

Understanding

Cervical cancer

Caring for people with cancer

Understanding

Cervical cancer

This booklet has information on:

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

Useful numbers

Specialist nurse

Family doctor (GP)

Gynaecologist

Surgeon

Medical oncologist

Radiation oncologist

Radiation therapist

Medical social worker

Emergency

Hospital records number (MRN)



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Fast facts

What kind of treatment might I have?

Page 41

Surgery: An operation to remove the cancer.

Radiotherapy: Uses high-energy rays to kill cancer cells. It can be given internally and/or externally.

Chemotherapy: Drugs intended 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 target cancer cells in different ways to stop or slow down their growth.

Will I be OK?

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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. Your doctor will advise you on what is likely to happen in your situation.

Can my cancer be treated?

Page 27

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

Are there any side-effects from treatment?

Pages 41, 71

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

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Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you. You can also see a list of current cancer trials at www.cancertrials.ie

We're here for you

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

Ways to get in touch

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

See page 108 for more about our services.

Reading this booklet



This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference.

If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

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

We cannot give advice about the best treatment for you. Talk to your hospital team about your treatment and care – they know your medical history and your individual circumstances.

We use the term 'woman / women' in our cervical cancer information but we understand that not everyone who has a cervix identifies as a woman.

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

About cervical cancer

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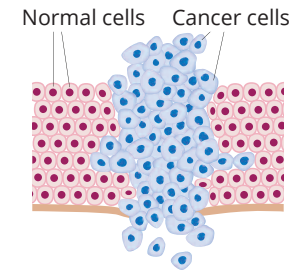
What is cancer?

Cancer is a disease of the body's cells.

Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).

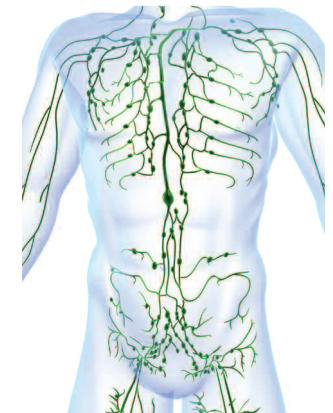
Cancers are named after the organ or cell where the cancer starts. Cervical cancer starts in cells in the cervix.

Cancers sometimes spread. If a tumour is cancerous (malignant), a cell or group of cells can be carried by your blood or lymph fluid to another part of your body, where it can form a new tumour. This is called metastasis. Sometimes cancer cells spread into nearby lymph nodes.



What is the lymphatic system?

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

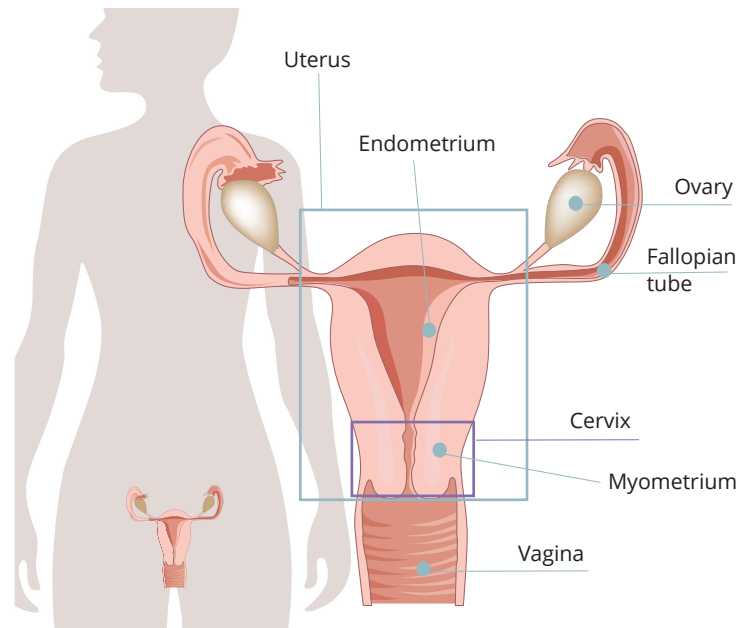


Support Line Freephone 1800 200 700

What is the 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 and is about 2.5cm long. Usually your cervix is closed but opens during labour to allow for birth.

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 cervical cancer?

Cervical cancer is cancer of the cells lining the cervix. It usually 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.

When cancer occurs, the cells in the cervix form a tumour. These cells may then 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.

Cervical screening

Ireland's cervical screening programme (CervicalCheck) offers women a screening test every 3-5 years, depending on your age. It checks the health of your cervix. The sample is tested for human papillomavirus (HPV), which is a virus that can cause cervical cancer. If HPV is found, the sample is tested for any abnormal cell changes in your cervix. These cells can then be treated, and this will reduce your risk of developing cancer.

What caused my cancer?

Smoking and HPV are the two main risk factors for developing cervical cancer. If you want to find out more about the risk factors, see our website www.cancer.ie or talk to a cancer nurse – call our Support Line or visit a Daffodil Centre.

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 thin flat cells called squamous cells, which are found on the surface of your cervix and vagina. These cells are like skin cells.

Cervical adenocarcinomas are less common. They develop in the gland cells that make mucus in the cervical canal. These cells are shaped like columns.

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

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

How common is cervical cancer?

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



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
- Angry that this is happening to you

However you feel, you are not alone.

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

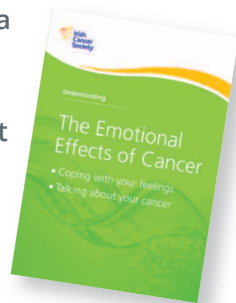
- **Ask to speak to the cancer (oncology) liaison nurse or the medical social worker at the hospital.** They can help you and your family to cope with your feelings and advise you about practical matters.
- **Talk to one of our cancer nurses in confidence** – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- **Speak to an Irish Cancer Society Survivor Support volunteer** who has had a cancer diagnosis and really knows what you are going through. Our cancer nurses can put you in touch with a volunteer.
- **Talk to other people affected by cancer.** Join our online community at www.cancer.ie/community
- **Go to your local cancer support centre.** For more information, see page 114.

Telling people about your diagnosis



Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straight away. You may be unsure how to break the news. You may also worry about how other people will react. For example, they may fuss over you or be upset.

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



What tests will I have?

- Tests after diagnosis may include an MRI and CT scan. Sometimes the medical team will request a more detailed scan, called a PET CT scan.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

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 between your hip bones. Tests you may have include:

Blood tests

Blood tests can help to check your general health. A blood count and blood tests will see how well your kidneys and liver are working.

Vaginal and rectal examination

Your doctor may do a vaginal and rectal examination to help with staging the cancer (see page 20 for more on staging cervical cancer).

CT scan (CAT scan)

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

During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.

MRI scan

This is a scan that uses magnetic energy to build up a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine. Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiation therapist if you're feeling anxious.



An MRI can also be noisy, but you will be given earplugs / headphones to wear to help block out the sound. You might get 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

A PET scan can show if the cancer has spread to other tissues and organs. A low dose of radioactive sugar is injected into your arm. An hour or so later you will have a scan. The radioactivity can highlight cancer cells in your body.

During the scan, you will lie on a table which moves through a scanning ring. The scan can last up to an hour. Before the scan, you may have to fast (not eat) for a few hours.

You will be slightly radioactive for 6 hours after the scan. You should avoid contact with young children and pregnant women during this time.

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

Examination under anaesthetic (EUA)

Sometimes an EUA is carried out. 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 only in your cervix.

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.

Waiting for test results

It usually takes up to 2 weeks for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse. Once all the tests have been completed, the multidisciplinary team will meet to decide on how to manage your cancer.

Support Line Freephone 1800 200 700

Staging cervical cancer

- Staging cancer means finding out its size and if it has spread.
- Staging helps your doctor to decide the best treatment for you.

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 helps your doctor to decide the best treatment for you.

What are the stages of cervical cancer?

There are two systems that may be used to stage cancer of the cervix.

TNM staging system: The TNM system 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 1 to 4. A higher number, such as stage 4, means a more advanced cancer. Some stages are further divided into stage A and B.

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

FIGO staging system: Doctors more often use the FIGO (International Federation of Gynecology and Obstetrics) system for staging cervical cancer. This system is similar to the TNM system and also has 4 stages. (See FIGO stages described on pages 21-24.)

These are numbered I (1) to IV (4). Each number stage is further divided using the letters A, B and C. Again, the higher the letter and number within each stage, the more advanced the disease.

Despite the similarities in the systems, the TNM and FIGO stage are not always the same. Your doctor will explain what your stage means, depending on which staging system they use.

FIGO staging

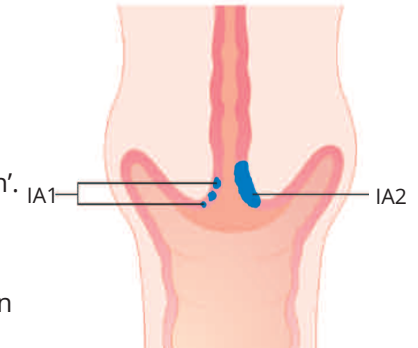
Stage I

The cancer cells are on the surface of the cervix and have not invaded the deep tissue of the cervix.

Stage IA

The cancer growth is very small. How deep the cells go is very important, however. Your doctors may call this the 'depth of invasion'. Based on the size of the growth, stage IA can be divided into:

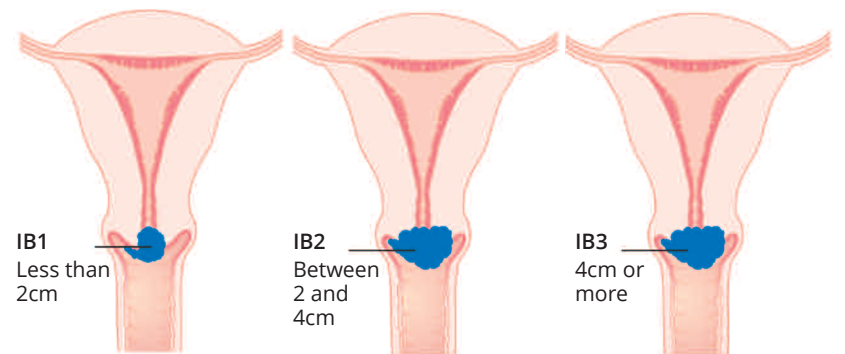
- **Stage IA1** The cancer is less than 3mm deep.
- **Stage IA2** The cancer is 3-5mm deep.



Stage IB

The cancer has grown into the tissues of the cervix but has not spread beyond. This stage can be further divided by its size into:

- **Stage IB1** The cancer is more than 5mm deep but less than 2cm in total size.
- **Stage IB2** The cancer measures between 2 and 4cm.
- **Stage IB3** The cancer measures 4cm or more.



Images courtesy of Cancer Research UK / Wikimedia Commons

Stage II

The cancer has started to spread beyond the neck of the womb (cervix) to nearby tissues.

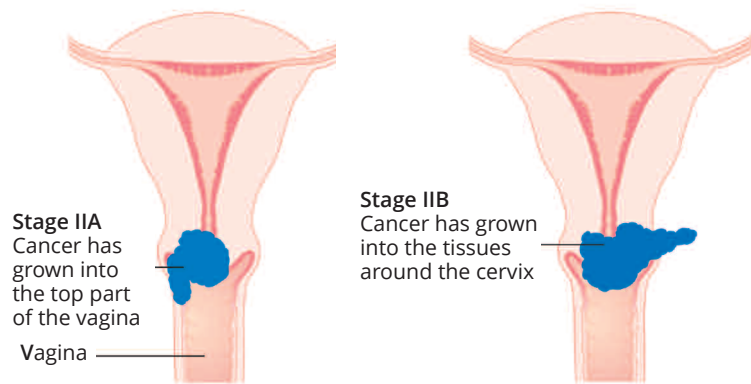
Stage IIA

The cancer is in the upper part of the vagina but has not spread up into the womb. This stage is further divided into:

- **Stage IIA1** The cancer measures 4cm or less.
- **Stage IIA2** The cancer measures more than 4cm.

Stage IIB

Cancer cells have spread into the tissues at the side of the cervix, but have not grown into the wall of the pelvis.



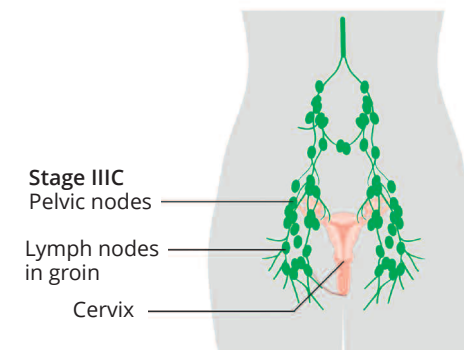
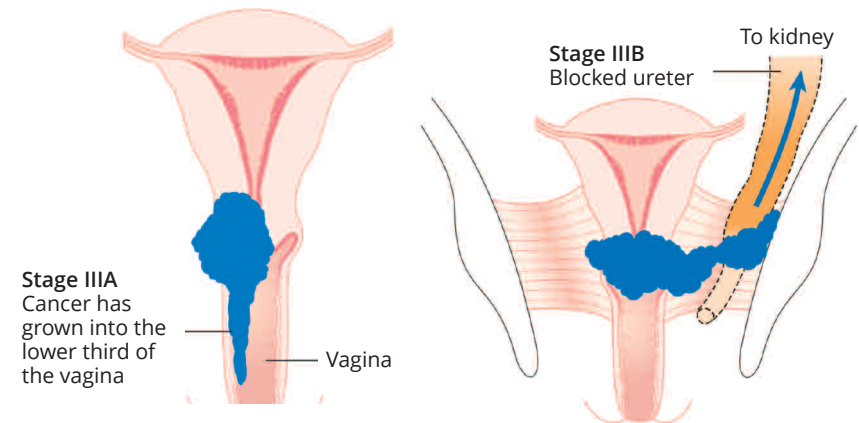
Images on this spread courtesy of Cancer Research UK / Wikimedia Commons

Email: supportline@irishcancer.ie

Stage III

The cancer has spread further away from the cervix. It has moved into the lower part of the vagina and to the side wall of the pelvis.

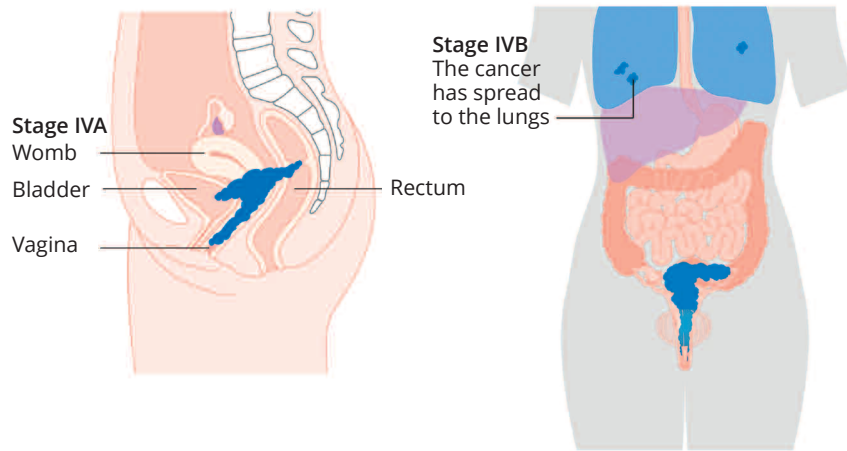
- **Stage IIIA** The cancer has spread to the lower third of the vagina but not the pelvic wall.
- **Stage IIIB** The tumour has spread to the pelvic wall. When this happens, it can block the tubes that drain the kidneys (ureters).
- **Stage IIIC** The tumour has spread to pelvic and abdominal lymph nodes.



Stage IV

In this stage, the cancer has spread to other body organs.

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



Images courtesy of Cancer Research UK / Wikimedia Commons

Staging is helpful for your medical team to decide the best treatment for you. However, you don't need to understand the staging system in depth.

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 67 for more information on recurrent cervical cancer.

Asking about your prognosis



Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy.

It's not always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.



Should I ask about my prognosis?

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

If you decide you want information on your prognosis:

- **Think carefully about how you will cope with the information.**
- **Get information on prognosis from your doctor.** They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Ask a friend or family member to go with you**, if you would like some support.
- **Be careful with online information.** It may be hard to understand or even incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.
- **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 Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treatment overview

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How is cervical cancer treated?

- Surgery, radiotherapy, or a combination of radiotherapy and chemotherapy can be used to treat cervical cancer.
- A team of healthcare professionals will be looking after you (multidisciplinary team).

The type of treatment you have will depend on:

- The size and stage of your cancer
- The type of cancer
- Your general health
- Your age and fertility
- Your own wishes

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



Types of treatments

Surgery

Surgery aims 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 43 for more details about surgery.

Radiotherapy

Radiotherapy is the use of high-energy rays to kill the cancer cells. It can be given externally or internally. It can be used as the main (primary) treatment or as an extra treatment (adjuvant) after surgery. See page 53 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 61 for more about chemotherapy.

Often cervical cancer is treated with chemotherapy and radiotherapy together.

Targeted therapies/immunotherapies

Targeted therapies and immunotherapy can help your body to fight cancer, slow its growth or control side-effects from other cancer treatments. Your medical oncologist will tell you if there any therapies available that will be of benefit to you. See page 66 for more information.

Specialist cancer centres

Cervical cancer is treated in specialist gynaecological centres in Ireland. The staff at these centres have a lot of experience in managing patients with cervical cancer. As a result, you may be transferred to another hospital from the one where you received your diagnosis, depending on your diagnosis and treatment plan.

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 gynaecologist, specialist nurse, radiologist and oncologist (cancer doctor). The team will meet to discuss your test results and treatment plan.



Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. It is always best to bring a friend or family member along to your consultation. You could write down any questions you have in advance, so you don't forget anything. If you do forget something or need more explanations, ask your specialist nurse or talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Time to think

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 treating doctor or your GP can 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 a particular treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.

Email: supportline@irishcancer.ie

Who will be involved in my care?

Some of the following health professionals may be involved in your care. Usually a team of specialists (multidisciplinary team) will decide your treatment.

Gynaecologist A doctor who specialises in treating problems with the female reproductive organs and functions.

Gynaecological oncology surgeon 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 type.

Radiologist A doctor who specialises in reading scans and X-rays.

Medical oncologist A doctor who specialises in treating cancer patients using chemotherapy and other drugs.

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

Radiation therapist A healthcare professional who delivers the radiotherapy and gives advice to cancer patients about their radiation treatment.

Gynaecological oncology clinical nurse specialist A specially trained nurse who cares for patients who have cervical cancer and other cancers of the female reproductive system.

Oncology liaison nurse/clinical nurse specialist A specialist nurse who works in a cancer care unit. They give information and reassurance to you and your family throughout your treatment.

Medical social worker A healthcare professional trained to help you and your family with all your social issues and practical needs. They can give counselling and emotional support. They can also give advice on benefits and financial matters and on practical supports and services available to you when you go home.

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. Your GP will remain an important point of contact throughout your treatment.



Pharmacists Pharmacists – in hospital and in your local pharmacy – dispense chemotherapy and other cancer drugs. They can give advice on cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

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 can be based in hospitals as well as within the community. They are sometimes known as the ‘symptom management team’. A specialist palliative care service is available in most general hospitals.

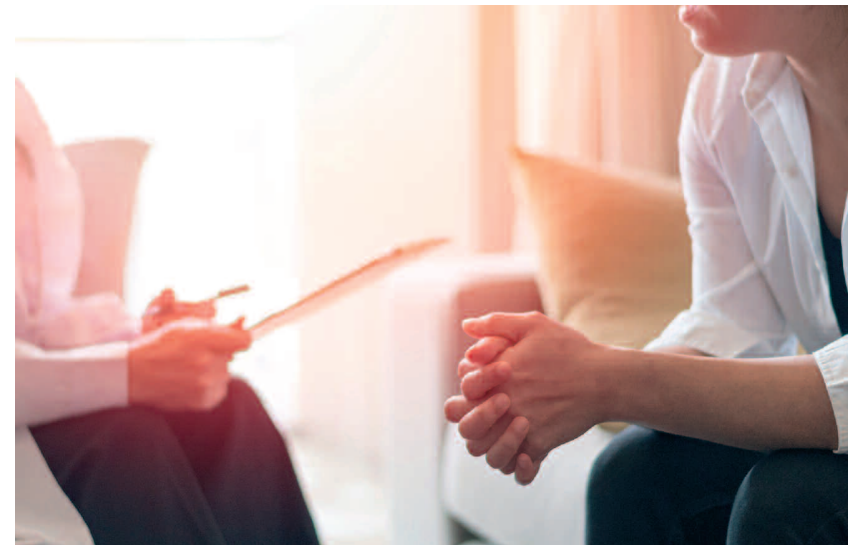
Physiotherapist A therapist who treats injury or illness with exercises and other physical treatments.

Dietitian An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms.

Psycho-oncology team These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.

Psychologist A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.

Counsellor A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.



Community health services This includes 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.

Giving consent for treatment

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

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

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

Individual treatment



You may notice that other people with 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.

Email: supportline@irishcancer.ie

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.

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

While you're waiting for treatment, you might like to focus on eating well, avoiding alcohol, being active and quitting smoking. This can help you prepare for your treatment and feel more in control.

How can I help myself?

It can be very difficult to cope with a cancer diagnosis and all the changes that this can bring. Your healthcare team can offer you different types of support, but there are also things you can do yourself to prepare for treatment and feel better.

Eat well

Eating well can help you feel better. It can also help you to:

- Feel stronger and maintain a healthy weight
- Cope better with the side-effects of treatment
- Recover

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



Stay active

Keeping active has many benefits. It can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Strengthen your muscles, joints and bones
- Reduce the risk of other health issues



Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you. Be careful not to overdo it at the beginning; it's best to build up gradually.

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking. However, research tells us that:

- Non-smokers have fewer side-effects during cancer treatment
- Smoking can reduce how well chemotherapy or radiotherapy work
- Smoking increases risk of complications following surgery such as delayed wound healing and chest infections



If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. Some hospitals have smoking cessation officers who can help and support you – you can ask your doctor or nurse for a referral to this service.

Other ways to help yourself

Get information about your cancer and treatment

Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. If it makes you anxious, you could ask a friend to do the research for you, and tell you anything important.

Involve your family and close friends

Don't keep any worries or physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.

Use your support network

Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example, lifts to the hospital, practical help at home, child-minding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Try relaxation and stress management techniques

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

Accept change in your life

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

Know that there will be ups and downs

Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. Get help if you are finding it hard to cope.

Try to cope day by day


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



Types of treatment

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Surgery

- 
- Surgery aims to remove the cancer.
 - A team of specialists will decide if surgery is the best option for you and the kind of approach that would suit you best.

The aim of surgery is to remove the cancer and the area close to it. The type of operation considered 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 a large loop excision of the transformation zone (LLETZ). A thin wire loop is used to remove the abnormal cells in the transformation zone (see page 118) 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.
- **Salpingo oophorectomy:** one or both your ovaries are removed when you are having a hysterectomy.
- **Radical trachelectomy:** the cervix and nearby soft tissues are removed but the womb is left in place and stitched back onto the vagina.
- **Lymphadenectomy:** the lymph nodes in the pelvis are removed. This operation may be done along with one of the above operations or before you start radiotherapy.
- **Pelvic exenteration:** the bladder, part of the bowel, ovaries, womb, cervix and vagina are removed.

Ovarian transposition

If your ovaries are not being removed in the operation, 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.

Surgery options

The decision on the best type of surgery for you will be made by highly trained specialists at the cancer centre. Usually, more than one gynaecologist cancer surgeon is involved in this decision.

They will also decide on how they will operate – either through open surgery or minimal access (keyhole) surgery.

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

Open surgery

Open surgery is where the surgeon operates through a cut (incision) in the abdomen or tummy wall. It is a more invasive procedure than keyhole surgery and recovery is longer. However, you will be given good pain relief and the nurses will help you to get up and about and back on your feet. Your recovery will be supported by a number of specialties, if you need them, such as a physiotherapist or dietitian.

Laparoscopy (keyhole surgery)

Your doctors may consider minimal access surgery as an option for you. This is also known as laparoscopy or keyhole surgery.

This surgery is done by making small openings (usually 4) in your abdomen or tummy wall. In some centres a 'robot' is used to assist the surgeon with performing the keyhole surgery.

The benefits of keyhole surgery include a shorter hospital stay and a quicker recovery.



Your doctor will explain the surgery options to you and which they feel is best for you. More multidisciplinary teams are now recommending open surgery, as a recent study suggests women who have open surgery have better overall outcomes.

Getting ready for surgery

Your surgical team and specialist nurse will tell you about your surgery. It is natural to feel very anxious about having surgery. Talk to your doctor or nurse if you are feeling anxious. If there is anything that you do not understand, ask again. Your doctor or nurse will be happy to answer your questions. They will tell you what to expect after the operation and help you find ways to cope. You can also call our Support Line nurses on 1800 200 700.

If your womb or your ovaries are removed as part of your surgery, you won't be able to get pregnant. 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.

Tests before surgery

Before surgery, in most centres, patients will be sent an appointment to attend the pre-operative assessment clinic. At this clinic extra tests are done to make sure you are strong enough for surgery. These may include blood tests and an ECG heart test. Sometimes an ECHO (heart ultrasound) and pulmonary function (lung/breathing) tests will be needed, depending on your age and general health.

You will also meet the anaesthetic doctor. These doctors are responsible for putting you to sleep for the surgery. If you are a smoker, giving up before your operation will improve the quality of your breathing and reduce the risk of a chest infection after surgery. See page 39 for more on giving up smoking.

Before surgery

You will not be allowed to eat or drink for a few hours before surgery. You may get an anti-clotting injection like heparin, and elastic stockings may be put on your legs to prevent blood clots. Before you go to theatre, you may be given medication that will make you feel more relaxed and sleepy.

After surgery

When you wake up, you will have some tubes attached to your body. Don't be alarmed as they are normal after an operation like this.

- You may have a drip in a vein in your arm. You will be given fluids through this until you can drink again.
- You may have an oxygen mask over your face.
- A thin tube called a catheter may be in your bladder to drain urine. It is usually removed after 24 hours.
- Drainage tubes may be in place at the wound site.

Pain

For the first few days after open surgery you will probably have some pain and may feel sick at times. Your nurse can give you medicine to control the pain and prevent you feeling or getting sick. You may have an epidural tube in your back to relieve pain after the surgery. If you have a patient controlled analgesia pump (PCA), your nurse will show you how to use it. Always ask for help if you have any pain or feel sick.

You will be given a prescription for pain relief when you're discharged from hospital.

After keyhole surgery, you may experience 'wind type' pain or cramps. This is because air is put into the tummy or pelvis during the operation. This pain may radiate to your shoulder and may be quite severe. This is normal. A combination of pain-relieving medication, peppermint water and moving about may help.

Eating and drinking

After open surgery, usually you will be back drinking within 12-24 hours. Once you can sip liquids, you will gently move back to eating and drinking. With keyhole surgery, you will be able to take sips of water or even a light meal later that day. Your drip will be stopped when you are taking enough fluid by mouth.

Bladder and bowel function

The bladder can be slow to empty after a hysterectomy. Your surgeon may leave a tube (catheter) in place to drain your bladder for 24-48 hours after open surgery or 12-24 hours after keyhole surgery.

Following surgery, you may get constipated, and you may need to take a laxative for a few weeks or months. See page 51 for more on bladder and bowel side-effects.

Getting up and about

For the first few hours after surgery, while you are in bed, you will be encouraged to move your legs and do deep breathing exercises at least once an hour.

With open surgery, it will be difficult to move around at first but the nurses will help and encourage you to get up and about. A physiotherapist may help with exercises. After keyhole surgery, you will be able to move about that evening or the following morning.



Recovery period

With open surgery, you may be in hospital for 4-5 days. With keyhole surgery, you may be ready to go home after 1-2 days.

You should avoid strenuous activity (including heavy housework) and driving for 6 weeks following open surgery or 2-3 weeks after keyhole surgery, if you're feeling up to it. Following both types of surgery, you will be encouraged to walk regularly, increasing the time spent walking every day. Your nurse or physiotherapist will discuss this with you in more detail.

It is normal to experience vaginal bleeding or discharge at times for about 6-8 weeks after both open and keyhole surgery. This happens because there are internal stitches at the top of the vagina, which dissolve over a period of a few weeks.

After leaving hospital, if you experience heavy vaginal clotting or bleeding or foul-smelling vaginal discharge, you should contact your medical team or specialist nurse for advice.

It is normal to experience tiredness as your body recovers from the surgery. You may need plenty of rest.

Exercise

It is important to continue with exercises as advised by the physiotherapist or specialist nurse. They will be happy to give specific advice on your individual needs. You should avoid strenuous exercise such as jogging or swimming until healing has taken place.

The physio or specialist nurse may recommend pelvic floor exercises, as well as leg exercises to reduce your risk of developing lower limb swelling (lymphoedema) in the future. Women who have had pelvic lymph nodes removed as part of their surgery are at risk of developing lymphoedema. See page 50 for more on lymphoedema.

Sexual activity

Following surgery, it is advisable not to start having sexual intercourse again for at least 6 weeks, to allow your body to heal. Following a diagnosis of cervical cancer you may not feel physically or emotionally ready to start having sex for a while. See page 74 for more on how a cancer diagnosis and treatment can impact on your sex life.

Possible side-effects of surgery

Risk of clotting (DVT)

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 for 4 weeks after your surgery, so you or a member of your family will be shown 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 if you are spending a lot of time in bed. 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. If you had open surgery and you notice any leakage from your wound or it becomes foul smelling, you should also contact your specialist nurse or team 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 or call our Support Line on 1800 200 700. You can also find out more about lymphoedema on our website www.cancer.ie

Bladder and bowel side-effects

With any pelvic surgery there is a risk of damage to the bladder, your ureters (tubes that carry urine) or bowel. If this does happen during surgery your surgeon is usually able to repair it there and then, but in some cases you may need to go back for further surgery.

Bowels may be sluggish immediately after your surgery. Constipation is very common and can take a few days to improve. You may need to take a laxative. Your doctor or nurse will discuss medication to help.

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, they 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 for a check-up, usually between 2 and 6 weeks after your operation. 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.

Pathology report

During your surgery samples of tissue will be taken. The samples will be tested by a doctor, called a pathologist, to give more information about the cancer. The pathology report will show how effective the surgery has been and help your doctors to decide if you need further treatment. Your doctor will talk to you about your test results and future plans for monitoring / treating you at your first follow-up appointment at the outpatient clinic, once you have had a chance to recover from your surgery.

Other possible side-effects of surgery

Depending on your age and the stage you are at in life, you may experience early menopause after surgery. Also, depending on the type of surgery you have, your fertility can be affected. Talk to your doctor about these issues prior to your operation.

Early menopause

If your ovaries are removed during surgery, you may get menopausal symptoms. These include hot flushes, night sweats, dry skin, vaginal dryness, decreased sex drive (low libido), low mood, poor concentration and difficulty sleeping. Your doctor may talk to you about medication to reduce the effects of the menopause. Not all women are suitable for hormone replacement therapy (HRT) following a diagnosis of cervical cancer. However, a decision on HRT is made based on your individual circumstances.

See page 79 for more on coping with early menopause.

Infertility


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 78 for more information.

If you have a radical trachelectomy, you may be able to get pregnant and have children in the future. Most likely, 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.

You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

Radiotherapy

- 
- Radiotherapy uses high-energy rays to kill cancer cells.
 - You normally have treatment every weekday for a number of weeks – or you may have a much shorter course of radiotherapy.
 - Side-effects affect the area being treated.

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 of radiotherapy: 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. Your doctor will let you know how many sessions or treatments you need.

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. Treatment normally takes no more than a few minutes. The radiation oncologist at the hospital will decide the dose and number of treatments you need, depending on your situation.

The type of radiotherapy you receive will depend on the stage of the cancer and if you have had surgery. If you do not have surgery, both external and internal radiotherapy may be given to destroy all the cervical cancer cells. If you have had a hysterectomy, 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 symptoms such as 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, 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. 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 what the team decides.

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

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

Special radiotherapy treatment centres

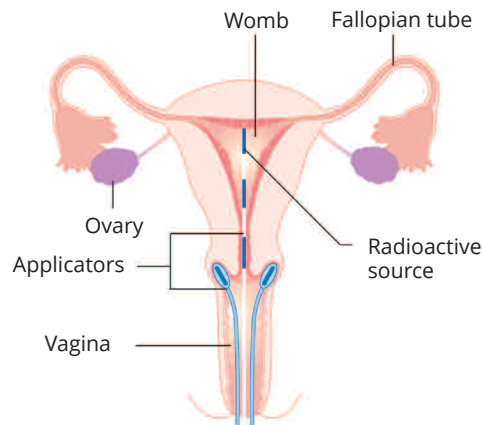


Radiotherapy is normally given in special cancer treatment centres, usually hospitals or clinics. These centres need highly trained staff and space for the large equipment involved. As a result, the centre may be some distance from the hospital where you received surgery or chemotherapy.

Internal radiotherapy – brachytherapy

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 is given in a slightly different way after a hysterectomy (see page 57).



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 be taken to theatre and have special tubes inserted into your cervix and sometimes your womb, usually under spinal anaesthetic (which means you are awake but can't feel the procedure). Sometimes a general anaesthetic is used, which puts you to sleep.

After the tubes have been inserted, you will have a scan to help your doctors plan your treatment. Planning 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. The radiation therapist will connect the tubes to the treatment machine. You will be on your own 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 to having to travel long distances for treatment. See page 73 for more about fatigue.

Diarrhoea

Diarrhoea is when you pass watery bowel motions (poo) more than 3 times a day. 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. They may advise you to avoid high-fibre foods – such as wholegrain cereals, fruit and vegetables – for a while. Or they may 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 your bladder may become irritated. As a result, you may pass urine more often. Sometimes a trace of blood may be found in the urine. If this happens, tell your doctor or nurse. Passing urine may also be painful, like cystitis. But your doctor can give you medication to help.

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 or specialist nurse.



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 76)
- Difficulty having sex (see page 74)
- Early menopause (see page 79)
- Vaginal dryness (see page 76)
- Infertility (see page 78)
- Lymphoedema (see page 50)
- Damage to the small and large bowel, causing a change in the way your bowel works
- Shrinkage of the bladder, causing you to pass urine more often

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 deal with the above side-effects.

Side-effects will mostly go away when treatment is over, but let your doctor and nurse know if they continue. A helpful booklet called *Understanding Radiotherapy* is available from the Irish Cancer Society. Call our Support Line 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.

Chemotherapy

- Chemotherapy uses drugs to kill cancer cells.
- Chemotherapy can cause a range of side-effects.
- Side-effects normally go or lessen after treatment ends.

Chemotherapy is a treatment using drugs that cure or control cancer. These drugs travel through your bloodstream to almost every part of your body. With cervical cancer, chemotherapy is often given with radiotherapy to make it more effective. This is known as chemoradiation 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 infusion or drip. It may also be given in tablet form. Usually the treatment is given in the chemotherapy day care unit.

Understanding your drug treatment

It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you. If you know the name of your chemotherapy drug, visit the Health Product Regulatory Authority's website at www.hpra.ie for more information about the drug and possible side-effects.

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Support Line 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 healthy cells and cancer cells.

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

Side-effects may include:

Fatigue

Fatigue is where you feel tired and weak and rest does not seem to help. Sometimes exercise can help. See more about fatigue on page 73.

Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting.



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 or low 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. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.

Mouth and throat problems

Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.



Hair loss (alopecia)

Some chemotherapy drugs can cause hair loss. This is more likely during treatment for advanced cancer. Your hair will grow back after you stop chemo.

Constipation and diarrhoea

Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).

Skin and nail changes

Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle.

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. It is important to report altered sensation in your hands and feet to your chemotherapy nurse or doctor, as early treatment and intervention can prevent longer term damage.

Changes in kidney or liver function

Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination, swelling of the hands or feet (oedema) or headaches, as these can be a sign of kidney damage. Yellowing of the skin or eyes (jaundice) can be a sign of liver problems. Blood tests will check your kidney and liver function before your chemo treatment.

Other side-effects

If you notice side-effects or you are feeling unwell, tell your doctor or nurse straight away. They will tell you what to do. For more information on the side-effects of chemotherapy or a copy of the booklet *Understanding chemotherapy and other cancer drugs*, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also look at our website, www.cancer.ie for tips on coping with side-effects.

Treatment for cancer that has spread (metastatic cancer)

If the cancer spreads to another part of your body, it is called metastatic or secondary cancer. Your cancer may be in more than one part of your body when it is first diagnosed.

If your cancer has spread it can still be treated. Treatment in this case is to try to control the cancer rather than to cure it. There is a range of treatment options for most metastatic cancers, and new treatments are being developed all the time.

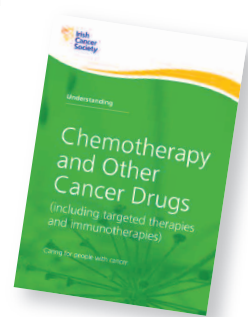
Often metastatic cancer is treated with chemotherapy, targeted therapies or immunotherapy. There may also be treatments that you can have as part of a clinical trial (see page 68).

You can also have treatment to help with symptoms. You may be referred to the palliative care team, who are experts in managing the symptoms of metastatic cancer.

Targeted therapies

Targeted therapies are drugs that target certain parts of cancer cells that make them different from other cells. In other words, they take advantage of differences between normal cells and cancer cells. Sometimes a treatment called bevacizumab is given for advanced cervical cancer. It is usually given in combination with chemotherapy drugs. New targeted therapies 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 page 68).

For more information on targeted therapies, or to ask for a copy of the booklet *Understanding Chemotherapy and other cancer drugs*, call our Support Line on 1800 200 700 or visit a Daffodil Centre.



Immunotherapy

Immunotherapy drugs help the body's natural defences or immune system to fight cancer cells. Our immune system can often be the most effective weapon to clear cancer cells from our body. But sometimes cancer cells find a way of hiding from the immune system. This allows a tumour to develop or spread.

Immunotherapy treatment helps your immune system to work better to destroy cancer cells. The side-effects of immunotherapy depend on the drugs being used and vary from person to person. Because immunotherapy acts on the immune system, it can cause inflammation in any part of your body.

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 straight away if you don't feel well or if you are having any symptoms that are troubling you.

Checkpoint inhibitors

The newest class of systemic therapy (cancer treatment that targets the entire body) are immune checkpoint inhibitors. One type of checkpoint inhibitor used in treating cervical cancer is Pembrolizumab.

How checkpoint inhibitors work

A T-cell is a type of lymphocyte (white blood cell) that can be distinguished from other lymphocytes by the presence of a T-cell receptor on the surface of the cell.

The receptor, or protein complex, can turn on an immune response while other proteins turn it off. These are called checkpoints. Cancer cells sometimes find ways to use these checkpoints to hide from the immune system. They do this by making high levels of proteins to switch off T-cells, when the T-cells should really be attacking the cancer cells.

Checkpoint inhibitors work by blocking the proteins that stop the immune system from killing cancer cells. When checkpoint inhibitors block these proteins, this turns the immune system back on and the T-cells are able to find and destroy the cancer cells.

Treatment for 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 (see page 61) or targeted therapies (see page 66) may help. Your doctors will talk to you about your options.

Surgery for locally recurrent metastatic cancer

If the cancer has returned to the cervix only (locally recurrent cervical cancer), sometimes it is possible to aim for a cure using surgery.

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 within your pelvis.

This operation is a major one and not one suitable for everyone. It may involve removing your cervix, vagina, womb, ovaries, fallopian tubes, lower bowel and bladder.

Your doctor or nurse will give you more detailed information and advice if you need this kind of surgery.

Clinical trials

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

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

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

More information

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

Palliative care



Palliative care helps you to manage your symptoms and improve your quality of life. Palliative care includes end-of-life care, but your doctor may also recommend palliative care to relieve symptoms earlier in your illness. The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors. Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with advanced cancer. You don't need medical insurance.





Managing side-effects and symptoms

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How can I cope with fatigue?

- Fatigue means feeling extremely tired.
- There are things that can improve fatigue, depending on what is causing it.

It's common to feel fatigue when you have cancer. This extreme tiredness 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

Usually fatigue starts to improve 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.

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



Hints & Tips – Fatigue



- Try to do some exercise – ask your doctor for advice about the best exercise for you. They may also be able to recommend an exercise programme for you.
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Try to eat well and drink plenty of fluids.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling (see page 94) may help too.
- If you are not sleeping well, try relaxation techniques and avoid stimulants like caffeine and alcohol before bedtime.
- Try complementary therapies if your doctor says they're safe for you. These might include meditation, acupuncture, aromatherapy or massage.

Will treatment affect my sex life?

Sex and sexuality

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take quite a while. It can also be hard to relax when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment and lose interest in sex as a result.

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 may find that talking about your feelings may ease any worries you have. 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.

There is no set time for you to be ready to have sex again. It varies from person to person. Your doctor will advise you about having sex again after treatment.

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



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 (see page 76). If any of these are 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 or silicone vaginal lubricants can be used during sex. 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 is very important to 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 will recommend that you use vaginal dilators – phallic (penis) shaped and made from silicone – to try to prevent these vaginal changes from happening. Or you could use a vibrator, which come in a large 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.

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 talking about these matters, so try not to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at supportline@irishcancer.ie

Hints & Tips – Sex after cervical cancer treatment



- Always speak with your specialist nurse about any concerns you may have about your sex life. Try not 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 is important to 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?

Your fertility will be affected if you have a hysterectomy or radiotherapy. Sadly, you will not be able to become pregnant after these treatments. Talk to your doctor or nurse before treatment starts to see if there are any options if you would like to have a child or more children.

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 is carried out in specialist centres and doesn't always work but you can talk to your doctor to see if you are suitable.

Dealing with infertility

Dealing with infertility can be as hard as dealing with a cancer diagnosis for some women. Feelings of anger, grief, sadness and loss of identity are common at this time. It is important to talk openly to your partner or a friend about these feelings. If you are finding it hard to deal with infertility, it may help to talk to your nurse or doctor. Do not be afraid to ask for help in dealing with this matter. Your doctor may arrange for you to speak to a trained counsellor or a specialist.

You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

Sex and contraception

You should use contraception to prevent pregnancy during radiotherapy or 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. Your doctor will advise you about having sex during treatment and about contraception.

Coping with early menopause

If you have not been through menopause, you may experience menopausal symptoms. While this may happen after a hysterectomy and removal of your ovaries, you may also have an early menopause following radiotherapy or chemotherapy. Symptoms of the menopause include hot flushes (see tips on the next page), night sweats, dry skin, vaginal dryness (see page 76), 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. Your doctor may prescribe hormone replacement therapy (HRT) following treatment for cervical cancer. HRT can be given in different ways. For example, in tablet form or through a patch worn on your arm or leg. Your doctor will talk to you about HRT, and whether it is suitable for you.

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. This may include taking a calcium and vitamin D supplement.

Talk to your nurse if you are having problems with the symptoms of menopause. See more about managing menopausal symptoms on our website, www.cancer.ie

Hints & Tips – Hot flushes



The following tips may help to ease the effects of hot flushes:

- Wear cotton or special wicking-fabric clothing. Cotton absorbs moisture and wicking fabrics take moisture away from the body to keep you dry and comfortable.
- Have layers of clothing and bedding so that you can remove or add layers as your body temperature changes.
- It may help to avoid spicy foods, caffeine, alcohol and hot drinks – try to keep a note of any food or drink that makes your flushes worse so that you can avoid them.
- Have cool drinks, avoid warm areas, use an electric fan.
- Use sprays or moist wipes to help lower your skin temperature.
- Avoid hot baths or showers, as they may trigger a hot flush.



Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, massage, mindfulness or counselling.

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

It's very important to talk to your doctor if you're thinking of using complementary therapies. Some can interfere with your treatment or be harmful to you, even if you used them safely before your cancer diagnosis.

Integrative care



Integrative care means combining (integrating) your standard cancer treatment with complementary therapies to try to feel as well as possible and to cope better with your cancer.

What's the difference between complementary and alternative therapies?

Complementary therapies are used **together with** standard medical treatment. Alternative therapies are used **instead of** standard medical care. Modern medical treatments are very effective at curing cancer and keeping it under control. An unproven alternative therapy could harm your health, or you might miss out on a treatment that could really help you.

More information

To find out more about complementary therapies, you can talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet *Understanding cancer and complementary therapies*, or download it from our website www.cancer.ie



After treatment

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What follow-up will I need?

After your cancer treatment has ended you will still need regular check-ups. This is called follow-up. Your gynae-oncology team will discuss your follow-up with you. How often and the type of follow-up will depend on the type and stage of your cancer. The follow-up is often shared between the teams that have treated your cancer. This may be the surgical team as well as the radiation oncologist and/or medical oncologist.

The purpose of follow-up is to:

- Help with any side-effects that you may have
- Check for signs of new side-effects that may develop after you have finished treatment
- Check for signs of the cancer coming back (recurrence)

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



For some patients, follow-up may involve consultations over the phone; for others, they may need to go to the hospital for clinical assessment. There may be a combination of phone consultations and outpatient visits. You will be told about the symptoms you should be alert to, so you can report them to your doctor or specialist nurse.

The 'alert symptoms' are:

- Vaginal bleeding or discharge
- Pain or discomfort in abdomen or pelvis
- Pain or discomfort in back or legs
- Swelling in tummy or legs
- Unexplained weight loss
- Unexplained lethargy or tiredness
- Loss of appetite
- New or persistent cough or shortness of breath



If you're between check-ups and have a symptom or problem that's worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment, if necessary. Go to your GP if you're unwell and you can't contact the hospital team, or attend the hospital's emergency department if necessary.

What if the cancer comes back?

Sometimes after treatment the cancer comes back (recurs), either in the cervix itself or somewhere else (metastatic disease). There are treatment options still available to you if it does come back (see page 67). Your doctor will discuss these treatments with you if they think they would help.

Life after treatment

It can take some time to adjust to life after cancer treatment. It's normal to feel quite low and lost after your treatment has ended, especially during the first few months.

Feelings you may have include:

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

There is more about how to cope with these feelings and adjusting to life after cancer on our website www.cancer.ie. You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 95 for other ways to get emotional support.

Living a healthy lifestyle

Having a healthy lifestyle after cancer treatment is important as it can help you to:

- Feel better
- Heal and recover faster
- Keep up your energy and strength
- Reduce your risk of further illness

A healthy lifestyle includes:

- Exercising
- Eating well
- Trying to stay at a healthy weight
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun
- Getting any vaccinations recommended for you

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



Planning ahead

Many people find it puts their mind at rest to have medical plans in place and sort out legal and practical matters, even though they still hope to live for a long time. Planning ahead is useful for everyone, whether they have an illness or not.

Planning ahead might include:

- **Thinking about how you feel about different types of medical treatment**, including if you want to stop treatment at any stage or carry on for as long as possible.
- **Writing an advance care directive**. This is where you can write down your wishes about your medical care. Doctors can use this if you are not well enough to say what you want.
- **Picking someone to make medical decisions for you** if you are not well enough.
- **Making a will**.
- **Talking about what you want** to your family, friends, carers and healthcare providers.
- **Sorting financial affairs**.

Who can help me plan?

Think Ahead is a planning booklet with easy-to-read forms to fill in to record your personal, medical, financial and legal information and preferences. It's available from the Irish Hospice Foundation at www.hospicefoundation.ie





Coping and emotions

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How can I cope with my feelings?

Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer. You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed.

Emotions like sadness, fear, grief, hopelessness and anger can happen at different times, sometimes months or years after treatment.

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



Anxiety and depression

If you feel that anxiety or low moods are getting the better of you or you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family. Your doctor may also suggest medication to help with anxiety or depression. Often a short course of medication can work well. Professional counselling can also be very helpful.

A cancer diagnosis can be hard on you – mentally and emotionally. Give yourself time and space to deal with your emotions, and get help if you need it.

Counselling

If you're feeling very distressed or finding it hard to cope, a trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support, help you to make decisions and learn ways to cope better.

Free one-to-one counselling is available at some local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline@irishcancer.ie

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

It's not a sign of failure to ask for help or to feel unable to cope on your own.

'Counselling has helped me with every part of my life. I feel I have a future now.'

Ways to get emotional support

Find out about cancer support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 114 for more about cancer support services.

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

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

Get online support: Special groups called online communities let you write questions, share stories, and give and receive advice and support. Visit www.cancer.ie/community to join the Irish Cancer Society online community.

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

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

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

Survivor support



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

'Talking about cancer made it less awful and helped ease my fears. I learned to cope and understand myself better.'

Positive feelings



In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships. Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

'I am very happy and content ... even though I have to live with this.'

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 children, especially older children.

Talking to children

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.



Further information and support

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.

Changing relationships



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



Email: supportline@irishcancer.ie

Advice for carers

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Supporting someone with cancer

Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support the person with cancer, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

Here are some things that can help to make life a little easier:

Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one's illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Visit our website www.cancer.ie or call our Support Line for free copies of our cancer information booklets.

Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence.

How to talk to someone with cancer

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

If you want advice on how to support a friend or loved one with cancer, call our Support Line on 1800 200 700. Ask for a copy of our booklet *Caring for someone with cancer*. The booklet has a section on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can also pick up a copy of the booklet at any Daffodil Centre, or download it at www.cancer.ie

Support for you



Our cancer nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information.

Our booklet, *Caring for Someone with Cancer*, has lots of information on:

- Getting organised
- Managing and giving medications
- Giving personal care
- Practical and money matters
- Relationships with other people
- Looking after yourself
- Life after caring




Free copies are available from our Daffodil Centres and our Support Line, or download it from our website www.cancer.ie

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Money matters

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

A diagnosis of cancer often means that you will have extra expenses, such as 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 your illness 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
- Medical aids and equipment (appliances), like wigs

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

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

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

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

If you don't have a medical card you will have to pay some of the cost of your care and medication.

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

Benefits and allowances

There are benefits that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.



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

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

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

If you have money problems

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 111 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

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

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

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

Irish Cancer Society services

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

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

Support Line Freephone 1800 200 700

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

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



Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide free confidential advice, support and information to anyone concerned about or affected by cancer.



Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- End-of-life services
- Chemotherapy group education sessions
- Lifestyle and cancer prevention
- Emotional support
- Local cancer support groups and centres
- Practical entitlements and services
- Living with and beyond cancer

You can email daffodilcentreinfo@irishcancer.ie or visit www.cancer.ie to find your local Daffodil Centre.

Survivor Support



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

Support in your area

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

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

Patient travel and financial support services



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

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

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

Irish Cancer Society Night Nursing



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

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

Publications and website information



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

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

Local cancer support services

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

For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free one-to-one counselling through many affiliated support services)



- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society's *Strides for Life* walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation

- **Complementary therapies** like massage and reflexology
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics



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

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

What does that word mean?

Benign	Not cancer.
Biopsy	The removal of a small amount of tissue to find out if abnormal cells are present.
Cervical intraepithelial	The cell abnormality in the cervix neoplasia (CIN) 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.

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)	Some strains of HPV can cause abnormal changes in the cells of the cervix.
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.

Precancerous	Abnormal changes which are not cancer. If left untreated they may become cancerous over time.
Radical hysterectomy	An operation to remove your womb, upper part of your vagina and soft tissue beside your womb.
Radioactive source	A radioactive material that gives off high-energy rays. These rays can kill cancer cells.
Radiotherapy	A treatment that uses high-energy X-rays to cure or control cancer and other diseases.
Speculum	An instrument used by a doctor or 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.
Transformation zone	A small area of skin at the end of your cervix where two types of cells meet and overlap. This is the area from which a smear is taken.
Uterus	The womb.

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 screening tests after surgery?

Your own questions

Join the Irish Cancer Society team

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

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

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

Contact our Support Line on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

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

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