

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 cervical cancer. It has been prepared and checked by surgeons, cancer doctors, nurses, radiation therapists and patients. The information in this booklet is an agreed view on cervical cancer, its treatment and how it may affect you.

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

	Name	Telephone
Specialist nurse		
Family doctor (GP)		
Gynaecologist		
Medical oncologist		
Radiation oncologist		
Radiation therapist		
Medical social worker		
Emergency		

This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We especially thank the people who generously shared their personal experiences of cancer throughout this booklet. We also acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

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Quick facts

Can my cancer be treated?

Page 21

Yes. All stages of cervical cancer can be treated. Your doctor will discuss with you what treatments will be of most benefit to you.

Will I be OK?

Page 20

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things, and everyone's prognosis is different.

The prognosis for cervical cancer is good for most people. Your doctor will advise you on what is likely to happen in your situation.

What kind of treatment will I have?

Page 21

Surgery: An operation to remove the cancer.

Radiotherapy: X-rays to destroy the cancer cells. It can be given internally and/or externally.

Chemotherapy: Drugs to slow down and control the growth of cancer.

Radiotherapy and chemotherapy: Sometimes called chemoradiation. Chemotherapy can make the radiotherapy more effective.

Targeted therapies: Drugs that work with your body to help fight cancer. May be given to treat cervical cancer that comes back.

Sometimes you will have a choice of treatment.

See page 23 for advice about making a decision.

Are there side-effects from treatment?

Page 47

Your doctor and the team caring for you will talk to you about possible side-effects. Read about each of the treatments to learn more about their side-effects.

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

Clinical trials

Page 44

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

We're here for you

Page 76

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

Ways to get in touch

- Call our Cancer Nurseline on 1800 200 700
- Drop into a Daffodil Centre
- Email us: cancernurseline@irishcancer.ie

Introduction

This booklet has been written to help you to understand more about cancer of the cervix.

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



Reading this booklet

Remember you do not need to know everything about cervical cancer straight away.

Read a section that you are interested in. Then read another section when you want to know more. If you do not understand something that has been written, discuss it with your doctor or nurse.

You can also call our Cancer Nurseline on Freephone 1800 200 700 or email the nurses at cancernurseline@irishcancer.ie. You can also visit a Daffodil Centre. See page 76 for more about Daffodil Centres. You can email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.



About cervical cancer

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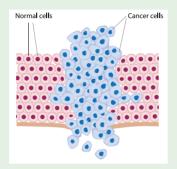
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What is cancer?

Cancer is a word used to describe a group of diseases, not just one. There are more than 200 different types of cancer. Each is named after the organ or type of cell in which the cancer first grows. For example, prostate cancer starts in cells in the prostate gland, breast cancer starts in cells in the breast and

cervical cancer starts in cells in the cervix.

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



Tumours can be either benign or malignant.

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

What is the lymphatic system?

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





To sum up

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

What is the cervix?

The cervix is found deep inside your vagina at the lower end of your womb (uterus). 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. Usually your cervix is closed but opens during labour to let the baby be born.

The cells in your cervix are changing all the time. Most changes happen in an area called the transformation zone. Sometimes abnormal changes happen.

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, starting with precancerous cells 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 cervix, including organs in the pelvis such as the bladder and bowel, and lymph nodes around the pelvis.

10 Understanding cancer of the cervix

How common is cervical cancer?

Each year in Ireland, about 300 women are diagnosed with cervical cancer. Cervical cancer can happen at any age but is more common in women in their 40s.

What are the types of cervical cancer?

Cervical cancers are recognised by how they look under a microscope.

Squamous cell carcinoma is the most common type of cervical cancer. 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 and start higher up in the cervical canal. They develop in the gland cells that make mucus in the cervical canal. These cells are shaped like columns.

Adenosquamous carcinomas, mixed carcinomas, clear-cell and small-cell carcinomas are rarer forms of cervical cancer.

If you would like to know more about your type of cancer, ask your doctor to explain it to you.



To sum up

- The cervix is part of the female reproductive system. It is found in the lower part of the womb.
- The area of the cervix that changes most is called the transformation zone.
- Early changes to the cells of the cervix are called precancerous or CIN.
- CIN is not the same as cervical cancer.
- Squamous cell carcinoma is the most common type of cervical cancer.

What increases my risk of cervical cancer?

Risk factors can increase your chances of getting the disease. Having a risk factor doesn't mean you will definitely get cancer. Sometimes people without any known risk factors develop cancer.

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

Human papilloma virus (HPV)

99.7% of cervical cancers are caused by a virus called the human papilloma virus (HPV).

The human papilloma virus is a common infection spread by sexual contact. Most women who have sexual contact will have HPV at some point in their lives. In fact, this virus is so common that even if you have only one sexual partner in your lifetime, you could still be infected. Condoms do not give full protection against it.

It is important to remember that having HPV is not a problem in itself and most women have had it. Most of them get rid of the virus within a short time. Because it has no symptoms, they are unaware they have had it, but a small number of women have trouble getting rid of it, especially if they smoke. These women are at a higher risk of cervical cancer.

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 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. But there is no reason to blame yourself. Most people have had the HPV infection at some point.

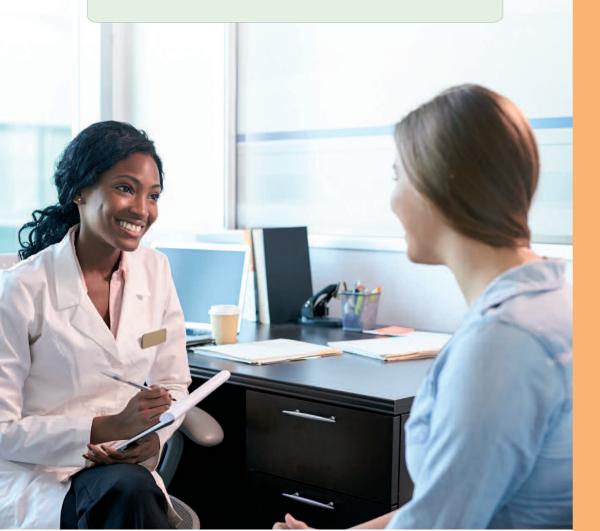
Cancer of the cervix is not infectious and so cannot be passed on to others.

Smoking

Smoking increases your risk of abnormal changes (CIN). Chemicals in cigarettes can affect how your cervix fights HPV infection. For this reason, if you smoke, you can have trouble getting rid of the HPV infection.

Being vaccinated against HPV

The HPV vaccine targets the high-risk HPV types that cause cervical cancer. The vaccine is now available in Ireland for all girls in their first year of secondary school. In time, it is hoped that the vaccine will significantly reduce the number of cervical cancer cases in Ireland. If you have any questions, talk to your family doctor (GP) or call the Cancer Nurseline on 1800 200 700.



Diagnosis and tests

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Being diagnosed with cervical cancer

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

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

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

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

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

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

6 Being told the word 'cancer' is absolutely traumatising and nothing can prepare you for it. 9

Telling people about your diagnosis

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

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

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you would like to talk things over with a cancer nurse. You can also ask for a copy of our booklet *Who Can Ever Understand?* This booklet can help you find ways to talk about your cancer and to ask for the help and support you need.



What tests will I have?

After being diagnosed with cervical cancer, you may have more tests to find out about your cancer and your general health.

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

Tests you may have include:

Blood tests: Blood 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. An 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. During the test you will lie inside a tunnel-like machine. Some people are afraid they may feel claustrophobic inside the tunnel. If you are anxious, contact the radiographer the day before. They may be able to give you medication to relax you on the day. An MRI can also be noisy, but you will be given earplugs to wear during it.

You may have an injection before the scan to show up certain parts of your body. You cannot wear metal jewellery during the scan. If you have a medical device implanted, like a pacemaker or metal pin you may not be suitable for the test. Usually you can go home soon after the scan.

PET CT scan: This is a scan that gives a detailed picture of the tissues inside the body. It also uses a low dose of radioactive sugar to measure the activity of your cells. This sugar is first injected into your arm and travels to all the cells in your body. Because cancer cells absorb large amounts of the sugar, there will be more radioactivity where the cancer cells are found. An hour after the injection, the scan is taken and can show if the cancer has spread to other tissues and organs. During the scan, you will lie on a table which moves through a scanning ring. Before the scan, you may have to fast (not eat) for a few hours. You will be radioactive for 6 hours after the sugar injection. You should avoid contact with young children and pregnant women during this time.

Waiting for test results

It usually takes about a week for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Staging cervical cancer

The tests you have after diagnosis are usually done to help the doctor to stage your cancer. Staging means finding out the size of the cancer and if it has spread to other parts of your body. Staging is very important, as it helps your doctor to decide the best treatment for you

How is cervical cancer staged?

There are different ways to describe the stages of cancer. The staging system normally refers to the size of the tumour (T), if there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis). Your doctor often uses this information to give your cancer a number stage – from 0 to 4. A higher number, such as stage 4, means a more serious cancer. The stages of cervical cancer can be further divided into stage A and B. Staging can be hard to understand, so ask your doctor and nurse for more information if you need it.

In general, the lower the number, the less the cancer has spread.

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 cells are on the surface and have not invaded the deep tissue of the cervix. Stage 0 is a pre-cancer and is also called CIN (see page 9).

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'.

- Stage 1A1 The earliest stage. The cancer cells are less than 3mm deep.
- Stage 1A2 The cancer cells are 3–5mm deep.
- Stage 1B1 The cancer cells are more than 5mm deep and less than 2cm wide.
- Stage 1B2 The cancer cells are more than 5mm deep and less than 4cm wide.
- Stage 1B3: The cancer cells are more than 5mm deep and more than 4cm wide.

The cancer in stages 1B1, 1B2 and 1B3 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. In stage 2A, the cancer has spread into the upper part of the vagina but has not spread to the tissues at the side of the cervix.

- Stage 2A1 The cancer is less than 4cm in size.
- Stage 2A2 The cancer is greater than 4cm in size.
- Stage 2B Cancer cells have spread to the tissues at the side of the cervix.

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/or to the side wall of the pelvis.

- Stage 3A The cancer has spread to the lower third of the vagina but not the pelvic wall.
- Stage 3B 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 3C: The cancer has spread to the lymph nodes.

Stage 4: In this stage, the cancer involves other body organs.

- Stage 4A The cancer has spread to nearby organs such as the bladder or back passage (rectum).
- Stage 4B The cancer has spread to distant organs, such as the lungs. Stage 4B cervical cancer is also called metastatic cervical cancer.



>>> Staging is very important as it allows your doctor to decide the best treatment for you.

Recurrent cervical cancer

If the cancer returns after treatment it is called recurrent cervical cancer. Local recurrence is when the cervical cancer returns in the pelvis. When it returns to distant organs, it is called distant recurrence. See page 45 for more information.



To sum up

- Tests to show the stage of cervical cancer include a pelvic examination under anaesthetic (EUA), MRI scan and PET CT scan.
- Cervical cancers can be staged 0 to 4 or recurrent cancer.
- Staging cancer means finding out its size and how far it has spread in the body.

Email: cancernurseline@irishcancer.ie

Asking about your prognosis

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

Should I ask about my prognosis?

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

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

If you decide you want information on your prognosis:

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

Treating cervical cancer

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How is cervical cancer treated?

The way cervical cancer is treated mainly depends on the stage of the disease at diagnosis. In general, there are a number of things that will affect what type of treatment you receive. These are:

- The size and stage of your cancer
- The type of cancer
- If it has spread or not
- Your general state of health
- Your age and fertility

Often cervical cancer is treated with a combination of chemotherapy and radiotherapy. This is sometimes called chemoradiation. Surgery and radiotherapy are also used. Rarely, chemotherapy on its own may be used.

Surgery: Surgery involves an operation to remove the cancer cells with the minimum risk of them returning. The types of surgery can include a cone biopsy, hysterectomy, radical hysterectomy, bilateral oophorectomy, lymphadenectomy and radical trachelectomy. See page 28 for more details about surgery.

Radiotherapy: Radiotherapy is the use of high-energy rays to destroy the cancer cells. It can be given externally and/or internally. It can be used as the main (primary) treatment or as an extra treatment (adjuvant) after surgery. See page 34 for more about radiotherapy.

Radiotherapy and chemotherapy: Radiotherapy and chemotherapy may be given together. Chemotherapy can make the radiotherapy more effective. Sometimes chemotherapy is given alone. See page 40 for more about chemotherapy.

Targeted therapy: Targeted therapies may be given to treat recurrent cervical cancer. They may be offered to you alongside chemotherapy. See page 43 for more about targeted therapies.

Specialist cancer centres

Cervical cancer is treated in specialist gynaecological cancer centres in Ireland. The staff at these centres have great expertise in managing patients with cervical cancer. As a result, you may be transferred to a cancer centre once you have received your diagnosis.

Deciding on treatment

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

Treatment options: Your doctor and nurse will explain your treatment options to you. Do ask as many questions as you like, no matter how small or trivial you think they are. All questions are important. You could use the fill-in page at the back of this booklet for your questions and answers. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

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

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

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

Giving consent for treatment

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

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

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

Waiting for treatment to start

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

Cancer treatment should start soon after diagnosis. But for most cancers, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works. This also gives you time to talk about all your treatment options with your doctors, family, and friends.

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

Individual treatment

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

Who will be involved in my care?

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

surgeon

Gynaecological oncology A doctor who specialises in the surgical

treatment of cancers of the female reproductive

system.

Pathologist A doctor who specialises in looking at cells

under a microscope and diagnosing the cell

Radiologist A doctor who specialises in reading scans and

Radiation oncologist A doctor who specialises in treating cancer

using radiotherapy.

Radiation therapist A specially trained person who delivers the

> radiotherapy and gives advice to cancer patients about their radiation treatment.

A doctor who specialises in treating cancer Medical oncologist

using chemotherapy and other drugs.

specialist

Gynaecology clinical nurse 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 cancer care unit. She or he gives information and

reassurance to patients and their families from

diagnosis and throughout treatment.

GP (family doctor) You can talk to your GP about your medication

> and any side-effects you have. You can also contact your GP about any worries you have or

if you are finding it hard to cope.

Medical social worker A person trained to help you and your family

> with your social issues and practical needs. They can give counselling and emotional support. They can give advice on benefits and financial matters and on practical supports and services

available to you when you go home.

Physiotherapist	A therapist who treats injury or illness with exercises and other physical treatments related to the illness.
Dietitian	An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms.
Occupational therapist (OT)	A therapist who specialises in helping people who are ill or disabled learn to manage their daily activities, e.g. self-care.
Psycho-oncology team	These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.
Psychologist	A specialist who can talk to you and your family about emotional and personal matters and can help you make decisions.
Counsellor	A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.
Community health services	These include family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.
Palliative care team	This team is specially trained in managing pain and other symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the 'homecare team' or the 'hospice homecare team'. A specialist palliative care service is available in most general hospitals and in the community.



To sum up

- Surgery, radiotherapy, or radiotherapy and chemotherapy together can be used to treat cervical cancer.
- Chemotherapy and targeted therapies can be used to treat recurrent cervical cancer.
- A team of specialists will decide which treatment is best for you.

Treatment types

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Surgery

Understanding cancer of the cervix

The aim of surgery is to remove the cancer and the area close to it. Which type of operation is best for you will depend on the stage of your cancer.

If you have early stage cervical cancer, it may be possible to treat it by removing a cone-shaped piece of tissue from the cervix. This is called a cone biopsy.

It may be possible to treat very early stage cervical cancer using LLETZ. This 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.

Other types of surgery include:

- Hysterectomy: the cervix, womb and fallopian tubes are removed.
- Radical hysterectomy: the cervix, womb and top part of the vagina are removed.
- **Bilateral oophorectomy:** your ovaries are 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. This is for women who would still like to be able to have children.
- Lymphadenectomy: the lymph nodes in the pelvis are removed.

 This operation may be done along with one of the above operations or before you start radiotherapy.
- **Pelvic exenteration:** the bladder, part of the bowel, ovaries, womb, cervix and vagina are removed.

It is important that the surgery decision is made by highly trained specialists at the cancer centre. Usually, more than one gynaecologist or cancer surgeon is involved in that decision and in your surgery as well.

For most types of surgery for cervical cancer you will be admitted to hospital and have a general anaesthetic.

Laparoscopy (keyhole surgery)

For some women, minimal access surgery is an option. This is also called laparoscopy or keyhole surgery. Your doctor will advise you about whether it is an option for you. The surgery is done through small openings (key holes) in your abdomen (tummy wall). Otherwise, a cut is made in your abdomen to do an open surgery.

If you are keeping your ovaries, the surgeon may advise you to have one ovary moved from the pelvis to protect it from any radiotherapy that might be given after cancer surgery. This is called ovarian transposition.

6 I had a radical trachelectomy. There was very little pain during my recovery 9

Getting ready for surgery

Preparation for the different kinds of surgery depends on your age and general health and the type and stage of your cancer. You will need a blood test to check your blood cell count, liver and kidney function tests and a viral screen that includes an HIV test. You may need a chest X-ray, heart test (ECG) and lung (pulmonary function) tests. These are normally done before you are admitted to hospital.

In the time between your diagnosis and your surgery it is important to stay active and exercise as much as you can. You should also eat healthy food and take iron supplements if your blood level is low. If you smoke, try to quit. This will help your wound heal after the operation. It will also reduce the risk of chest complications during and after your general anaesthetic.

Surgical removal of your womb or ovaries will mean you are no longer able to have children. This can feel devastating. Discuss your worries about fertility with your doctor before treatment starts. They can tell you if there are any options open to you at this time. They can refer you to a specialist fertility centre for advice, counselling and support.

On the day before surgery you will sign a consent form with your surgeon (see page 24). Write down any questions that come to mind beforehand and ask your questions before signing the form.

You may be told not to eat anything (fast) for a few hours before your surgery. Take plenty of fluid and calories until the time that you start to fast.

Before you go to the operating theatre, elastic stockings or compression boots may be put on your legs to prevent a clot developing in your legs during surgery. You may also be offered a tablet that will make you feel more relaxed and sleepy.

In theatre, you may be offered an epidural before the general anaesthetic if you are having open surgery. This is a pain-relieving injection given in your back. You will be given an oxygen mask to breathe on. The anaesthetic to put you to sleep is given through a drip in the vein of your hand or arm.

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' / IV cannula may be put into a vein in your arm. This is a small plastic tube which will be used to give you fluids until you are able to drink again.
- A small thin tube called a catheter may be put into your bladder to drain your urine into a bag. This rests your bladder after surgery. It may need to stay in place for several days.
- Drainage tubes from your wound may be present to make sure it heals well.
- A vaginal pack may be in place for 24 hours. This is like a tampon made of bandages.
- If you have an epidural there will be a thin tube (catheter) in your back to give you pain relief.

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

Pain

You will have some pain for the first few days. Some patients may also feel sick (nausea). The ward nurses and specialist pain nurse will assess you frequently to make sure you have the best control of pain and nausea. To control pain you may be given a pump into your vein, which sends pain medication into your blood when you press a button (PCA). Or you may have an epidural. You may also be given injections into your muscle, tablets, patches on your skin, or suppositories that are put in your back passage (rectum). A combination of pain relieving medications is often used. You may also need medication for nausea. Always ask for help before the pain or nausea gets too bad. You will be given a prescription for pain relief when you're discharged from hospital.

Eating and drinking

Any pelvic operation will slow down the movement of your bowels. As a result it will take a day or two before you can return to normal eating and drinking. You will be able to take sips of water or glucose drinks and suck sweets the day after surgery. Most people can manage a light meal within 2 or 3 days of surgery. Your drip will be stopped when you are taking enough fluid by mouth.

Bladder and bowel problems

The bladder is often slow to empty after a radical hysterectomy. Your surgeon may leave a tube (catheter) in place to drain your bladder for day or two. Sometimes the tube is left in for longer. After the tube is removed, your bladder may still be slow and need to be emptied with a catheter on and off. You may also get constipated, 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.

The recovery period will depend on whether you had keyhole surgery or open surgery. Following keyhole surgery, you may be ready to go home after 2 or 3 days. You should avoid strenuous activity (including heavy housework), heavy lifting and driving for 3 weeks after keyhole surgery and 6 weeks after open surgery. Your doctor and nurse will discuss this with you in more detail.

Possible side-effects of surgery

Risk of clotting (DVT) after surgery: Surgery in your pelvis puts you at risk of clotting in the deep veins of your legs and body. This is called deep venous thrombosis (DVT). You may be given an injection to prevent this. Usually this will be continued after you go home until four weeks after the date of surgery. So you or a member of your family will be invited to learn how to give the injection. It is very easy and is given with a very fine needle just under the skin. Keep the injection well away from the surgical wounds. You may also wear special elastic stockings while you are on bed rest. Getting up and about and exercising your legs is most important in preventing DVT.

Infection: You will be at higher risk of infection, such as a urinary tract infection, after the surgery. Antibiotics will be given during your surgery. You may also be prescribed antibiotics after 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.

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. Ask your physiotherapist for more information about lymphoedema. For a factsheet on lymphoedema, call our Cancer Nurseline on 1800 200 700. You can also pick up a copy from a Daffodil Centre or download one from www.cancer.ie

Fertility

If you have a hysterectomy, you will no longer be able to have children. This can be difficult to deal with emotionally and you may need extra support to help you cope. See page 53 for more information. If you have a radical trachelectomy, you may be able to get pregnant and have children in the future. If this is your wish, you will be referred to a specialist fertility centre. Your doctor will advise you to wait for a period of time before planning a pregnancy. There is a higher chance of miscarriage after a radical trachelectomy so you will be referred to a high-risk obstetrician if you do become pregnant. The baby will also need to be delivered by caesarean section.

If you have a cone biopsy, this can weaken the cervix. If you become pregnant, talk to your doctor or obstetrician about this.

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.



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, difficulty moving, bladder and bowel problems, lymphoedema (swelling in one or both legs), infection and fertility issues.

Radiotherapy

Radiotherapy is a treatment that uses high-energy X-rays to kill cancer cells. The aim of radiotherapy is to destroy the cancer cells with as little damage as possible to normal cells.

Radiotherapy is often given in combination with chemotherapy. This is called chemoradiation.

There are two types: external beam radiotherapy and internal radiotherapy (brachytherapy).

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.

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 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. Internal radiation allows for a bigger dose of radiation to be given directly to the cervix. If you have had a hysterectomy, external beam radiotherapy (and occasionally brachytherapy) may be given.

Treating symptoms of cancer

Radiotherapy 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.

External radiotherapy

Planning your external radiotherapy

Radiotherapy must be carefully planned so that the highest dose is given to the tumour area and as little as possible to the nearby cells. In external radiotherapy an important part of the planning process is simulation. This involves using a CT scanner to pinpoint the area to be treated. You may have extra scans or X-rays taken, but this is to plan your treatment only. The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. The dose of radiation will be decided and tightly controlled for your treatment.

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 treatment

During treatment you will first be positioned carefully on a treatment table, usually on your back. Then the machine will move around you so that you receive the precise treatment at different angles.

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

How much radiotherapy do I need?

Your doctor will let you know how many sessions or treatments you need. Usually you have treatment every day during the week, with a rest at weekends. Sometimes up to 28 sessions are given and treatment may go on for several weeks, but it will depend on your doctor's decision.

External radiotherapy does not make you radioactive. It's completely safe for you to mix with family and friends, including pregnant women and children.

Radiotherapy is normally given in special cancer treatment centres, usually hospitals or clinics. These centres need highly trained staff and space for the large equipment involved. As a result, the centre may be some distance from the hospital where you received surgery or chemotherapy.

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



Brachytherapy – internal radiotherapy

Understanding cancer of the cervix

With brachytherapy the radiation source is placed inside your body on or near your tumour. The idea is to give a high dose of radiation to the cancer cells, while minimising the amount of radiation delivered to normal tissues.

With cervical cancer, brachytherapy is often given to deliver a boost of treatment to the cervix following your external radiotherapy treatment. Occasionally it is given during external radiotherapy treatment. Brachytherapy after a hysterectomy is given in a slightly different way (see below for more information).

How much internal radiotherapy will I need?

You will normally require three treatments, but this may vary. The radiation oncologist at the hospital will decide the dose and number of treatments you need, depending on your situation.

Getting your treatment

You may need to stay in hospital overnight while you have preparations for brachytherapy. You will have a general anaesthetic or a spinal anaesthetic. In order to prepare you for brachytherapy, you will be taken to theatre to have special tubes inserted into your cervix and sometimes your womb.

After the tubes have been inserted in theatre you will have a scan to help your doctors plan your treatment. This can take 2-3 hours, during which you will be looked after on one of the wards. When the plans are ready you will be brought to a special room for treatment.

When you are come to the treatment room the radiation therapist will connect the tubes to the treatment machine. You will be on your own in the room during treatment. However, there is an intercom and camera in the room so the doctor, radiation therapist and nurse can see and talk to you from outside. Treatment can be interrupted if necessary.

Once the treatment is finished (5–10 minutes) the tubes are removed.

This may be uncomfortable. If you are in pain, you will be given pain medication. You will then be taken back to the ward and usually you will be able to go home the same evening. For some internal radiotherapy you may have to stay in hospital for a few days.

Brachytherapy treatment after a hysterectomy

If you have had a hysterectomy it is not usually necessary to have brachytherapy. If your doctors do recommend brachytherapy for you, the way it is given is different. You will not need to have an anaesthetic or stay overnight in hospital. Treatment involves putting a plastic tube into the vagina on 3 or 4 occasions. The tube stays in place for 5-10 minutes. You may feel a pressure sensation but you should not feel pain.

Will I have any side-effects?

Radiotherapy is given directly to the area where the cancer is found. This means any side-effects tend to affect the part of the body being treated. Most side effects develop during or shortly after your treatment and get better within a few weeks. When the cervix is being treated, the most common side-effects are:

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. See page 48 for more about fatigue.

Diarrhoea: Passing watery bowel motions more than twice a day is known as diarrhoea. You may also have some cramping and/or pain in your tummy. 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. Tell your doctor if these symptoms are troubling you, as he or she may be able to give you medication to help.

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. 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. Check with your radiation therapist or nurse before applying anything to your skin. You should also protect your skin from the sun.

Feeling sick (nausea): Your doctor can give you medication to help prevent you feeling sick. Take this one hour before treatment. It can help to eat small amounts often. Also, drink plenty of clear fluids such as water.

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 or nurse. Passing urine may also be painful, like cystitis. But your doctor can 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.

Stomach cramps: With high-dose radiotherapy, you may get some cramps after treatment. These may feel like period pains, but they do not last long. Your doctor and nurse will give you advice on suitable painkillers to take.

How severe these side-effects are will vary from person to person, depending on the amount of treatment received.

Long-term side-effects

Late side-effects may develop months or even years after treatment. Some side-effects are long-term or may even be permanent.

They may include:

- Shortening or narrowing of the vagina (see page 50)
- Difficulty having sex (see page 50)
- Early menopause (see page 49)
- Vaginal dryness (see page 50)
- Infertility (see page 53)
- Lymphoedema (see page 32)
- Damage to the small and large bowel, causing a change in the way vour bowel works
- Shrinkage of the bladder causing you to pass urine more

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.



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

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 sideeffects 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. Call our Cancer Nurseline on 1800 200 700 for a free copy. You can also pick up a copy from a Daffodil Centre or download the booklet from www.cancer.ie



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



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 of radiotherapy depend on the area being treated and the type of radiotherapy given. They include fatigue, diarrhoea, skin changes, feeling sick, shortening or narrowing of the vagina, abdominal cramps, and wanting to pass urine more often.

Chemotherapy

Chemotherapy is a treatment using drugs to kill cancer cells. The doctor who specialises in chemotherapy is called a medical oncologist.

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.

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

>>> Chemotherapy is often given with radiotherapy to make it more effective.

How often will I have chemotherapy?

Chemotherapy is given in cycles with a rest period between treatments. This rest period allows your body time to recover from the side-effects of treatment. The number of cycles can vary, depending on your cancer type and how well it is responding to treatment.

How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (drip). It may also be given in tablet form. Usually your treatment will be given in the chemotherapy day care unit

What kinds of drugs are used?

There are several chemotherapy drugs used to treat cervical cancer. Your doctor or nurse will discuss your treatment with you. Chemotherapy drugs can be used on their own or in combination with each other.

Hints and tips: Understanding your drug treatment

It's important that you understand the medicine you have been given. Don't be afraid to ask your doctor or specialist nurse for more information about any drugs you are taking, what they are for and any possible side-effects. They may be able to give you a printed sheet to take home with you.

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

What are the side-effects of chemotherapy?

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

Most side-effects can be helped by medication. In most cases the sideeffects go away once the treatment ends or soon after.

Side-effects may include:

Fatigue (feeling very tired): Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 48.

Infection: Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high temperature, having a cough, or pain passing urine.

Anaemia: Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment.

Bleeding and bruising: Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. You will have regular blood tests to count the number of platelets in your blood. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums. **Nausea and vomiting:** Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting.

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 dietitian, who will give you advice on what to eat. You can also call our Cancer Nurseline for a free copy of the booklet, *Diet and Cancer*. You can also pick up a booklet from a Daffodil Centre or download it from **www.cancer.ie**

Kidney damage: Some chemotherapy drugs 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.

Hearing loss: Chemotherapy drugs used to treat cervical cancer 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. Your doctor will keep a regular check on your hearing.

Numbness or pins and needles in the hands and feet (peripheral neuropathy): Some drugs can affect your nerve endings. They may cause numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy. You may also have trouble picking up small objects or buttoning up a shirt or cardigan. This side-effect normally goes away after treatment stops, but if it is becoming noticeable during treatment, let your doctor know.

Hair loss (alopecia): Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Before treatment your doctor and nurse will tell you if you are likely to have any hair loss. For more information on hair loss and cancer, see www.cancer.ie

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. He or she will tell you what to do.

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



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 of chemotherapy vary between people and depend on the drugs used.
- Side-effects may include feeling tired, feeling sick or getting sick, not wanting to eat, hearing loss, kidney damage, numbness or pins and needles in the hands and feet.

Targeted (biological) therapies

Targeted therapies may be given to treat recurrent cervical cancer. These drugs may be offered to you alongside chemotherapy.

Targeted therapies works with your body. They can help fight cancer, stop it spreading or control side-effects from other cancer treatments.

Different types of targeted therapies work in different ways. For example:

- Monoclonal antibodies trigger your immune system to attack cancer cells or target the cancer cells with drugs or a radioactive substance.
 For example, bevacizumab.
- Immunotherapy boosts your body's immune system to fight cancer.

Some drugs are given in tablet form. Others are given into a vein through a drip.

New treatments are being developed all the time and existing therapies are being used in new ways. You may also be given a targeted therapy as part of a clinical trial (see below). Ask your doctor if there are any new treatments available to treat your cancer or if there are any trials that are suitable for you.

Side-effects

Side-effects depend on the drugs being used and vary from person to person. Common side-effects include:

- Feeling tired
- Loss of appetite
- Diarrhoea
- Pain in your muscles and joints

Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects. Always tell your doctor or nurse if you don't feel well or if you are having any symptoms that are troubling you.

Clinical trials

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

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

Drugs that are used in a clinical trial have been carefully tested to make sure they are safe to use in a clinical trial.

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

More information

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

How is advanced cancer treated?

Advanced cancer is when cancer has spread to another part of your body. Cancer that has spread to another part of your body can also called metastatic or secondary cancer. Your cancer may be advanced when it is first diagnosed.

If your cancer is advanced it can still be treated. The aim of treatment is usually to try to control the cancer rather than to cure it. Your doctor may advise different chemotherapy drugs or targeted therapies that may help. There may also be treatments that you can have as part of a clinical trial (see page 44). Your doctor will tell you if there are any clinical trials that might be helpful for you.

In many cases, treatment can help you to live longer with better control of your symptoms. Your doctor will discuss the best treatment option for you with the healthcare team. Your doctor may refer you to specialist palliative care doctors and nurses, who are experts in managing the symptoms of advanced cancer. Palliative care also offers emotional support and comfort to patients and their families.

Treating 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 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.



Managing side-effects and symptoms

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How can I cope with fatigue?

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

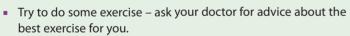
Fatigue when you have cancer can be caused by many things, including:

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

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

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

Tips & Hints – fatigue





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

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



Early menopause

You will experience menopausal symptoms following radiotherapy to your pelvis. This is because radiotherapy stops your ovaries from working. Women who have had their ovaries surgically removed will also have an early menopause. Chemotherapy may also stop your ovaries from working. Symptoms of the menopause include hot flushes, night sweats, dry skin, vaginal dryness, decreased sex drive, low mood, poor concentration and difficulty sleeping.

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.

Do talk to your nurse if you are having problems with the symptoms of early menopause. You could also read about managing menopausal symptoms on our website, **www.cancer.ie**

Will treatment affect my sex life?

Treatment for cervical cancer can cause physical and emotional changes that can affect your sex life.

Physical side-effects

Cervical cancer treatments can cause side-effects like vaginal dryness, a narrower or shorter vagina, pain during sex and low sexual desire (low libido). These problems usually improve with time, and there are things you can do to help improve these side-effects. If any side-effect is troubling you talk to your nurse specialist or doctor.

Vaginal dryness

After pelvic radiotherapy your vagina may be drier than before. This can make having sex uncomfortable. Vaginal lubricants can be used regularly to help with day-to-day dryness. Water-based, oil-based or silicone vaginal lubricants can be used during sex to make it more comfortable and pleasurable. Hormonal creams can also help with vaginal dryness. Your doctor, nurse specialist or pharmacist can give you advice about this.

Shortening/narrowing of the vagina

Your vagina may become shorter or narrower if scar tissue forms after pelvic radiotherapy. This generally happens over a period of time. Also, the walls of the vagina can become less stretchy and drier than before treatment. These changes may make it uncomfortable to have sex. It can make internal examinations more uncomfortable. These are an important part of your follow-up care after treatment.

Vaginal dilation may prevent the vagina becoming shorter or narrower by preventing scar tissue developing in the vagina. Regular gentle sex can help too. Dilation means 'stretching and opening'. Your nurse specialist may recommend that you use vaginal dilators to try to prevent these vaginal changes from happening. Dilators are tamponshaped plastic tubes of different sizes that you use with a lubricant. Or you could use a vibrator. They tend to be more flexible and come in a larger variety of shapes and sizes.

Your specialist nurse will advise you on how helpful a dilator or vibrator may be in your situation and explain how to use them. You may feel embarrassed or uncomfortable about using them. Talk to your specialist nurse or medical team – they will understand your concerns and will always respect your feelings.

Pain

You may feel tender or sore for a few weeks after surgery or radiotherapy. You may want to avoid sex during this time to allow the area to heal fully and avoid any further damage. It is also a good idea to avoid using tampons and jacuzzis during this time.

Intimacy problems

Many women have no problem starting to have sex again 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. Some women lose the desire for sex (libido), which can happen during treatment for a serious illness.

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

There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner.

You can also enjoy other forms of closeness, such as touching, caressing and holding each other. If you have a supportive partner, talking to them about how you feel is important. Your partner may feel uncertain about how to react to all the changes that are happening. Communicating openly helps to reduce worries and avoid misunderstandings.

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

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

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment. For more information, see page 53. The National Cancer Control Programme also has a booklet called Sexual wellbeing after breast or pelvic cancer treatment. Ask your doctor or nurse for a copy.

Asking for advice

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

Tips & Hints – Sex after cervical cancer treatment

 Always speak with your specialist nurse about any concerns you may have about your sex life. You don't need to feel embarrassed. The nurse will be happy to talk to you and give you advice.



- Lubricants can be used during sex to make it more comfortable and pleasurable.
- Vaginal dilation means gently stretching and opening the vagina. This can help to prevent the vagina becoming shorter and narrower.
- Dilation can be done by regular use of a dilator, vibrator or regular gentle sex.
- It may be useful to become more aware of your vaginal muscles and learn how to relax your muscles when you are having sexual intercourse.
- If having sex is uncomfortable try different positions. Lying on your side or having your partner underneath you may be easier.

Will treatment affect my fertility?

Infertility

Your fertility will be affected if you have a hysterectomy or radiotherapy. You will not be able to become pregnant after these treatments. Discuss any worries you have about infertility with your doctor before treatment starts. He or she can tell you if there are any options open to you at this time.

Ovarian transposition: Radiotherapy for cervical cancer affects your ovaries and stops them from producing eggs and pregnancy hormones.

Ovarian transposition is a type of surgery where the ovaries are moved away from the area where the radiotherapy will be given. This is to try to stop the radiation from affecting your ovaries to allow you to keep producing eggs. This operation doesn't always work but you can talk to your doctor to see if you are suitable.

Dealing with infertility: Dealing with infertility may not be easy, depending on your age and if you have already had children. Feelings of anger, grief, sadness and loss of identity are common at this time. It can help to talk through your feelings with someone who is a good listener or with a professional counsellor (See page 62). You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.



>>> Your fertility will be affected if you have a hysterectomy or radiotherapy.

Contraception

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

You may still be fertile during chemotherapy — even if your periods stop. And you may be fertile for a short time after starting radiotherapy.

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

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

Cancer and complementary therapies

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

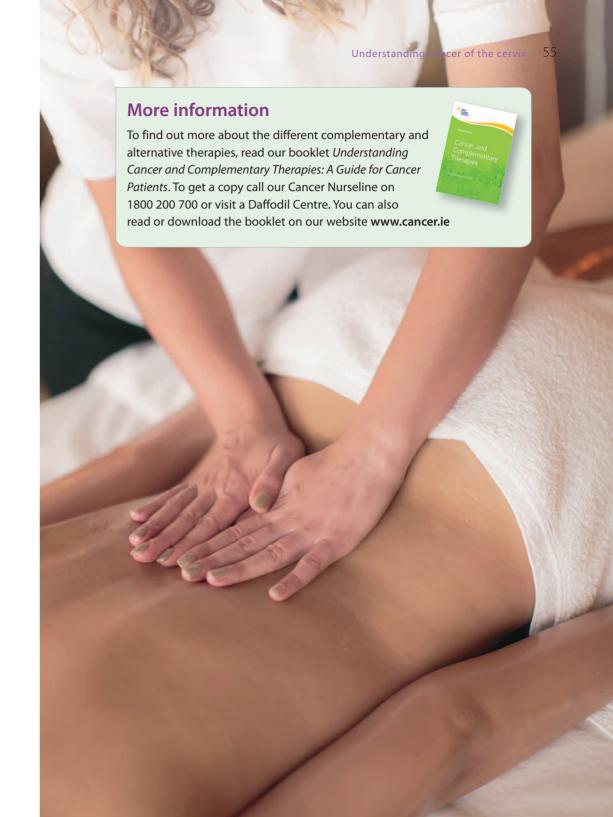
Complementary therapies: Complementary therapies are treatments that can be given in addition to standard medical treatment. Examples of complementary therapies are yoga, meditation, acupuncture, aromatherapy and massage.

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

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

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

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





After treatment

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What follow-up will I need?

After your treatment has ended you will need to go back to the hospital for regular check-ups. This is called follow-up. It may involve having a physical exam, blood tests and scans. At first you will see your consultant every 3 months but these check-ups will become less frequent over time.

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope. This is also an opportunity to discuss any side-effects you might have from your treatment. Sometimes it helps to write down what you want to say before you see the doctor. That way you won't forget what you wanted to say.

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

Staying healthy after treatment

Many people want to make positive changes to their lives after their treatment has ended. Having a healthy lifestyle can help you to:

- Feel better
- Heal and recover faster
- Cope better with the side-effects of treatment
- Keep up your energy and strength

A healthy lifestyle includes:

- Exercising
- Eating healthy foods
- Staying at a healthy weight
- Not smoking
- Protecting yourself from the sun

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

Life after cancer

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

Feelings you may have include:

Fear of cancer coming back and worrying about every small symptom

Loneliness without the company and support of your medical team and fellow patients

Stress at having to deal things that may have been on hold during your treatment, such as your finances, going back to work and family issues

Isolation or guilt if your family and friends expect you to get back to normal before you are ready

Anxiety and self-doubt about sexual and romantic relationships **Anger** at what has happened and the effect on you and your loved ones

Depression or sadness

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

You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 63 for other ways to get support.

6 In terms of my health, everything is going well. I now go back to the clinic every three months for a smear and check-up. 9



Coping and emotions

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How can I cope with my feelings?

There are many reactions when you hear you have cancer. Reactions differ from person to person. There is no right or wrong way to feel and there is no set time to have one particular emotion or not.

Common reactions include:

- Shock and disbelief
 Sorrow and sadness
 Resentment
- Fear and uncertainty
 Denial
- Blame and guilt

- Loss of control
- Anger
- Withdrawal and isolation

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

Anxiety and depression

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

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

Counselling

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. A trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support, help you to make decisions and learn ways to cope better.

Counselling is available free of charge at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at cancernurseline@irishcancer.ie

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



Ways to get emotional support

Find out about cancer support services in your area: There are lots of local cancer support services that provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 78 for more about cancer support services.

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

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

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

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

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

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

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

Learning to cope

Understanding cancer of the cervix

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

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

While it's true that some treatments can have some unpleasant sideeffects, most people are able to adjust to life during treatment.

How can I help myself?

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

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

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

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

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

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



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

Try complementary therapies: Complementary therapies are treatments like acupuncture, yoga and aromatherapy that are given in addition to your standard treatment. They may help to relieve the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 54 for more information on complementary therapies.

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

Know that there will be ups and downs: Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. Get help if you are finding it hard to cope.

Keep busy: Try to keep busy and make plans for the things you would like to do. This can mean taking trips, visiting loved ones or doing certain activities.

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

Express yourself: Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of what you are going through. Other forms of creative expression, such as music and art, may help too.

6 As time has gone on I have learned a way of coping. There is always a fear of the cancer coming back but you just have to learn to cope and be grateful.

Practical planning

It's very understandable that you might feel anxious or reluctant to talk to your family or friends about how you might like to be looked after if your cancer progresses, for fear of upsetting yourself or them. However, it can give you the chance to plan and deal with any practical concerns or worries you may have in your personal life. If your cancer is advanced, you can look at our advanced cancer web pages on our website **www.cancer.ie** for more help with planning ahead. You can also call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice, information and support.

Positive emotions

A cancer experience can also bring positive emotions. However, it may be some time before you are ready to accept these emotions as positive. You may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and even the healthcare team. With that can come a sense of gratitude too. The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what's important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.

You and your family

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

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

Talking to children and teenagers

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

Saying nothing

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

How to tell your children

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

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

Further information and support

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

How can my family and friends help?

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

So many kind and generous people asked me what I needed. I mostly had no idea! Specific questions helped, like "I'm at the supermarket, can I bring you dinner?" or "I'm off tomorrow, can I call in at 3?"



Advice for carers

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Caring for someone with cancer

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

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

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

Plan as much as you can ahead of the discharge date: Ask to speak to a medical social worker about the community services that are available. Tell your GP and local public health nurse that your loved one will be coming home. If dressings or other medical supplies are needed, make sure you have some at home before the discharge date. Ask for a contact name and telephone number at the hospital so that you can talk to somebody if you have a problem.

Talk to the dietitian: If your relative or friend has had major surgery, talk to the dietitian before the discharge date. He or she will give you useful advice on the best foods and how to prepare them so that they can be easily swallowed.

Encourage your relative or friend: At first your relative or friend may feel very tired after treatment. As soon as they are feeling stronger, encourage them to do things for themselves. The more involved they are in their own care, the quicker they will adapt to a new way of life.

Support for you

Our cancer nurses are there to support you as a carer. Call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie for confidential support, advice and information. You could also ask for a copy of our booklet, Caring for Someone with Cancer, or download it from our website www.cancer.ie

Looking after yourself

Share worries: You may feel tired with all the worry and extra work. It can also be very difficult as you try to adapt to a new way of life. Make sure you share your worries with someone else. Call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence. Stay in touch with your own friends and get out when you can, even if you don't always feel like it.

Take regular breaks: If your partner or friend is anxious or depressed, try to take a break each day, even if it's just a walk to the shops. Ideally, try to organise a longer break as well, such as an evening out with friends or a trip to the cinema each week. If you have young children, organise for your family or a babysitter to mind them for an hour or two, if possible.

Have little treats: If you don't want to take a break, then at least give vourself little treats to keep yourself going. Order your favourite magazine each week and give yourself an hour to sit down with a cup of tea or coffee to read it. Or make sure that you can watch your favourite TV programme, have a long soak in the bath after a difficult day, or an early night with a good book.

If you find it difficult to cope, get help: Talk through your feelings and frustrations with a friend or your GP. Your GP can suggest other services and sources of help.

Look after your own health: See your GP sooner rather than later if you have any health concerns of your own.

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

Email: cancernurseline@irishcancer.ie



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Coping with the financial impact of cancer

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

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Appliances, like wigs

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

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

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

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

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

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

Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

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

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

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

If you have financial difficulties

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 77 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

More information

For more information go to www.cancer.ie/publications and check out our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*.

This explains:

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

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

Irish Cancer Society services

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

- Cancer Nurseline
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support services
- Night nursing
- Publications and website information
- Our Cancer Nurseline Freephone 1800 200 700. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie
 - For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie
- Our Daffodil Centres. Visit our Daffodil Centres, located in thirteen
 hospitals nationwide. The centres are staffed by cancer nurses and
 trained volunteers who provide confidential advice, support and
 information to anyone concerned about or affected by cancer.

- Our Survivor Support. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.
- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page xx for more information.
- Patient travel and financial support services. We provide practical
 and financial support for patients in need, travelling to and from their
 cancer appointments. There are two services available through the
 Society:
 - Travel2Care is a limited fund, made available by the National Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
 - Irish Cancer Society Volunteer Driver Service is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

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

- Irish Cancer Society Night Nursing. We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.
- Our publications and website information. We provide information on a range of topics including cancer types, treatments and sideeffects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.

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

Local cancer support services

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

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

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

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

Helpful books

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, treatments, and coping.

For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: www.cancer.ie.

You may find the following helpful:

Treatment and side-effects

Understanding Chemotherapy
Understanding Radiotherapy
Understanding Cancer and
Complementary Therapies
Diet and Cancer



Coping and emotions

Coping with Fatigue

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



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 neck of the womb at the top of

the vagina.

Chemotherapy A treatment that uses drugs to cure

or control cancer.

Colposcope A machine with binoculars and 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 magnifying binoculars

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.

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

to see if the cancer has spread.

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.

Abnormal changes which are not Precancerous

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 vour 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.

Smear taker The person who takes the smear. For

example, your GP or nurse.

An instrument used by a doctor or **Speculum**

nurse to keep your vagina open so that it is easier to examine your

cervix.

Trachelectomy 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.

A small area of skin at the end of your Transformation zone

> cervix where two types of cells meet and overlap. This is the area from

which a smear is taken.

The womb. Uterus

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?

Join the Irish Cancer Society team

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

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

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

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

Did you like this booklet?

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

More information and support

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

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