GP has concerns about the results of your smear test or repeated smears, you will be referred to a nurse specialist and/or gynaecologist for further tests at the hospital. A colposcopy will be done to check if you have precancerous changes (see page 16 for more about colposcopy). Depending on the grade and your age, your nurse or gynaecologist may decide to repeat the smear or treat the CIN using LLETZ, laser treatment, cryosurgery or cone biopsy. The most common treatment is LLETZ.

LLETZ stands for large loop excision of the transformation zone. A thin wire loop is used to remove the abnormal cells in the transformation zone with an electric current. In a cone biopsy, a cone-shaped section of your cervix containing the abnormal cells is removed.

Remember having abnormal changes (CIN) is not the same as having cervical cancer. For more information about the treatment of CIN, contact the National Cancer Helpline 1800 200 700 for a free copy of Understanding Cervical Smear Test Results.

What are the symptoms of cervical cancer?

When cervical cancer occurs, there are a number of symptoms. These can include:
- Abnormal vaginal bleeding:
  - Periods may be heavier and last longer
  - Bleeding in between periods
  - Bleeding after sex
  - Bleeding after the menopause
- Vaginal discharge that may have a foul odour
- Discomfort or pain during sex or in the pelvis

Even though these symptoms can be caused by conditions other than cancer, it is important to have them checked out by your doctor.

To sum up

- Cervical cancer is mainly caused by the human papilloma virus (HPV). Smoking increases your risk of developing it too.
- Regular smear tests will reduce your risk of developing cervical cancer.
- Be vaccinated against HPV if you have not already been exposed to HPV.
- The symptoms of cervical cancer are abnormal vaginal bleeding, a foul-smelling vaginal discharge and discomfort or pain in the pelvis.

How is cervical cancer diagnosed?

If your GP has concerns about you, he or she will examine your cervix with a speculum to see if it is healthy. After that, you may be referred to a hospital to see a gynaecologist and have further tests. At the hospital you will first be asked some questions about:
- Your periods
- The type of contraception you use
- Any operations or illnesses you have had
- Any relevant questions about your general health

After that, you will have a physical exam involving a speculum. The doctor will also do another type of physical exam. He or she will put two gloved fingers into your vagina to check your womb as well. You may feel uncomfortable during these physical exams but it is all part of looking after you and your health.

Other tests

If you have had an abnormal smear test, your gynaecologist may have had a closer look at your cervix using colposcopy. A sample of cervical cells (biopsy) can also be taken.
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Blood tests: Bloods tests may be done to check your general health. This will include a blood count and tests to see how well your kidneys and liver are working.

Chest X-ray: This is taken to check your general health.

Examination under anaesthetic (EUA): In this test your doctor can look at your cervix and vagina while you are asleep under general anaesthetic. This is done to check the size of your womb and see if the cancer is found only in your cervix. A EUA is often done if women have large tumours, but it usually does not need to be done.

A sample of cells (biopsy) from the lining of your womb can be taken to see if cancer cells are present. Normally, you may have some slight bleeding or mild pain for a few days afterwards. Your doctor can advise you on what painkillers to take.

During the test, your doctor can also check your bladder (cystoscopy) using a thin, lighted tube to see if the cancer has spread. A biopsy can be taken of any abnormal areas during the test as well. Your doctor and nurse will let you know what is involved and give you advice on what to do afterwards.

MRI scan: This is a special scan that uses magnetic energy to build up a picture of the tissues inside your body. It does not hurt but can be very noisy. So you will be given earplugs to wear during it. Some people may be anxious about the scan because of ‘fear of the unknown’. But every effort will be made to put you at your ease.

You may have an injection before the scan to show up certain parts of your body. You cannot wear metal jewellery during the scan and patients who have medical devices implanted, like pacemakers, are not suitable for the test. Usually most people go home after the scan.

Colposcopy

A colposcopy is an exam of the cervix using a bright light and a colposcope. This is a large magnifying glass or microscope that helps the doctor look closely at the surface of your cervix. It can be linked up to a computer screen to see the cervix more clearly.

The test can be a little uncomfortable. But the colposcope does not touch or go inside you, so do not worry about it being painful. The test usually lasts about 10 to 15 minutes.

Biopsy

A biopsy can be done to find out if cancer cells are present. There are two ways of taking a biopsy:

* As part of a colposcopy exam in the outpatient clinic. This is done under local anaesthetic.
* As part of an examination under anaesthetic (EUA) – see page 17. In this small operation, a cone-shaped section of the cells is taken. It is done in theatre under general anaesthetic. You may have to stay overnight in hospital.

Special tests after diagnosis

If the tests show that you have cervical cancer, you will need more special tests. Your doctor will arrange for them to be done at the hospital. These tests will check your general health as well as finding out the size and location of the cancer:

* Blood tests  * Chest X-ray  * MRI scan  * CT scan

Many of the tests will focus on your pelvic area (pelvis). This is the lower part of your abdomen found between your hip bones.

Cervical biopsy and colposcopy are used to diagnose cervical cancer.
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Staging is very important as it allows your doctor to decide the best treatment for you. The stages of cervical cancer are usually numbered 0 to 4 and can be further subdivided into A and B.

Stage 0 cancer cells are found in the surface layer of the cervix only.
Stage 1 cancer cells are found in the cervix only.
Stage 2 cancer cells have spread to the top of the vagina or side of the cervix.
Stage 3 cancer cells have spread to the pelvis.
Stage 4 cancer cells have spread to other body organs and tissues.

Stage 0
In stage 0, the cancer is very superficial. It is only found in the layer of cells on the surface of the cervix. It has not invaded the deeper tissues of the cervix. It may also be called precancerous or CIN.

Stage 1
This means that the cancer cells are found in the deeper tissues of the cervix but nowhere else. How deep the cells go is very important. Your doctors may call this the ‘depth of invasion’.
- If the cells are less than 3mm deep and 7mm wide, it is the earliest stage. This is called stage 1A1.
- If the cells are 3–5 mm deep and less than 7mm wide, it is stage 1A2.
- If the cells are greater than 7mm wide or 5mm deep but less that 4cm in size, it is stage 1B1. If the cells are greater than 4cm, it is stage 1B2.

The cells in 1B can be seen without a microscope.

Stage 2
In stage 2, the cancer has started to spread beyond the cervix to nearby tissues, but is still inside the pelvis. Stage 2 can be divided into stage 2A and stage 2B. In stage 2A the cancer is in the upper part of the vagina but has not spread into the womb. In stage 2B cancer cells have spread to the tissues at the side of the cervix.

CT scan (CAT scan): This is a special type of X-ray that gives a detailed picture of the tissues inside your body. The scan is painless. For some CT scans you may be asked to fast for 4 hours beforehand. For others you may be given a special drink which helps show up parts of your body on the scan. Preparation for a CT scan can vary but your doctor or nurse will tell you what to do. The test is usually done as an outpatient.

Other tests: If there is a concern that the cancer has spread to other organs, you may need a special test called a PET scan. Your doctor and nurse will explain what is involved with this scan, if you need it.

Waiting for results
It may take some time for all the test results to come back. Naturally, this can be an anxious time for you. It can help to talk things over with the specialist nurse or with a relative or close friend. You may also wish to call the National Cancer Helpline 1800 200 700 to speak to one of our specially trained nurses.

What are the types of cervical cancer?
Cervical cancers are recognised by how they look under a microscope. The most common type is squamous cell carcinoma. It develops in the thin flat cells called squamous cells, which are found on the surface of your cervix and vagina. These cells are like skin cells.

Cervical adenocarcinomas are less common. They develop in the gland cells that make mucus in the cervical canal. These cells are shaped like columns. Rarer again are adenosquamous carcinomas, mixed carcinomas, or clear-cell and small-cell carcinomas. If you would like to know more about your type of cancer, ask your doctor to explain it to you.

What are the stages of cervical cancer?
Your doctor will arrange some tests to stage the cancer. Staging means finding out the size of the tumour and seeing if it has spread to other parts of your body. Some of these staging tests are mentioned on pages 16–18.
Stage 3
In this stage, the cancer has spread further away from the cervix. It has moved into the lower part of the vagina and to the side wall of the pelvis. It can be divided into stage 3A and stage 3B. Stage 3A is when the cancer has spread to the lower third of the vagina but not the pelvic wall. Stage 3B occurs when the tumour has spread to the side wall of the pelvis. When this happens, it can block the tubes that drain the kidneys (ureters).

Stage 4
In this stage, the cancer involves other body organs outside the pelvis. Stage 4 can be divided into stage 4A and stage 4B. Stage 4A is when the cancer has spread to nearby organs such as the bladder or back passage (rectum). If the cancer has spread to distant organs, such as the lungs, it may be called stage 4B. Stage 4B cervical cancer is also called metastatic cervical cancer.

To sum up
- Tests to diagnose cervical cancer include colposcopy and cone biopsy.
- Tests to show the stage of cervical cancer include a pelvic examination under anaesthetic (EUA), MRI scan and CT scan.
- Squamous cell carcinoma is the most common type of cervical cancer.
- Cervical cancers can be staged 0 to 4 or recurrent cancer.
Radiotherapy and chemotherapy: Radiotherapy and chemotherapy may be given together, often after surgery. Chemotherapy when given with radiotherapy can make it work better. See page 38 for more about chemotherapy.

At this time you may be anxious about what is going to happen next. Do not be afraid to ask your doctor. He or she will discuss your treatment options with you.

Sometimes, depending on the stage of your cancer, you may have fewer choices. So do ask as many questions as you like, no matter how small or trivial you think they are. You may want to use the fill-in page at the back of this booklet to write down your questions and the answers you receive.

Who will be involved in my care?
Some of the following healthcare professionals may be involved in your care at the hospital. Usually, a team of cancer care doctors will decide your treatment.

- **Gynaecologist / Gynaecological oncologist**: A doctor who specialises in treating cancers of the female reproductive system.
- **Radiation oncologist**: A doctor who specialises in treating cancer using radiotherapy.
- **Medical oncologist**: A doctor who specialises in treating cancer using chemotherapy and other drugs.
- **Gynaecology clinical nurse specialist**: A specially trained nurse who cares for patients who have cervical cancer and other cancers of the reproductive system.
- **Liaison oncology nurse / clinical nurse specialist**: A specially trained nurse who works in a special cancer care unit. She or he gives information and reassurance to patients and their families from diagnosis and throughout treatment.

Giving consent for treatment
It is important that you fully understand what is involved in your treatment. Before you start any treatment, your doctor will explain the aims of the treatment to you. You may be asked to sign a consent form saying that you give permission for the treatment to be given. In some cases you may give verbal permission. No medical treatment will be given without your consent.

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Radiation therapist</strong></td>
<td>A radiotherapist who specialises in giving radiotherapy and advice to cancer patients.</td>
</tr>
<tr>
<td><strong>Physiotherapist</strong></td>
<td>A therapist who treats injury or illness with exercises and other physical treatments related to the illness.</td>
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<tr>
<td><strong>Dietitian</strong></td>
<td>An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms.</td>
</tr>
<tr>
<td><strong>Occupational therapist (OT)</strong></td>
<td>A therapist who specialises in helping people who are ill or disabled learn to manage their daily activities, e.g. self-care. They are mainly concerned with hand strength and the use of arms and hands.</td>
</tr>
<tr>
<td><strong>Medical social worker</strong></td>
<td>A person specially trained to help you and your family with all your social issues and practical needs. They are skilled in giving counselling and emotional support to children and families at times of loss and change. They can give advice on benefits, entitlements and services available to you when you go home.</td>
</tr>
<tr>
<td><strong>Psychologist</strong></td>
<td>A specialist who can talk to you and your family about emotional and personal matters and can help you make decisions.</td>
</tr>
<tr>
<td><strong>Counsellor</strong></td>
<td>A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.</td>
</tr>
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</table>
Before treatment, you should have been given full information about:
- The type and amount of treatment you are advised to have
- The benefits or drawbacks of the treatment
- Any other treatments that can be given
- Any major risks or side-effects of the treatment

If you do not understand what you have been told, let your doctor or nurse know straight away. They can explain it to you again. Do ask them, even if you think they are too busy. Some cancer treatments are hard to describe, so people usually need more than one explanation.

If you find it hard to take in all the information at first and are still unsure, ask for more time to decide about the treatment. It is important that you do not feel you have been rushed into having the treatment.

You are also free to choose not to have the treatment. But it can be helpful to let your doctor or nurse know your worries first. They will tell you what might happen if you decide not to go ahead with treatment.

No treatment will be given without your consent.

Individual treatment
You may notice that other women with cervical cancer are not having the same treatments as you. Don’t be worried by this – it only means that everybody is different. Their cancer may not be at the same stage as yours and their treatment needs may be different.

To sum up
- The treatment of cervical cancer includes surgery, radiotherapy, or radiotherapy and chemotherapy together.
- A team of specialists will decide which treatment is best for you.

Surgery
The aim of surgery is to remove the cancer and the area close to it. It is the first treatment in very early stage cervical cancer. Which type of operation is best for you will depend on the stage of your cancer. The types of surgery include:
- **Cone biopsy** – a cone-shaped piece of tissue is removed from the cervix.
- **Hysterectomy** – the cervix and womb are removed.
- **Radical hysterectomy** – the cervix, womb and top part of the vagina are removed.
- **Bilateral salpingo-oophorectomy** – you may choose to have your ovaries and fallopian tubes removed during a hysterectomy as well.
- **Radical trachelectomy** – the cervix and nearby soft tissues are removed but the womb is left in place and stitched back onto the vagina.
- **Lymphadenectomy** – the lymph nodes in the pelvis are removed.

This operation may be done along with one of the above operations.

It is important that the surgery decision is made by highly trained specialists at the hospital. Many of the surgeons work as part of a team with medical specialists too. Often it is clear which type of surgery should be done. But sometimes a meeting between specialists is needed before a final decision is made.

New surgery options
With new technology, surgery options are changing all the time.
In certain cases, a new type of operation may be an option, especially if you still want to have children. The operation is called a **radical trachelectomy**. It involves removing your cervix, the top of your vagina and the lymph glands in your pelvis, but most of your womb is left behind to allow you to have children. The organs and tissues are usually removed through the vagina. The lymph nodes can be removed during the operation or by keyhole surgery. With keyhole surgery, a small cut in your abdomen is made and the nodes removed.

Not all women are suitable for this treatment. Usually only women with early stage cancer are suitable. Trachelectomy is still at an experimental stage and only available in some hospitals in Ireland. Your doctor will discuss with you if you are suitable for this kind of surgery.

**Emotional impact**

Surgery for cervical cancer can be a worrying time for you. It can affect your job, lifestyle, and looking after your family. It is important that you are aware of what is involved and any long-term effects of surgery. Do ask for advice from your doctor or nurse if you are unsure about any aspect of the surgery. There are also specially trained people and support groups that can help you at this time. You can also contact the National Cancer Helpline 1800 200 700 for more information.

**Getting ready for surgery**

Preparation for the different kinds of surgery may vary. Normally, very little preparation is needed for a cone biopsy or keyhole surgery. To make sure you are fit for surgery some extra tests may be done. These could include a chest X-ray, heart test (ECG) and some more blood tests. A day or two before surgery you will be given special medication to empty your bowels. You may be told to take one light meal only. During this time you can drink lots of clear fluids such as water and fruit juice.

A physiotherapist or specialist nurse will show you how to do deep breathing and leg exercises. These exercises will help to prevent you getting a chest infection or blood clot after your operation.

You will not be allowed to eat anything from the midnight before surgery. You may receive an injection of heparin to prevent a clot developing in your legs after surgery. Before you go to theatre, you may be given a tablet that will make you feel more relaxed and sleepy.

>>> After your operation, you may have a few tubes attached to you.

**After your operation**

When you wake up, you may notice some tubes attached to your body. They may look alarming, but they are normal after operations on the womb and cervix.

- A ‘drip’ will be put into a vein in your arm. Through this, you will be given fluids until you are able to drink again.
- A thin plastic tube may be placed in your nose. It will lead down into your stomach. By drawing up fluid in your stomach through this tube, the nurses can keep your stomach empty. This will stop you from feeling sick.
- A small thin tube called a catheter may be put into your bladder and urine drained off into a bag. This will save you having to get out of bed to go to the toilet.
- Drainage tubes from your wound may be present to make sure it heals well.
- A vaginal pack may be in place for 24 hours.
- A thin tube called an epidural catheter may be placed in your back to give you pain relief.

**Side-effects of surgery**

**Pain**

You will have some pain for the first few days. Some patients may also feel sick. The nurses can give you painkilling injections and medication to prevent you feeling or getting sick if you need it. Always ask for help before the pain or sickness gets too bad. If the injections do not work, let your nurse know as they can be changed.

Your doctor may arrange for you to have patient controlled analgesia (PCA). This is a small infusion pump that is attached to you, where
you control the amount of painkillers you get. You push a button and the pump sends the painkiller into your bloodstream.

**Eating and drinking**
A hysterectomy will slow down the movement of your bowels. As a result it will take a few days before you can return to normal eating and drinking. But you will soon be able to take sips of water again. The amount of fluids you can take will then be increased. Most people can manage a light meal within 2 or 3 days of surgery. As you begin to drink again, the drip will be removed.

**Bladder and bowel problems**
The bladder is often slow to empty after a radical hysterectomy. Your surgeon may leave a tube (catheter) to drain your bladder for a week to 10 days. After the tube is removed, your bladder may still be slow and need to be emptied with a catheter on and off. Similarly, you will be more prone to constipation as your bowels may be lazy after surgery. You may need to take a laxative for a few months.

Very rarely, serious complications happen after radical surgery. These can include leakage from the bladder or bowel or narrowing of the tubes that bring the urine from the kidneys to the bladder. You may need more surgery to help these problems.

**Getting up and about**
For the first few days a physiotherapist will visit you every day to help with your exercises. Even when you are in bed you will be encouraged to move your legs and do deep breathing exercises at least once an hour. On the day after surgery the 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.

You may not find it easy to sit down for any length of time at first. But that should get better as your wound begins to heal. Most women are ready to go home 8 to 10 days after surgery. Strenuous activity such as vacuum cleaning or lifting heavy bags of shopping should be avoided for at least 3 months. You will not be able to drive for at least 6 weeks after surgery. Your doctor will discuss this with you in more detail.

**Lymphoedema**
Lymphoedema or swelling in one or both of your legs may happen in the long term if your lymph glands are removed during surgery. When the glands are removed, they can no longer drain away excess fluid in your body, so there is a build-up of fluid in your legs. Your physiotherapist will show you some exercises to help drain the fluid and arrange elastic stockings for you. You may also need a technique called manual lymph drainage. Ask your physiotherapist for more information about lymphoedema. For a factsheet on leg lymphoedema, contact the National Cancer Helpline 1800 200 700.

**Infection**
You will be at higher risk of infection, such as a urinary tract infection, and may be prescribed antibiotics after the surgery. For the first few weeks, you will have a brown discharge from your vagina. If it gets heavier, foul smelling or if you have bleeding, contact your specialist nurse or doctor for advice.

**Fertility**
If you have a hysterectomy, you will no longer be able to have children. But if you have a radical trachelectomy, you may be able to get pregnant and have children. Even so, there is a high risk of miscarriage – 1 in every 2 women will miscarry. You will need to use contraception for 6 months after the trachelectomy, so do ask your doctor and nurse for advice about this. See page 44 for more details.

**Going home**
If you live alone or have problems getting around the house, talk to the medical social worker or nurse on your ward as soon as you are admitted to the hospital. That way, he or she can organise the community services that you may need after you leave hospital. On the day you go home, you will be given a date to come back for a check-up in about 6 weeks’ time.

If you have a worry or symptom that is causing you concern before your check-up date, contact your doctor, cancer nurse specialist or hospital ward for advice.
Understanding cancer of the cervix

The type of radiotherapy you receive will depend on the stage of the cancer and if you have had surgery. If you do not have surgery, both external and internal radiotherapy may be given to destroy all the cervical cancer cells. If you have had a hysterectomy, brachytherapy or external beam therapy may be given.

External and internal radiotherapy

With external beam radiotherapy, the X-rays come from a machine called a linear accelerator. They are aimed directly at your cancer cells to destroy them. The radiation only affects the cells in the treated area. Your doctor will let you know how many sessions or treatments you need. Sometimes up to 28 sessions are given, but it will depend on your doctor’s decision.

With internal radiotherapy, a tiny radioactive source is put into your vagina and/or into your womb. A radioactive source is material that gives off high-energy rays. The length of time it stays there depends on the dose given. It can be left in place for 2 or 3 days with low dose therapy or for several minutes with a high strength source. Nowadays the preference is for high dose therapy over a short time. The radiation oncologist at the hospital will decide the dose and number of treatments you need, depending on your situation.

Because the radiation source is put very near your cancer site, the cancer cells can be killed, while at the same time reducing the radiation to nearby healthy cells. As a result, there are less side-effects.

Treating symptoms of cancer

Radiation can also be given to the pelvic area to control or relieve any symptoms you may have. This could include any pain, discomfort or bleeding if the cancer comes back after having been treated.

Planning your external radiotherapy

Before radiotherapy, your doctors and other specialists plan how best to give the treatment to you. They work out how to give you the right amount of radiotherapy with the least damage to normal cells.

Tips & Hints – after surgery

- Get plenty of rest as you may feel tired and weak for several weeks.
- Avoid heavy jobs like hoovering or cleaning for the first few weeks.
- Avoid sex for up to 6 weeks to let the top of the vagina heal.
- Avoid swimming and tampons for the first 6 weeks to prevent infection to the area.
- Avoid baths for the first few weeks or soaking in the bath for 6 weeks.
- Wait a few weeks until you feel fit to drive. Avoid long distance driving for several weeks.
- Return to work 4–6 weeks after surgery, depending on your type of job.

To sum up

- A team of specialists will decide which type of surgery is best for you.
- Side-effects of surgery include pain, immobility, bladder and bowel problems, lymphoedema (swelling in one or both legs), infection, fertility issues. Most of these effects do not last long.

Radiotherapy

Radiotherapy is a treatment with high-energy X-rays. There are two types: external beam radiotherapy and brachytherapy. With external beam radiotherapy, high-energy X-ray beams are aimed at a cancer to cure or shrink it. Brachytherapy involves putting a radioactive source into your vagina close to the cervix. It is also known as internal radiotherapy or implant therapy.
Your first visit to the radiotherapy department will prepare you for treatment only. You may be asked to lie under a machine called a simulator that takes X-rays of the area to be treated or you may have a CT scan for planning your treatment. Treatment planning is a very important part of radiotherapy and it may take a few visits before your treatment can go ahead.

The area to be treated will be marked on your skin. These marks are like dots and are made with a permanent tattoo. That way the X-rays can be aimed at the same area each day. Before starting radiotherapy, you will be told how to look after your skin during and after treatment. If you have any queries, do ask the radiation therapist or nurse for advice.

Getting your radiotherapy
External radiotherapy treatment is quite straightforward. You will be asked to come for treatment every day during the week with a rest at weekends. Your treatment can go on for several weeks. Each treatment session only lasts a few minutes. It will not cause you any pain but you will be asked to lie still. How many sessions you need will depend on the type and size of your tumour. Your doctors will discuss this with you.

Each time you come for treatment you will go into a special room. The radiation therapist will ask you to lie or sit in a certain position under the machine. To prevent less radiation reaching your small bowel and so reduce any side-effects, a special piece of equipment called a belly board may be used.

When you are ready the radiation therapist will leave the room. The machine will then be turned on and your treatment given. Even though you are on your own in the room, your radiation therapist will be able to see you all the time through a closed circuit camera. You can talk through an intercom to the staff if you need to.

Brachytherapy/internal radiotherapy
With internal radiotherapy, a tiny radioactive source is put into or near your tumour. To do this the source is put in your vagina or womb using an applicator. The radioactive source is also known as an implant. Applicators may be steel or plastic tubes. Once the applicators are in place, an X-ray or CT scan will be done to see if they are in the right area.

High dose rate and low dose rate
usually with brachytherapy to the cervix, you are brought to theatre to have the applicator put in under spinal or general anaesthetic. How long the applicator stays there will depend on the dose you are to receive. For low dose therapy, the applicator is left in place for 2 or 3 days while you stay in a low dose rate unit. For high dose therapy, the application time is much shorter, like several minutes. A tube to drain urine from your bladder (catheter) may be put in as well.

Giving treatment
Once all the preparations are made, you will be taken to a special room for treatment. The applicators will be linked to a machine. When the machine is switched on, it passes a small radioactive source into the applicator. You may hear this called ‘afterloading’. During the treatment, you will be on your own in the room but there will be an intercom and camera so that the doctor, radiation therapist or nurse can talk to you. Or if you have any concerns, you can talk to them. Depending on your situation, you may be able to go home straight after the treatment or rest in the ward for a few hours.

Your doctor, radiation therapist and nurse will carefully explain what will happen during treatment, how long the applicator and implant must stay in place, when you can go home, and any precautions that you must take. In general high-dose rate implants are removed after each treatment. Low-dose rate implants can stay in for 6–24 hours.
Will I have any side-effects?

Radiotherapy is given directly to the area where the cancer is found. As a result, side-effects will only occur in the part of the body being treated. How severe these side-effects are will vary from person to person and depend on the dose and length of treatment. Side-effects can be either short term or long term.

Radiotherapy does not make you radioactive. There is no danger to you and your family so you can mix with them freely. You also do not have to avoid children or pregnant women.

External radiotherapy does not make you radioactive. It is perfectly safe for you to mix with family and friends.

Short-term side-effects

When the pelvic area is being treated, the most common side-effects are:
- Fatigue
- Diarrhoea or soreness when passing a bowel motion (proctitis)
- Skin changes – redness, soreness
- Feeling sick
- Wanting to pass urine more often
- Pain when passing urine
- Vaginal discharge
- Abdominal cramps

The belly board device can sometimes help to prevent or improve side-effects such as diarrhoea and feeling sick. These side-effects usually last for 4 to 6 weeks after treatment.

Fatigue

Fatigue or severe tiredness can build up over the course of your treatment. It may be due to the treatment itself or because you have to travel long distances for treatment. In that case, rest as much as you can. Cut down on the things you normally do while on treatment as well. A helpful booklet called Coping with Fatigue is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.

Diarrhoea

Passing watery bowel motions more than twice a day is known as diarrhoea. You may also have some cramping and/or abdominal pain. Tell your doctor, as he or she may be able to give you medication to prevent it. If you have diarrhoea, drink plenty of clear fluids to replace the fluid you are losing. Let your doctor know if the diarrhoea lasts for longer than 24 hours.

You may also get some soreness when passing a bowel motion. This is known as proctitis. Your doctor can prescribe some medication to help this problem.

Skin changes

During external radiotherapy, the skin in the treated area may become red and sore. It may look like sunburn. A special cream can be used to treat this problem. Only use creams recommended to you by the nurses and radiation therapists. If you need to wash the area, use warm water and pat it dry with a soft towel. Do not rub the skin while washing and drying. It is also best to avoid perfumed creams or powders. Check with your radiation therapist or nurse before applying anything to your skin.

Feeling sick

Your doctor can give you medication to help prevent you feeling sick. Take these one hour before treatment. It can help to eat small amounts often. Also, drink plenty of clear fluids such as water or fruit juice.

Problems with passing urine

During radiotherapy for cervical cancer the urinary bladder may be irritated. As a result, you may pass urine more often. Sometimes a trace of blood may be found in the urine. If this happens, do tell your doctor and nurse. Passing urine may also be painful like cystitis. But your doctor will give you medication to help this problem.

Vaginal discharge or bleeding

You may get some discharge from your vagina after treatment. It may be yellowish in colour and may last for several days. Or you may get some vaginal bleeding. If it continues for more than a few weeks or becomes heavy, talk to your radiation therapist.
Abdominal cramping
With high dose radiotherapy, you may get some cramps after treatment. These may feel like period pains. But they do not last long and your doctor and nurse will give you advice on suitable painkillers to take.

Long-term side-effects
There can also be some long-term side-effects of radiotherapy to the pelvis. They may include:
- Narrowing of the vagina
- Difficulty having sex
- Early menopause
- Infertility
- Damage to the small and large bowel, causing a change in the way your bowel works
- Shrinkage of the bladder causing you to pass urine more

Some women may have changes in the way their bladder and bowel work after radiotherapy. It may also cause changes in the vaginal area. Narrowing of the vagina can occur after radiotherapy to the vagina. Also, it can become less stretchy and drier than before treatment.

Regular gentle sex, a vaginal dilator, hormonal creams and lubricants may help. Your nurse will give you advice about suitable ones. See page 43 for more details.

For some side-effects, you might have to make changes to your life so that you can deal with them. Your doctor or nurse will give you advice on how to reduce any of the above side-effects.

Other side-effects
These or any other effects you develop will be watched carefully during the radiation treatments. Information will be given on how to prevent side-effects and medication will be prescribed if needed.

All these side-effects should go away when treatment is over, but do let your doctor and nurse know if they continue. A helpful booklet called Understanding Radiotherapy is available from the Irish Cancer Society and a DVD called Radiation Therapy: A Patient Pathway. Call the National Cancer Helpline 1800 200 700 for a free copy.

To sum up
- Radiotherapy is a treatment using either high-energy X-ray beams or internal radiation called brachytherapy.
- The X-rays are aimed at the cancer to cure or shrink it.
- Brachytherapy involves putting a radioactive source into or near your tumour.
- A lot of preparation is needed before the actual treatment is given.
- Radiotherapy is painless and only takes a few minutes.
- The treatment may be as short as one session or continue for several weeks.
- Side-effects to radiotherapy depend on the area being treated and the type of radiotherapy given. They include fatigue, diarrhoea, skin changes, feeling sick, narrowing of the vagina, abdominal cramps, and wanting to pass urine more often.
Chemotherapy

Chemotherapy is a treatment using drugs that cure or control cancer. These drugs travel through your bloodstream to almost every part of your body. With cervical cancer, chemotherapy is often given with radiotherapy to make it more effective. This is known as chemoradiotherapy and is given once a week during your course of radiotherapy.

How is chemotherapy given?

Chemotherapy is usually given directly into a vein as an injection or through an infusion or drip. Usually the treatment is given to you as a day patient at the hospital. Cisplatin is the most commonly used drug for cervical cancer when it is given as part of chemoradiotherapy.

If the cancer has spread beyond the pelvis, chemotherapy may be used. Even if the cancer comes back after surgery or radiotherapy, it may still be treated with chemotherapy. Chemotherapy can control or improve your symptoms and give you a better quality of life.

Side-effects of treatment

The side-effects of chemotherapy vary from person to person and depend on the drugs used. These unwanted side-effects happen because chemotherapy can affect both cancer cells and normal cells. In most cases the side-effects go away once the treatment ends or soon after. Your doctor or nurse can give you something to stop most side-effects or make them easier to cope with.

Side-effects may include:
- Feeling very tired
- Feeling sick or getting sick (vomiting)
- Not wanting to eat
- Kidney damage
- Hearing loss
- Numbness or pins and needles in the hands and feet
- Hair loss (alopecia) – rarely occurs

Feeling very tired

You may feel very tired or fatigued during treatment. This may be due to fewer red blood cells (anaemia) in your bloodstream or as a general effect of chemotherapy, surgery or radiotherapy. See page 41 for more about fatigue. A helpful booklet called Coping with Fatigue is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.

Feeling sick or getting sick

Not everyone feels sick or gets sick with chemotherapy. It all depends on the drugs being given. If you do, it can happen before, during or after treatment. It may last for several hours. Your doctor or nurse will give you medication to stop you feeling sick. This may be in injection or tablet form. It is important that you take your medication while on treatment, so you do not feel unwell.

Not wanting to eat

It is best to eat as much as you can while on chemotherapy to keep up your strength. Eat small amounts and often. If you do not feel like eating during treatment, you could try replacing some meals with special high-calorie drinks. Talk to the hospital dietician, who will give you advice on what to eat. You can also contact the National Cancer Helpline for a free copy of the booklet, Diet and Cancer.

Kidney damage

Some chemotherapy drugs such as cisplatin can cause damage to your kidneys. To prevent this, fluids may be given into your vein before any treatment. Your kidney function may also be checked by blood tests before treatment. Drink as much fluid as you can – about 1½ litres per day.
Understanding cancer of the cervix

Fatigue is a common symptom with cancer and is often described as an overwhelming tiredness. You also may find it hard to concentrate or make decisions. The reason for this fatigue can be hard to identify at first. It can be caused by worry when a diagnosis of cancer is made or the added stress caused by treatment.

Even though you may find it hard to identify the reasons for your tiredness, there is action you can take to help. For many patients, treatment may help by relieving symptoms such as pain and nausea, allowing you to get back to your normal routine. Ask your doctor before you start treatment what side-effects you can expect.

If you are feeling very worried, you may find it hard to sleep at night. Do tell your doctor or nurse, who may be able to help. Also, try talking to your family or close friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to cope.

If your illness allows you to do physical exercise, get some regularly.

To sum up

- Chemotherapy is a treatment that uses drugs to destroy or control cancer cells.
- Chemotherapy is usually given with radiotherapy to make it more effective.
- The drugs can be given directly into a vein as an injection or in a drip, or may be given in tablet form.
- If the cancer comes back after having been treated, chemotherapy may be given.
- Side-effects to chemotherapy vary between people and depend on the drugs used.
- Side-effects may include feeling tired, sick or getting sick, not wanting to eat, hearing loss, kidney damage, numbness or pins and needles in the hands and feet.

Understanding cancer of the cervix

Hearing loss
Chemotherapy drugs used to treat cervical cancer, such as cisplatin, may cause damage to the inner ear. This can lead to hearing loss, balance problems and tinnitus, which is a buzzing or ringing in the ears. Because cisplatin is only given once a week this is less of a problem for those with cervical cancer. Even so, your doctor will keep a regular check on your hearing.

Numbness or pins and needles in the hands and feet
Some chemotherapy drugs can cause tingling or a burning sensation in your hands and feet. You may also have trouble picking up small objects or buttoning up a shirt or cardigan. This side-effect is known as peripheral neuropathy. It is almost always temporary and goes away after treatment stops. But if it is becoming noticeable during treatment, let your doctor know.

Hair loss (alopecia)
Many women having a single dose of cisplatin as part of chemoradiotherapy do not have a problem with hair loss. Your hair may just thin out a little bit. If you are having more intensive chemotherapy, you may lose your hair. Naturally, you may be worried about this before it happens. But your doctor will let you know if there is a chance you will lose your hair and your nurse will give you advice on what to do. A helpful factsheet called Hair Loss and Cancer is also available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a copy.

Other side-effects
If you have symptoms that are troubling you, and different from those listed above, let your doctor or nurse know. He or she will tell you what to do. A helpful booklet called Understanding Chemotherapy is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.
Understanding cancer of the cervix

Will treatment affect my sex life?

Most women do not have long-term sexual problems after treatment. Problems if they occur are usually in the short term. After surgery to the womb and cervix, it will take time for your wound to heal. To allow it to heal properly it is best to wait at least 6 weeks after your operation before having sex again. Also avoid using tampons and jacuzzis or douching at this time. Do ask your doctor, radiation therapist or nurse if it is safe to have sex between radiotherapy sessions.

Radiotherapy to the cervix can make your ovaries work less well. Narrowing of your vagina can happen, making it drier and less stretchy. As a result, sex can be painful and uncomfortable. The problem can be helped by keeping the muscles of your vagina as supple as possible. Regular gentle sex can help as can hormone creams, lubricants like KY gel or Replens, and vaginal dilators. Do talk to your nurse if you would like more information, especially about suitable dilators. Your doctor may prescribe hormone replacement therapy (HRT) if it is suitable for you.

Intimacy problems

Most women have no problem resuming sex once the area is fully healed. Others may be concerned about sexual intimacy and need more time to come to terms with what has happened. For some women, they lose the desire for sex (libido), which can happen during treatment for a serious illness.

If you have a supportive partner, you may find that talking about your feelings may ease your anxiety. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist counselling if you feel that would be helpful.

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

Tips & Hints – fatigue

• Stop before you get overtired.
• Build rest periods into your day. If you are going somewhere special, have a rest before you go out.
• Save your energy for doing the things you most enjoy.
• Ask for help at work or at home, especially with cooking, housework or childcare.
• Keep your energy for eating. Eat little and often and use ready-made meals or snacks.
• Wear clothes that are easy to put on and take off.
• Sit down when getting dressed or doing household jobs such as ironing, etc.
• If you find it hard to sleep, make sure your bedroom is quiet and not too hot or cold.
• Do some gentle exercise each day. Ask your doctor or nurse for advice.
• Go to bed each night at the same time. Each morning get up at same time and do not lie in.
• Use relaxation techniques to get to sleep: gentle exercise, relaxation tapes, etc.
• Avoid stimulants before bedtime, such as alcohol, coffee, tea, coke or chocolate.
Understanding cancer of the cervix

Right

During your pregnancy you will need specialist care. With a trachelectomy, babies are delivered by Caesarean section earlier than normal and will need special neonatal care. Discuss this with your doctor who will give you more advice.

Early menopause

Radiotherapy to your ovaries and surgically removing them will bring on early menopause. This may involve hot flushes, dry skin, dryness of your vagina, reduced sexual desire, night sweats, mood swings, poor concentration and osteoporosis.

Most of these effects can be prevented or reversed by replacing the hormones that your ovaries previously made. In young women it is very important that these hormones are replaced. Your doctor may prescribe hormone replacement therapy (HRT) following treatment for cervical cancer. However, you may not be suitable for HRT. For example, if you have a family history of breast or ovarian cancer. If you are not suitable for HRT, you may be at risk of developing osteoporosis (thinning of the bone). In this case, your doctor will give you advice on how to prevent it.

HRT can be given in different ways. For example, in tablet form or through an implant device put under your skin, or by a slow release patch worn on your arm or leg.

Some problems like dryness of the vagina can make sex uncomfortable. But this can be eased by using vaginal lubricants, e.g. KY gel, available in your local pharmacy. Do talk to your nurse if you are having problems with the symptoms of early menopause.

HINTS & TIPS – coping with early menopause

- Dress in layers, so you can cool off easily if you get hot flushes or flashes.
- Avoid caffeine and alcohol.
- During sex use a vaginal lubricant that is based on water or mineral oil (e.g. KY gel).
- If sex continues to be painful, discuss other treatments with your doctor and nurse.

Even if you do not wish to have sex, you can still enjoy a loving relationship with your partner.

Will treatment affect my fertility?

Infertility

Your fertility will be affected if you have a hysterectomy or radiotherapy. Sadly, you will not be able to have a child or more children. Dealing with infertility may not be easy for you, depending on your age. Younger women can find it hard to accept that they can no longer have children. This can be even harder than having cancer itself, and feelings of anger and loss of identity are common at this time.

It is important to talk openly to your partner or a friend about these feelings. If you are finding it hard to deal with infertility, it may help to talk to your nurse or doctor. Do not be afraid to ask for help in dealing with this matter. Your doctor may arrange for you to speak to a trained counsellor or a specialist.

Increased risk of miscarriage

After a radical trachelectomy, a stitch will be made at the bottom of your womb to keep it closed during pregnancy. You will be advised to use contraception for at least 6 months after surgery. After that you are free to get pregnant, although you will have a higher risk of premature labour and miscarriage – 1 in every 2 women will have a miscarriage.
What follow-up do I need?

No matter what type of cancer treatment you get, you will still need to come back for regular follow-ups once it is over. At first these visits to the specialist will be quite often, sometimes every 3 months. The follow-up may involve having a physical exam, blood tests and scans. These visits will continue for a number of years but will then become less frequent.

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

What if the cancer comes back?

Sometimes after treatment the cancer recurs, either in the cervix itself or somewhere else. There are treatment options still available to you if it does come back. Your doctor will discuss these treatments with you if he or she thinks they would help.

Metastatic cervical cancer

If the cancer has spread to other parts of your body (metastatic) after treatment, chemotherapy may be given. The aim of treatment here is usually to control the cancer rather than cure it.

Recurrent cervical cancer

If cervical cancer comes back after having been treated, it may be hard to treat it again. Even so, some chemotherapy treatments may help.

If the cancer has returned to the cervix only (locally recurrent cervical cancer), sometimes it is possible to aim for a cure using surgery. But before a decision is made about this, you will need a full exam and many tests. An operation called a pelvic exenteration can sometimes cure the cancer if it returns at the top of the vagina only.

This operation is a major one. It may involve removing your cervix, vagina, womb, ovaries, fallopian tubes, lower bowel and bladder. Because it is major surgery you will need counselling beforehand. It can be a shock to the system when you are left with stomas (openings from the bowel and bladder onto the abdomen) after surgery and having to learn how to care for them. Your doctor or nurse will give you more information and advice if you need this kind of surgery.
Understanding cancer of the cervix

Cancer and complementary therapies

There is great interest today in complementary treatments for cancer. Some people find them helpful during their illness. In many countries the way cancer is treated depends on the culture and environment in which you live. In Ireland cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted. You may hear about the following types of treatments or therapies.

Conventional therapies

Conventional therapies are treatments that doctors use most often to treat people with cancer. These include surgery, radiotherapy, chemotherapy and biotherapy. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

Complementary therapies

Complementary therapies are treatments that are sometimes given together with conventional treatment. They include therapies such as:

- Meditation
- Relaxation
- Visualisation
- Gentle massage
- Aromatherapy
- Reflexology
- Music, art and dance therapy
- Nutrition therapy
- Shiatsu
- Yoga
- Acupuncture
- Hypnotherapy

Many people find complementary therapies helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that it can often bring. Some complementary therapies also focus on the spiritual dimension of a person to aid healing.

Research – what is a clinical trial?

Research into new ways of treating cervical cancer goes on all the time. By using new drugs or new combinations of drugs and treatments that are already in use, doctors can find new and better ways of treating cancer. Many patients with cancer take part in research studies today. Even though the word ‘research’ or ‘new drug’ sometimes scares people, there is no need for fear. Before a drug or treatment is used on patients, it goes through many stages to make sure it is safe to use.

Phases of research

There are many stages or phases when research is done. If a drug or treatment looks as if might be useful in treating cancer, it is given to patients in research studies called clinical trials. These aim to find a safe dose, see what side-effects may occur and see which cancers can be treated.

If early studies suggest that a new drug may be both safe and effective, further trials are carried out. These aim to:

- Find out if the treatment is better than ones already in use.
- Find out if there are more benefits when the new treatment is given together with current ones.
- Compare the new treatment with current best standard treatments.

Taking part in clinical trials

Your doctor may ask you to try a new treatment. There are many benefits to this. You will be helping to improve knowledge about cancer and new treatments. There is no need for worry as you will be carefully monitored during and after the study.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, so that you understand what it is about. This is called informed consent. You will also need time to think about it and discuss it with your family or friends. If you decide not to take part, you will still be given the best proven treatment available. Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind. As part of research into the causes of cancer, your doctors may ask your permission to store some samples of your cancer cells or blood.

For more information, call the National Cancer Helpline 1800 200 700.
Coping and emotions

How can I cope with my feelings?

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

Common reactions include:

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

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

Shock and disbelief

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

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

**Fear and uncertainty**

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

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

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

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

**Loss of control**

After a cancer diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom. Because you don’t know enough about your illness at first, you may rely totally on the advice of your doctors and nurses. You may not feel confident to make any decisions about your treatment. When you experience a loss of control, it can lead to feelings of helplessness. You may also feel that you will be unable to cope with your treatment or that you will ‘fall to pieces’ or ‘go crazy’. You may even lose hope.

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

**Sorrow and sadness**

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

**Denial**

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

**Anger**

It is normal to be very upset when told you have cancer. Many aspects of your illness can result in anger and distress. Anger can often hide other feelings such as fear, sadness or frustration. You may feel angry towards the doctors and nurses who are caring for you. Or if you have a religious belief, you may feel angry with your God for allowing cancer to occur. You may vent your anger on those closest to you. Indeed being unable to protect the ones you love may frustrate you a lot.

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

**Resentment**

It is natural that you might be resentful and unhappy – even jealous – because you have cancer while other people are well. During the course of your illness similar feelings of resentment may occur for many reasons. You may resent that another patient receiving the same treatment as you has responded quicker than you have. You may resent your healthy relatives or having to change your lifestyle in some way.

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

**Blame and guilt**

When diagnosed with a serious illness such as cancer, it is natural to want to know what caused it. You may find that you blame yourself or your partner for passing on the virus linked to cervical cancer. You may even think that your partner has been unfaithful. But HPV should not be seen as a sign that you or your partner is having sex outside of your relationship. The virus is very common and condoms do not give full protection against it. In fact, it is often impossible to know when and from whom the virus was caught. Someone can have HPV for a very long time before it is found. For these reasons, it is not helpful or fair to blame yourself or your partner.

Other times, people feel guilty because they delayed going to the doctor with their symptoms, fearing the worst. No matter what the reason, don’t torture yourself at this time. Don’t feel guilty if you can’t keep a positive attitude either, especially when you feel unwell. Low periods are to be expected. There is no evidence at all that your attitude will affect your health or cancer. Regret and guilt serve no useful purpose. Instead focus on what you can change or do to make you feel more in control of your illness.

**Withdrawal and isolation**

There is no denying that a cancer diagnosis is stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may want to be left alone and withdraw from people. It is normal for you to want to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope. However, it is not a good idea to spend long hours on your own every day.
How can my family and friends help?

Families and friends can support people through their cancer journey in different ways. Some family members and friends can offer a listening ear and give advice if needed. Some may gather up-to-date information on cancer to know what their loved one can expect and what they are going through. Others may prefer to help 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 friend or relative best.

How to talk to someone with cancer

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

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

Be patient

Sometimes your friend or relative may get cross or irritable for what may seem to be no good reason. These feelings are completely normal. Be as patient and understanding as you can. Give them the space and time to adjust to the changes in their life. Above all, let them know that you are there, if they want to talk or need help. In time, life will begin to be normal again.
Lost for Words – How to Talk to Someone with Cancer is a useful booklet written for relatives and friends of people with cancer. It is available from the Irish Cancer Society and you can call the National Cancer Helpline 1800 200 700 for a free copy.

How can I talk to my children?

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

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

Be honest

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

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

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

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

Coping with children’s emotions

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

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

What else can I do?

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope, only your way. During your illness there are many things that you can learn, not only about cancer itself but also about you as a person. Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

- Communicate with your family and close friends: Do not keep your worries or symptoms secret from the people closest to you.
This includes physical or emotional problems. Ask the person closest to you to come with you when visiting the doctor and when treatments will be discussed.

- **Live one day at a time**: Don’t think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

- **Live well**: Try to eat as well as you can. Eat little and often, using lots of different types of foods with plenty of fresh fruit and vegetables. Do some regular exercise that you enjoy. Take it easy at first, building up the amount you do as you feel stronger.

- **Expect change in your life**: Even though you may want to stick to your old routines, sometimes this may not be possible. It may take a while for you to adjust to your new routine. Remember that change may bring new opportunities and blessings.

- **Keep an open mind**: Don’t feel you have to be positive all the time. Expect ups and downs during your cancer journey. There will be times when you feel low but don’t feel guilty about it, as it will pass.

- **Seek information**: Be sure to ask your doctor as many questions as you can and get involved in decisions about your treatment. Always ask for information that is personal to you. Ask what side-effects you can expect so you can prepare for them. Build up as much information about your cancer and treatment as possible. Follow your doctor’s instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor or nurse. Keep a notebook of all your dates for blood tests, X-rays, scans, treatments, symptoms, side-effects, medications, and your general health. Keep a record of any emotions you are feeling too, especially strong ones.

- **Find what works for you**: It can help to use whatever way of coping that has helped you solve problems in the past. Some people are comfortable talking about their illness, others are not. You may prefer relaxation, meditation, walking, listening to music, or other approaches helpful. Do whatever suits you. But if it’s not working, be open to finding a new way to cope.

- **Build a support network**: Be realistic about what you can manage by yourself. No man is an island, so seek help from those who want to support you. Talk to your family, friends, nurses or doctors. Meet with other patients in support groups and self-help groups as they can understand what you are going through. If the group does not suit you and is not helping, leave it.

- **Seek professional help**: If you have any low moods or strong emotions, talk to your close friends and family – or someone who is a good listener. If the emotions are still getting the better of you, discuss them with your nurse and doctor. They may recommend you talk to a trained counsellor or other specialist.

- **Spiritual care**: When faced with a cancer diagnosis and treatment, you may start thinking about the meaning of life and the afterlife. For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life. Even if you do not consider yourself a religious or spiritual person, it is still possible to get support from prayer or meditation. Some complementary therapies that have a spiritual dimension may also help you to focus on being positive and hopeful.

- **Express yourself**: Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of your cancer journey and can bring great healing and relief. Other forms of creative expression, such as music and art, may help too.

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

Who else can help?

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

- Medical social worker
- Oncology liaison nurses
- Cancer nurse co-ordinators
- Psycho-oncology services
- Community welfare officer and community health services
- Support groups
- Helpline nurses

The medical social worker in your hospital can help in many ways. He or she provides support and counselling to patients and their families and can provide advice on benefits, entitlements and services available when you go home.

Some of the major cancer treatment hospitals have oncology liaison nurses and/or cancer nurse co-ordinators. These specially trained nurses provide support to patients and their families from the time of diagnosis and throughout treatment. These people along with other members of your medical team work together to meet your needs.

In some larger hospitals there are special units that provide psycho-oncology services. This means that psychological care and support is given to patients with cancer during diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together.

When you go home there are various community health services available from your local health centre. These centres have family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live in an area which is remote or far from the hospital where you have been treated, your community welfare officer can also help with practical issues such as
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financial worries, etc. All these people in community health services can provide advice and support. You can get more information on the services available either from the social worker in the hospital before you go home or at your local health centre.

Joining a support group can put you in touch with people who have been in a similar situation. They can give you practical advice about living with cancer. You may find it easier to share your thoughts and feelings with someone who has a similar experience than with anyone else. There are a range of support groups that will support you and your family at time of diagnosis, throughout treatment and afterwards. A list of support groups is given at the back of this booklet.

Often you might need practical advice about your financial matters, e.g. getting a mortgage or travel insurance. The Irish Cancer Society Helpline nurses will be happy to discuss any concerns you or your family may have, at any stage of your illness. They can give you more information about any of the services outlined above and can also let you know about support services in your area.

Health cover

Health cover falls into two categories – cover for medical card holders and cover for all other categories. Details of what this involves are given in the following pages. At the end of this section there are also some useful telephone numbers and addresses for further help.

Hospital cover

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

Outpatient cover

If you go to the outpatients or A&E unit of a public hospital, without being referred there by a GP, you may be charged €100. There is no charge if you are referred there by a GP. This charge does not apply if you have a medical card or are admitted to hospital as a result of attending the A&E unit first.

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services, and outpatient services and medical appliances. You will have to pay a prescription charge of 50c per item up to a limit of €10 per family.

To qualify for a medical card depends on a means test. If you are over 70 and your weekly income is €700 or less, you can apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office. If your means are above but close to the guidelines, you should apply for a card anyway as a card is granted in some situations. For example, if you have a large amount of medical expenses. Also, you may qualify for a medical card because you have a cancer diagnosis. In this case your spouse and children will not be covered if your means are over the limit.

GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker or your HSE office to see if you are eligible.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families including spouses and dependent children pay a limit of €120 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your pharmacy.
Private healthcare cover
Private health insurance is used to pay for private care in hospital or from various specialists in hospitals or in their practices. In Ireland this is available through the VHI, Quinn Healthcare, VIVAS Health and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. Before attending hospital, it is best to check the level of cover provided by your insurance company, both for inpatient and outpatient services.

Benefits and Allowances

Illness Benefit
This is a benefit for insured people. Your eligibility will depend on your PRSI contributions. You must be under 66 and unable to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social Protection, PO Box 1650, Dublin 1. Tel (01) 679 7777. These certificates are available from your GP and from the hospital you attend during inpatient care. You should send your claim to the Department within 7 days of becoming ill and unable to attend work. A delay might result in loss of payment. The benefit lasts for two years.

Disability Allowance
You might qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least a year. Disability allowance is a weekly allowance paid to people with an injury, disease or a disability who are aged between 16 and 66. For this allowance you must satisfy a means test, live in Ireland and be medically suitable. To be medically suitable you should have an illness that has continued or may continue for at least 1 year. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Invalidity Pension
This is a pension paid instead of an illness benefit or disability allowance, if you are unable to work permanently. There are three cases where you can be eligible. (1) If you have been incapable of work for at least 12 months and likely to be incapable for at least another 12 months. (2) If you are permanently incapable of work. (3) If you are over age 60 and have a serious illness or incapacity. Your eligibility will also depend on your PRSI contributions and you must live in Ireland. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer’s Allowance
This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. You must be aged 18 or over, live in Ireland, satisfy a means test, not be self-employed or work more than 15 hours a week outside the home, and not live in a hospital or nursing home. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a respite care payment every year. For more advice, talk to your social worker and/or the Dept of Social Protection. Application forms are available from your social welfare office or from the Carer’s Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.
Carer’s Benefit
Under carer’s leave legislation, you may be entitled to unpaid temporary leave from your employment. Or if you are employed but wish to care for a sick relative full time, you may qualify for a carer’s benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. You must be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged 16 or over, live in Ireland, not be self-employed or employed while caring for the person, and not live in a hospital or nursing home. More information is available from the Carer’s Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Appliances
For patients who have medical cards most appliances are free of charge. For example, you are entitled to a new hairpiece or wig every 6 months.

Travel to hospital
Patients can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres. Sometimes the HSE may assist with transport costs for a person who has to travel a long distance to a hospital.

In general, those who do not have a medical card may be charged for the service. However, the practice varies between HSE areas and often depends on personal circumstances. Charges may be waived in certain cases, for example, hardship.

Further information
Depending on your circumstances at the time of your illness, there are many other benefits and entitlements which may be relevant to you. Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:
- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending.

For social welfare queries contact:
Information Service
Dept of Social Protection
Oisín House
212–213 Pearse Street
Dublin 2

Tel: 1850 662 244
Leaflet line: 1890 202 325
Email: info@welfare.ie
Website: www.welfare.ie

If you have queries about health and social services, contact the HSE office in your area: HSE Dublin North East, HSE Dublin Mid-Leinster, HSE South and HSE West. For more information: HSE infoline: 1850 241 850; Email: info@hse.ie; Website: www.hse.ie

HSE East Coast Area
[Co Wicklow, South East Dublin]
Southern Cross House
Southern Cross Business Park
Boghall Road
Bray
Co Wicklow
Tel: 01 201 4200

HSE Northern Area [North Dublin]
Swords Business Campus
Balheary Road
Swords
Co Dublin
Tel: 01 813 1800

HSE South Western Area [Co Kildare, West Wicklow, South Dublin]
Oak House
Millenium Park
Naas
Co Kildare
Tel: 045 880 400

HSE Midland Area [Counties Laois, Offaly, Longford, Westmeath]
Head Office
Arden Road

Tullamore
Co Offaly
Tel: 057 932 1868

HSE Mid-Western Area [Counties Clare, Limerick, Tipperary North]
Head Office
31/33 Catherine Street
Limerick
Tel: 061 483 286

HSE North Eastern Area [Counties Cavan, Monaghan, Louth and Meath]
Head Office
Navan Road
Kells
Co Meath
Tel: 046 928 0500

HSE North Western Area [Counties Donegal, Sligo, Leitrim and West Cavan]
Head Office
Manorhamilton
Co Leitrim
Tel: 071 982 0200 / 1850 636 313
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These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services.

The helpline can also put you in contact with the various support groups that are available. The helpline 1800 200 700 operates Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- All queries or concerns about cancer can be emailed to the CIS at helpline@irishcancer.ie
- The walk-in caller service allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- Message Board is a bulletin board on our website (www.irishcancer.ie) that gives you the chance to post your comments.
- The CancerChat service is a live chatroom with a link to a Cancer Information Service nurse.

The Breast Cancer Information Service (formerly Action Breast Cancer) provides breast cancer information and support. It also funds breast cancer research. Its services are free and confidential. They include a national helpline, publications, one-to-one support, breast awareness talks and advocacy. Contact 1800 200 700 for more information.

Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See page 74 for more details.

Peer-to-peer support

Many patients find it helpful to talk to someone who has had a diagnosis of cancer and who has recovered. The Society can put you in touch with someone who has been trained to provide emotional and practical support for you, the cancer patient. All volunteers have had a personal experience of cancer and understand the emotional and physical impact of the disease. If you would like to make contact with a volunteer, please call the National Cancer Helpline 1800 200 700.
**Counselling**
Coping with a diagnosis of cancer can be very stressful at times. Patients and their families sometimes find it difficult to come to terms with the illness. Many people also feel that they cannot talk to a close friend or relative. If this is the case, counselling can provide emotional support in a safe and confidential environment. Call the helpline to find out about counselling services provided by the Irish Cancer Society and services available in your area.

**Night nursing**
The Irish Cancer Society can provide a night nurse, free of charge, for up to 70 hours (mainly at night) to families who are caring for a seriously ill person at home. If you need help, you can find out more about this service from a member of the homecare team, your GP or local public health nurse. Homecare nurses are specialist palliative care nurses who offer advice on pain control and other symptoms. ICS night nurses provide care to the patient and support to families in their own home.

**Oncology liaison nurses**
The Irish Cancer Society funds oncology liaison nurses who provide information as well as emotional and practical support to the patient and his or her family. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

**Financial aid**
A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial help to patients in need. You may be suitable for schemes such as Travel2Care or Financial Aid. If you would like to request this kind of help, contact your oncology or medical social worker at the hospital where you have been treated. He/she should fill in an application form and return it the Irish Cancer Society. If there is no social worker, another health professional involved in your care may apply on your behalf. If you feel you are getting into debt or are in debt, talk to the Money Advice and Budgeting Service. The MABS Helpline is 1890 283 438. They can help you work through any financial issues you may have.

**Cancer information booklets**
These booklets provide information on all aspects of cancer and its treatment. They also offer practical advice on learning how to cope with your illness. The booklets are available free of charge from the Irish Cancer Society.

If you would like more information on any of the above services, call the National Cancer Helpline 1800 200 700.

**Useful organisations**

- **Irish Cancer Society**
  43/45 Northumberland Road
  Dublin 4
  Tel: 01 231 0500
  Fax: 01 231 0555
  National Cancer Helpline 1800 200 700
  Email: helpline@irishcancer.ie
  Website: www.cancer.ie

- **CervicalCheck: The National Cervical Screening Programme**
  PO Box 161
  Limerick
  Freefone: 1800 45 45 55
  Email: info@cervicalcheck.ie
  Website: www.cervicalcheck.ie

- **National Cancer Screening Service**
  King’s Inns House
  200 Parnell Street
  Dublin 1
  Tel: 01 865 9300
  Email: info@cancerscreening.ie
  Website: www.cancerscreening.ie

- **The Carers’ Association**
  Bulger House
  Patrick Street
  Tullamore
  Co Offaly
  Tel: 057 932 2933
  Email: info@carersireland.com
  Website: www.carersireland.com

- **Citizens Information Board (formerly Comhairle)**
  Ground Floor
  George's Quay House
  43 Townsend Street
  Dublin 2
  Tel: 01 605 9000
  Locall 1800 777 121
  Email: info@ciboard.ie
  Website: www.citizensinformation.ie

- **Dept of Social Protection – Information Service**
  Oisín House
  212–213 Pearse Street
  Dublin 2
  Tel: 1850 662 244
  Email: info@welfare.ie
  Website: www.welfare.ie

- **European Institute of Women’s Health**
  33 Pearse Street
  Dublin 2
  Tel: 01 671 5691
  Email: info@eurohealth.ie
  Website: www.eurohealth.ie

- **HARI Unit (Human Assisted Reproduction Ireland)**
  Rotunda Hospital
  Parnell Square
  Dublin 1
  Tel: 01 807 2732
  Website: www.rotunda.ie
Helpful books

Free booklets from the Irish Cancer Society:
- Understanding Chemotherapy
- Understanding Radiotherapy
- Radiation Therapy: A Patient Pathway (DVD)
- Coping with Fatigue
- Diet and Cancer
- Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients
- Understanding the Emotional Effects of Cancer
- Lost for Words: How to Talk to Someone with Cancer
- Who Can Ever Understand? Talking About Your Cancer
- Talking to Children about Cancer: A Guide for Parents

Cervical Cancer: All You and Your Partner Need to Know About Its Detection and Treatment
Jane Chomet, Julian Chomet, Peter Gardiner
HarperCollins, 1998
ISBN: 978-0722515839

Challenging Cancer: Fighting Back, Taking Control, Finding Options (2nd edn)
Dr Maurice Slevin & Nira Kfir
Class Publishing, 2002
ISBN 1-85959-068-3
### Questions to ask your doctor

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

- What stage is my cancer at?
- What treatment will I need?
- Will surgery cure my cancer?
- Are there other treatment options? Why is this one best for me?
- Would I be suitable for a clinical trial?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- What side-effects or after-effects will I get?
- Is there anything I can do to help myself during treatment?
- How soon can I have sex after treatment?
- Will I be able to have children?
- How often will I need check-ups?
- Will I need to have smear tests?

### Notes

#### Your own questions

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**Taking Control of Cancer**  
Beverley van der Molen  
Class Publishing, 2003  
ISBN 1-85959-091-8

**44½ Choices You Can Make If You Have Cancer**  
Sheila Dainow, Jo Wright & Vicki Golding  
Newleaf, 2001  
ISBN 0-71713-222-6

**What You Really Need to Know about Cancer**  
Dr Robert Buckman  
Pan, 1997  

**Explaining cancer to children**  
*Why Mum? A Small Child with a Big Problem*  
Catherine Thornton  
Veritas, 2005  
ISBN 1-85390-891-6

**The Secret C: Straight Talking About Cancer**  
Julie A Stokes  
Winston’s Wish, 2000  
Acknowledgements

We would like to extend a special word of thanks to the following for their invaluable contributions to this booklet and/or previous editions::
Eileen O’Donovan, Cancer Information Nurse
Ger Boyle, Clinical Nurse Manager (Radiotherapy)
Clara Cremin, Information and Support Radiation Therapist
Olive Stanley-Wetzel, Patient Reviewer
Debbie Kenny, Patient Reviewer

Would you like more information?

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

Would you like to be a patient reviewer?

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

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

Would you like to help us?

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

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4.
Tel: 01 231 0500 Email: info@irishcancer.ie Website: www.cancer.ie
The mission of the Irish Cancer Society is to play a vital role in achieving world-class cancer services in Ireland, to ensure fewer people get cancer and those that do have better outcomes. Our goals are focused around prevention, survival and quality of life, with three programme areas to achieve them: advocacy, cancer services and research.