

Understanding

Secondary Breast Cancer

Caring for people with cancer

Understanding

Secondary breast cancer

This booklet has been written to help you understand more about secondary breast cancer. It has been prepared and checked by surgeons, cancer doctors, nurses, radiation therapists and patients. The information in this booklet is an agreed view on this cancer, its treatment and how it may affect you.

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



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

The Irish Cancer Society has produced this booklet to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We especially thank the women who generously shared their personal experience of secondary breast cancer throughout this booklet. Some names have been changed.

We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave their time and expertise to previous editions of this booklet.

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

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Published in Ireland by the Irish Cancer Society.

© Irish Cancer Society, 2012. Revised 2018

Next revision: 2020

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ISBN 0953236901

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Quick facts

Can my cancer be treated?

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Yes. Secondary breast cancer treatments are to keep the cancer under control, rather than to cure it. There are lots of different treatments for secondary breast cancer. New treatments are being developed all the time.

How long will I live?

Page 18 ▶▶

Many women live a long time with secondary breast cancer.

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things. The best thing to do is to ask your consultant about your own situation. See page 18.

What kind of treatment will I have?

Page 21 ▶▶

- **Hormone therapy:** Used to treat breast cancers that are stimulated to grow by the hormones oestrogen and progesterone.
- **Chemotherapy:** Drugs to slow down and control the growth of the cancer.
- **Radiotherapy:** A course of X-ray treatments to control the disease and relieve symptoms
- **Biological therapies:** Drugs that find ways to stop breast cancer cells from dividing and growing.
- **Bisphosphonates:** Drugs used to treat secondary breast cancer in the bone.

Sometimes you will have a choice of treatment.

See page 23 for advice about making a decision.

We're here for you

Page 75 ▶▶

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

See page 75 for more about our services.

Are there side-effects from treatment?

Page 28 ▶▶

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

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

Clinical trials

Page 45 ▶▶

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

Rhona's story

🍷 I am married with three adult children. I've been living with secondary breast cancer for 13 years and lead a full, active life.

I was first diagnosed with primary breast cancer in September 2003 in my mid-forties. Having just completed treatment for that, I was diagnosed with secondary breast cancer in 2004.

I was devastated. Unlike primary breast cancer there was no longer a prospect of a cure. My prognosis was poor. I had overwhelming feelings of shock, disbelief, sadness, fear and anxiety. I grieved for all the things I thought the cancer would take from me, and the future I had imagined. But I had three young children so I was determined to beat the odds.

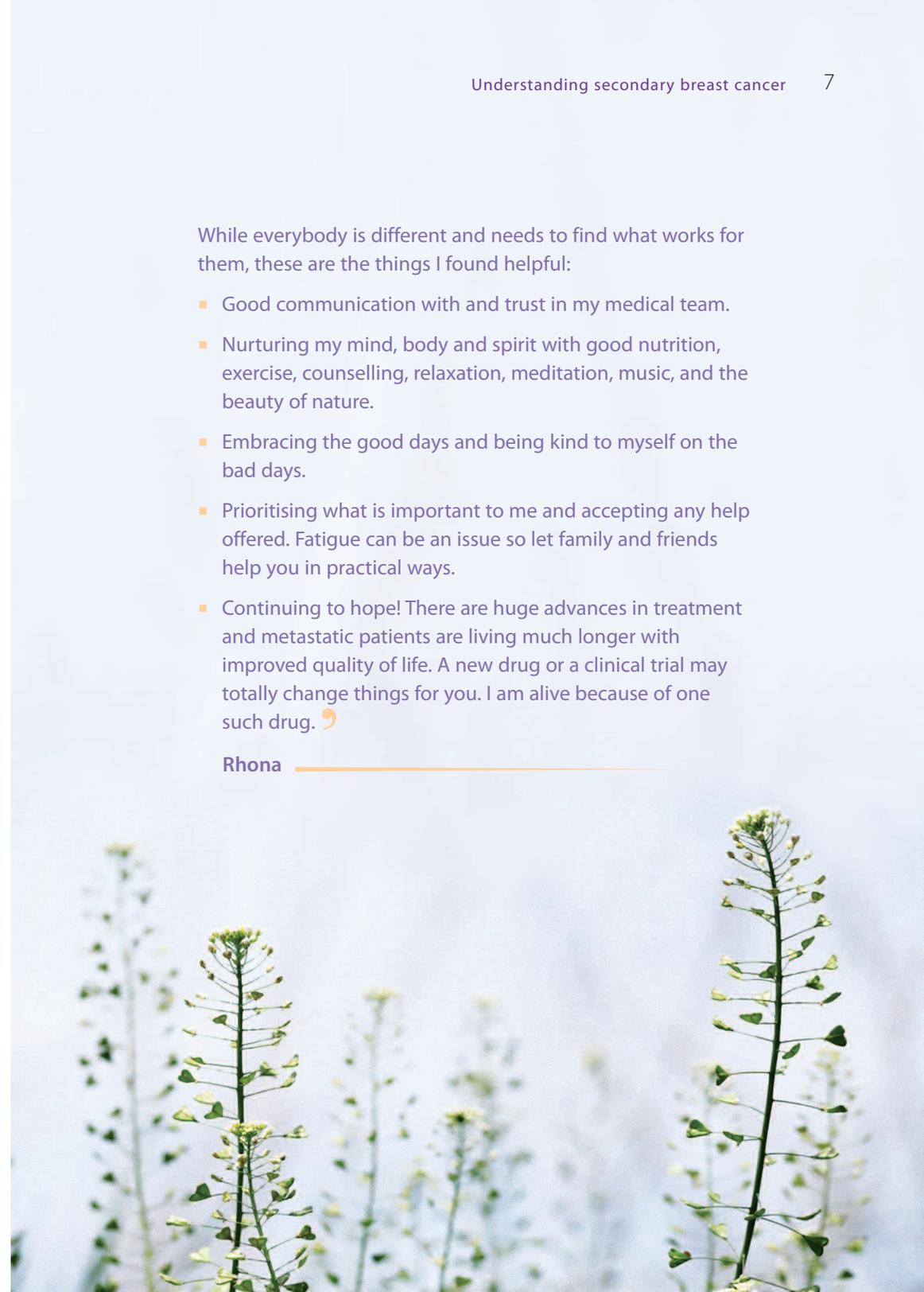
I started back on treatment – chemotherapy and Herceptin. I attended cognitive behaviour therapy and mindfulness sessions in the hospital to help me cope with the diagnosis, and the uncertainty of treatment and ongoing scans. I sought information on treatment, clinical trials, management of side-effects, nutrition, and exercise. I attended Arc Cancer Support for reflexology, relaxation and stress management classes – all of which helped to get my life back on track.

My first follow-up scans showed a huge improvement and to date the cancer has remained stable, for which I am very grateful. I am well and living a full, active life. I work part time, and also volunteer with the Irish Cancer Society and Arc Cancer Support. I am a member of the Plurabelle Paddlers, a breast cancer dragon boat team, and we have competed and won medals internationally. I have a deep appreciation of life and enjoy the simple things and spending time with family and friends.

While everybody is different and needs to find what works for them, these are the things I found helpful:

- Good communication with and trust in my medical team.
- Nurturing my mind, body and spirit with good nutrition, exercise, counselling, relaxation, meditation, music, and the beauty of nature.
- Embracing the good days and being kind to myself on the bad days.
- Prioritising what is important to me and accepting any help offered. Fatigue can be an issue so let family and friends help you in practical ways.
- Continuing to hope! There are huge advances in treatment and metastatic patients are living much longer with improved quality of life. A new drug or a clinical trial may totally change things for you. I am alive because of one such drug. 🍷

Rhona



Introduction

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

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

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

Reading this booklet

You don't need to know everything about secondary breast cancer straight away. Read a section about a particular item as it happens to you or if you are interested in it. Then when you want to know more, read another section.

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



Cancer Nurseline Freephone 1800 200 700

About secondary breast cancer

What is primary breast cancer?

Primary breast cancer is when breast cancer cells grow in your breast.

What is secondary breast cancer?

Secondary breast cancer is cancer that has spread from the first (primary) tumour in your breast to another part of your body. It is also known as metastatic breast cancer, advanced breast cancer or stage 4 cancer. Secondary cancer can happen months or years after your first breast cancer diagnosis. Occasionally, women are diagnosed with secondary cancer at the same time as the primary breast cancer is found. This is sometimes called 'de novo' metastatic breast cancer, meaning the breast cancer is metastatic from the start.

What causes secondary breast cancer?

Often primary breast cancer is cured, but sometimes treatment does not remove all the breast cancer cells. These breast cancer cells may be tiny and can't be picked up on scans. They may spread through the bloodstream or lymphatic system to other parts of the body, where they may eventually form another cancer or tumour. Cells may also spread to another part of the body before treatment starts. The cells may be inactive for many years and then start to grow and divide to form a new tumour. Doctors and scientists do not know why this happens.

Email cancernurseline@irishcancer.ie

What parts of the body can be affected by secondary breast cancer?

Secondary breast cancer may affect one part of your body, but it can also affect more than one place. The most common places breast cancer can spread to are the:

- Bones
- Lungs
- Liver
- Brain

Breast cancer can spread to other parts of the body, such as the skin, bone marrow, ovaries or lining of the abdomen (peritoneum).

The secondary cancer is made up of breast cancer cells. The secondary cancer is still breast cancer, even if it is in another part of your body. For example, if breast cancer spreads to your lung, it is described as secondary breast cancer in the lung, not lung cancer.

What are the symptoms of secondary breast cancer?

The symptoms of secondary breast cancer depend on where the breast cancer has spread. Some patients have no symptoms. Or you might have general symptoms at first. This can include feeling more tired than usual or losing your appetite.

There are specific symptoms of secondary breast cancer depending on which part of your body is affected. For example:

- Bone pain that does not go away
- Loss of power or weakness in your arms or legs
- Unexplained weight loss and loss of appetite
- A constant feeling of nausea
- Discomfort or swelling under your ribs or across your tummy
- Feeling constantly tired
- A dry cough or breathlessness
- Severe headaches

It is hard to list all the symptoms of secondary bone cancer because different parts of your body may be affected. Do tell your doctor about symptoms that are new, don't have an obvious cause and don't go away.

Cancer in the bone: A sign of secondary breast cancer in your bone can be an ache in the affected bone. If you get a new pain that lasts longer than about 2 weeks, talk to your doctor. Not every new ache or pain means that breast cancer has spread to the bone but all persistent pains need be checked out.

If breast cancer spreads to your bone, it can damage the bone and weaken it. Sometimes breaking a bone is the first sign of secondary breast cancer. These fractures can happen after a minor injury because the bone is weakened. The level of calcium in your blood can increase when bone is damaged. Too much calcium in your blood is called hypercalcaemia. It can cause symptoms such as tiredness, constipation, nausea, thirst and confusion. Often hypercalcaemia is found during blood tests before symptoms develop.

If the cancer spreads to the bones in your spine, it can press on your spinal cord and nerves. This is called spinal cord compression. It can cause symptoms such as pain, weakness or tingling in your leg and loss of bladder and bowel control. If this happens, visit your doctor immediately. It is very important to treat spinal cord compression quickly.

Remember secondary breast cancer in a bone can be treated. For most women, treatment starts long before the bone becomes weak enough to break or cause a lot of pain.

Cancer in the liver: If breast cancer has spread to your liver, you might complain of loss of appetite, tiredness, nausea and discomfort on the right side of your tummy. This is where your liver is found. The liver works by making bile to help digest food. If the drainage channels leading from your liver are blocked by secondary cancer, bile can build up in your blood. This can cause jaundice and turn your skin and the whites of your eyes yellow. Your skin can feel itchy as a result. It can also make your urine darker and your stools paler in colour.

Sometimes cancer can make your liver bigger or cause fluid to build up in your tummy. This fluid is called ascites and can make your tummy swell up. But your liver will continue to work when part of it, or even most of it, is out of action.

Cancer in the lungs: One of the first signs of secondary breast cancer in the lungs is shortness of breath or a persistent dry cough. The space between your lungs and ribcage is called the pleural cavity. If cancer cells enter this space, they can cause fluid to build up and put pressure on your lungs.

Cancer in the brain: Symptoms of cancer in the brain can include headaches and nausea. Sometimes it causes changes in the part of your body controlled by that part of the brain. For example, an arm or a leg may be weaker than usual or there may be a feeling of numbness, tingling or pins and needles. Cancer in the brain can also cause seizures and in rare cases confusion or a change in personality.

Can secondary breast cancer be treated?

Yes, secondary breast cancer can be treated but not cured. The aim of treatment is to relieve your symptoms and improve your quality of life by slowing down the growth of the cancer. There are many treatments that can keep the cancer under control, sometimes for many years. Your doctor will be very keen to ensure that any side-effects from your treatment are managed, to allow you live as full a life as possible.

For some women, living with secondary breast cancer is like living with a chronic (long-term) illness. Your specialist will tell you about the likely progress of your cancer and what you might expect.

See page 21 for more about treating secondary breast cancer.

What are local and regional recurrence?

Local recurrence: Local recurrence is when breast cancer comes back in your chest or breast area, or in the skin near the original site or scar. This means the cancer cells have remained in the local area and

have not spread to other parts of your body. A local recurrence can often be treated successfully.

Regional recurrence: Regional recurrence is when breast cancer comes back beyond your breast and armpit lymph nodes. It can occur in the tissues and lymph nodes around your chest, neck and under your breastbone. The treatment for this varies and will depend on what treatments you had previously. It might include surgery, radiotherapy and/or drug treatments. In most cases regional recurrence can be cured.

Having a local or regional recurrence of breast cancer is different to having secondary breast cancer.

Even though these recurrences are not in the body's organs, your doctor usually recommends tests to check the cancer has not spread further.

You can talk to one of our cancer nurses if you have any questions about local or regional recurrence or about secondary breast cancer. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.



To sum up

- Cancer is a disease of the cells of the body.
- Cells from a primary tumour can break away and be carried by the bloodstream or lymph to form a tumour somewhere else. This is called a metastasis or secondary tumour.
- Secondary breast cancer is breast cancer that has spread from the breast tissue to another part of your body.
- The most common parts of your body that breast cancer spreads to are the bones, lungs, liver and brain.
- The aim of treatment is to relieve your symptoms and improve your quality of life.
- Treatments can keep the cancer under control, sometimes for many years.

Being diagnosed with secondary breast cancer

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

- Upset and overwhelmed by your emotions
- Confused by all the information being given to you
- Worried about what will happen next
- Scared about the future
- Angry about your diagnosis, or angry that your cancer has come back after already going through treatment.

However you feel, you are not alone. There are many people who can help and support you at this time.

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

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

🗨 It is so difficult to describe the impact that such a diagnosis had on my life and that of my family. Devastation, pure and utter....a polite way of putting it. I almost instantly felt all hope vanish. But I want to tell you that I'm alive nearly 3 years later, simply taking letrozole, and I don't feel or look like I'm at death's door! Amazing! 🙏

Sarah

Telling people about your diagnosis



It can be hard to tell other people the news that your cancer has come back or that you have been diagnosed with breast cancer that has spread to other parts of your body.

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

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

🗨 It is a difficult and dark place when diagnosed with a life-threatening illness. I found meeting people with a similar diagnosis through the Irish Cancer Society's Living Life programme a huge benefit. Friends and family are amazing but it's hard to talk about your deep and dark fears with them. 🙏

Marian

Cancer Nurseline Freephone 1800 200 700

What tests will I have?

After being diagnosed with secondary breast cancer, you may have more tests to find out about your cancer and your general health. There are many tests you can have. Your doctor will tell you which tests they think you should have and why. Different tests are used to examine different parts of your body, for example, your bones, liver and lungs or sometimes your brain. As these are the most common places that breast cancer spreads to, you are more likely to have tests on those parts of your body.

Tests you may have include:

- **X-rays:** X-rays use high-energy rays to take pictures of the inside of your body. An X-ray of your bones can give a picture of the general condition of your bones. A chest X-ray may show if there is any breast cancer in your lungs. It might also look for a build-up of fluid in the space between your lungs and chest wall.
- **Bone scan:** This test is more sensitive than an X-ray and shows up any abnormal areas of bone more clearly. A mildly radioactive substance is injected into a vein. A scan of your bones is taken two or three hours later.
- **Blood tests:** Blood tests can check your general health, including how well your kidneys and liver are working. Some cancers make chemicals that can be found in your bloodstream. These are called tumour markers. Blood tests can show the level of tumour markers in your blood. Blood tests can also check the amount of calcium in your blood.
- **Ultrasound scan:** This is a scan that uses sound waves to look at your liver or other organs in your body. The scan is painless and only takes a few minutes. Some gel is first put on your tummy, which is then scanned with a small device like a microphone.
- **CT scan (CAT scan):** This is a special type of X-ray that gives a detailed picture of the tissues inside your body. During the scan you will lie on a table which passes through a large doughnut-shaped machine. It is painless and takes between 10 and 30 minutes. You might be asked not to eat for a few hours before the test. You may

also be given an injection or a special drink to help show up parts of your body on the scan. Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparations for a CT scan can vary but the doctor or nurse in your hospital will tell you what to do.



- **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 may feel claustrophobic during the MRI scan. If you are anxious, contact the radiographer the day before. They may be able to give you medication to relax you on the day. An MRI can also be noisy, but you will be given earplugs to wear during it. You might get an injection before the scan to show up certain parts of your body. During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test.
- **PET scan:** PET stands for positron emission tomography. PET uses a low dose of radioactive sugar to measure the activity of your cells. This sugar is first injected into your arm and travels to all the cells in your body. Because cancer cells absorb more sugar, there will be more radioactivity where the cancer cells are found. An hour after the injection, the scan is taken and can show if the cancer has spread to other tissues and organs. During the scan, you will lie on a table which moves through a scanning ring. Before the scan, you may have to fast (not eat) for a few hours.
- **Breast biopsy:** If secondary breast cancer is your first diagnosis of cancer, your doctor will take a small piece of tissue (biopsy) from your breast. This can confirm your diagnosis. The biopsy will also help to find out whether the cancer cells have certain receptors which encourage the cancer cells to grow. For example, the hormone oestrogen (ER) or HER2. You usually have a biopsy under

local anaesthetic. The doctor uses an ultrasound or a CT scan to help them guide the needle to the right place.

If you have been diagnosed with breast cancer before, you might have a repeat biopsy to test for changes in receptors.

Waiting for test results



It usually takes a week or two for all the test results to come back. There might also be a multidisciplinary team meeting to decide the best treatment for you. For more information, see page 23.

This can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Asking about your prognosis

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

Should I ask about my prognosis?

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

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

If you decide you want information on your prognosis:

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

Why was the cancer not picked up earlier?



You might wonder why the secondary breast cancer was not picked up earlier during your check-up visits to your cancer specialist. Remember your doctor is unlikely to do scans or other tests routinely after breast cancer treatment. They will only do them if they suspect something is wrong. Having these tests regularly cannot stop cancer from spreading because the cancer cells may be so tiny they cannot be seen on scans.

Often your doctor may not want to expose you to the radiation involved in some tests, unless absolutely necessary. You might assume the tests are not done because they cost too much. But this is not true, even though many scans are expensive. You might find it hard to accept that certain scans and tests are not part of your routine check-up. Do talk to your doctor who will reassure you.



Treatment and side-effects

How is secondary breast cancer treated?

The aim of treatment for secondary breast cancer is to control the growth and spread of the cancer rather than cure it. Treatment can also help to relieve your symptoms and improve your quality of life. The best treatment for you will depend on:

- Where the secondary cancer is in your body
- If your breast cancer cells are positive or negative for hormone receptors or HER2. See page 40.
- Your age and if you have reached the menopause or not
- Your previous cancer treatments and response to those treatments
- How the cancer affects your everyday living and quality of life
- Your personal preference

“ There are a number of lines of treatment options open to me if it does come back so I would feel very positive about the treatment of metastatic disease these days. ”

Marian

Types of treatment

There is a range of treatments available to manage secondary breast cancer. If one treatment doesn't work, or if the side-effects are difficult to manage, your doctor will look at other treatment options. You may receive more than one type. They include:

Hormone therapy: The female hormones oestrogen and progesterone can cause the growth of some breast cancer cells. Changing the level of these hormones in your body can slow down or stop the growth of secondary breast cancer. Hormone therapy is suitable if you have oestrogen-receptor positive or progesterone-receptor positive cancer. It is usually used as the first treatment for secondary breast cancer and may be used alone or with other treatments. See page 28 for more details.

Chemotherapy: Chemotherapy is the use of drugs to kill cancer cells. You may be offered chemotherapy if your secondary breast cancer is growing quickly or is affecting the function of your liver or lungs. It might also be given if you do not have hormone receptors on your breast cancer cells or if you have stopped responding to hormone therapies. You may have chemotherapy on its own or with other treatments. See page 33 for more details.

Radiotherapy: Radiotherapy uses X-rays to destroy cancer cells. The aim of radiotherapy in secondary breast cancer is to reduce the size of the cancer in some parts of your body and relieve symptoms such as pain. It is mostly used when the cancer has spread to your bones, lungs or brain. Or it may be given to control the cancer coming back in your skin or armpit. See page 37 for more details.

Biological therapies: These drugs work with your body to fight cancer. Different biological therapies work in different ways. The type used for breast cancer usually work by stopping the breast cancer cells from dividing and growing. See page 40 for more details.

Bisphosphonates: Drugs called bisphosphonates are used to treat the effects of secondary breast cancer in your bone. They work by relieving bone pain, reducing the risk of fractures and controlling the level of calcium in your blood. See page 42 for more details.

Surgery: Surgery is rarely an option for most people with secondary breast cancer. Drugs tend to be a better treatment option. Surgery is unlikely to remove all the cancer. If your cancer is confined to a small area, your doctor may consider surgery. See page 44 for more details.

Treatment of symptoms and palliative care: Some of your symptoms of secondary breast cancer may need to be treated straightaway. For example, bone pain or breathlessness. Treating symptoms is also called palliative care. See page 55 for more details.

Palliative care is care that aims to control your symptoms and give you the best quality of life possible. Palliative care includes end-of-life care, but may be given at any stage to relieve symptoms such as pain and nausea. The palliative care team may be involved in your care at many different times. See page 55 for more details.

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

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

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

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

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

Clinical trials: Ask your consultant if you are suitable for a clinical trial. For more information on clinical trials, see page 45.

Email cancernurseline@irishcancer.ie

Giving consent for treatment

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

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

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Always talk to your doctor or nurse if you have any worries about your treatment plan. Don't be afraid to ask about other treatment options.

🗨 In relation to your healthcare team, ask them the medical questions you need answers to and make separate appointments if you feel they are rushed in the ward. 🗨

Marian

Individual treatment

You may notice that other people with secondary breast 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.

Waiting for treatment to start

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

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

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



Who will be involved in my care?

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

Surgeon	A doctor who specialises in surgery and who can remove a tumour from your body.
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 person who delivers the radiotherapy and gives advice to cancer patients about their radiation treatment.
Oncology liaison nurse / clinical nurse specialist	A nurse who works in a special cancer care unit. They give information and reassurance to you and your family from diagnosis and throughout treatment.
Medical social worker	A person trained to help you and your family with your social issues and practical needs. They can give counselling and emotional support. They can 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.
Palliative care team	This team is trained in managing pain and other symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the 'homecare team' or the 'hospice homecare team'. A specialist palliative care service is available in most general hospitals.

Physiotherapist	A therapist who treats injury or illness with exercises and other physical treatments related to the illness.
Dietitian	An expert on food and nutrition. They are trained to give advice on diet during your 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	These include family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.



To sum up

- Treatment for secondary breast cancer aims to control the growth and spread of cancer, relieve your symptoms and improve your quality of life.
- Your treatment will depend on where the cancer is, if your breast cancer cells are positive or negative for hormone receptors or HER2, if you have reached the menopause or not, your previous cancer treatment, how the cancer affects your everyday life and your personal preference.
- Secondary breast cancer can be managed by hormone therapy, chemotherapy, radiotherapy, biological therapy, bisphosphonates, surgery, treatment of symptoms, and palliative care.

Hormone therapy

Hormone therapies are often used as the first treatment for secondary breast cancer. They can be used alone or with other treatments.

How does hormone therapy work?

Some breast cancers are oestrogen receptor (ER) and progesterone receptor (PR) positive. This means they are encouraged to grow by the female hormone oestrogen. Oestrogen can be produced in 2 ways:

- The ovaries produce oestrogen
- An enzyme called aromatase converts hormones called androgens into oestrogen.

All hormone therapies try to stop oestrogen from helping ER-positive breast cancer and PR-positive breast cancer to grow. Different types of hormone therapies work in different ways:

- **Aromatase inhibitors** stop aromatase from changing androgens into oestrogen. See page 29 for more about aromatase inhibitors.
- **Anti-oestrogen drugs** stop oestrogen from attaching to breast cancer cells and encouraging them to grow. See page 29.
- **Ovarian treatments** stop your ovaries from producing oestrogen. See page 30 for more about ovarian treatments.

If you had a hormone therapy to treat your primary breast cancer, you may need to have a different type to treat the secondary cancer.

The benefits of hormone therapy can sometimes last for several years.

How does the menopause affect the choice of hormone therapy?

Before the menopause (pre-menopausal)

If you haven't been through the menopause, all types of hormone therapies are suitable for you. You may be given a combination of treatments, usually:

- **An ovarian treatment** to stop your ovaries from producing oestrogen
- **An anti-oestrogen drug** to stop oestrogen from helping breast cancer cells to grow.

You may also be given an aromatase inhibitor if the anti-oestrogen drug stops working.

After the menopause (post-menopausal)

After the menopause the ovaries stop producing oestrogen, so ovarian treatments are not helpful for you. You will most likely be treated with either:

- **An aromatase inhibitor** or
- **An anti-oestrogen drug**

Types of hormone therapy

Aromatase inhibitors: Aromatase inhibitors block the enzyme aromatase, which changes hormones called androgens into oestrogen.

Examples of aromatase inhibitors include anastrozole (Arimidex®), letrozole (Femara®) and exemestane (Aromasin®). They are usually given in tablet form.

If your primary breast cancer was treated with an aromatase inhibitor, you may be given a different type to treat your secondary cancer. Or you may be prescribed an anti-oestrogen drug like tamoxifen, which stops oestrogen from helping the cancer cells to grow. You might have several types of hormone therapies one after another to keep your disease under control.

Aromatase inhibitors usually cause few side-effects. They can cause vaginal dryness, nausea, and muscle and joint pain. Side-effects tend to be mild if they do occur.

Bone density scans may be done before starting treatment and regularly during treatment, as the drug can increase bone loss. Treatments are also available that can improve your bone strength.

Anti-oestrogen drugs: Anti-oestrogen drugs stop the hormone oestrogen from helping oestrogen-receptor positive cancer cells to grow. They do this by stopping oestrogen from attaching to the receptors on the cancer cells. Examples of anti-oestrogen drugs include tamoxifen or fulvestrant (Faslodex®).

Tamoxifen can be given before or after the menopause. Fulvestrant is given to women who have been through the menopause.

Tumour flare

If you have secondary breast cancer in a bone, you may find that tamoxifen makes the bone pain worse for the first few days. This is known as tumour flare but it eases after a while. Do let your doctor know if it happens. In general, the benefits of taking tamoxifen far outweigh the risks if you are oestrogen-receptor positive.

If you would like more information on the different types of hormone drugs, call our Cancer Nurseline on 1800 200 700.

Ovarian treatments

If you have not been through the menopause and your secondary breast cancer is oestrogen-receptor positive, your doctor might suggest an ovarian treatment.

Ovarian treatments stop your ovaries making oestrogen. They can be temporary (ovarian suppression) or permanent (ovarian ablation).

These treatments are usually given in combination with an aromatase inhibitor or an anti-oestrogen drug.

There are three ways to stop your ovaries making oestrogen:

- **Drug treatment:** Drugs are used to ‘switch off’ your ovaries temporarily. The drugs change the levels of the hormones released in your brain that control how your ovaries work.
One example of this type of drug is goserelin (Zoladex®). When you stop taking the drug, your ovaries should start producing oestrogen again and your periods should return. If you are close to menopausal age, your periods may not return.
- **Surgery:** Surgery involves removing your ovaries. Your periods will stop immediately if your ovaries are removed.
The operation to remove your ovaries is called an oophorectomy. It may be done using keyhole surgery usually under general anaesthetic.
Your surgeon uses a thin flexible tube with a light and magnifying lens at the tip to look into your tummy (abdomen). A few small

cuts are first made in the skin and muscle of your tummy and the tube is put in. Usually you stay in hospital for a day or two.

- **Radiotherapy:** Radiotherapy uses X-rays to stop your ovaries from working to produce oestrogen. Normally you have one more period, which may be heavy, and then your periods stop completely.

>>> Both surgery and radiotherapy will stop your ovaries working permanently, so you will no longer have periods.

What are the side-effects of hormone therapy?

Hormone therapy may cause short- or long-term side-effects. As with all treatments, side-effects can vary. It also depends on whether you have had the menopause or not. Side-effects include:

- Changes to periods and menopausal symptoms
- Blood clotting
- Osteoporosis
- Thickened womb
- Bone loss and pain

Changes to periods and menopausal symptoms: For women who are still having periods, hormone therapy may cause periods to become irregular, lighter or stop altogether. The physical effects of this may include menopausal symptoms like hot flushes, night sweats, anxiety, lowered sex drive, dry skin, and dryness of your vagina. Usually the side-effects are mild and may reduce over time. See page 58 for more about menopausal symptoms. You can also visit our website, www.cancer.ie for more about ways to cope or get information and support from a cancer nurse by visiting a Daffodil Centre or by calling our Cancer Nurseline on 1800 200 700.

Infertility: Some hormone therapies can cause a permanent menopause. It is not easy to come to terms with infertility. It can be very distressing if you are already coping with secondary breast cancer. See page 58 for more about infertility.

Osteoporosis: Oestrogen helps to keep bones healthy. If you have hormone treatment to reduce the amount of oestrogen in your body, there is a risk that your bones may become weaker and more likely to break.

This is called osteoporosis. There is medicine that can help with osteoporosis. For more about bone health, see page 51.

Blood clotting: Some drugs slightly increase the risk of blood clotting. Tell your doctor if you have any vaginal bleeding, chest pain, swelling, or tenderness in your legs or arms.

Thickened womb: Some drugs can cause the lining of your womb to become thickened or put you at a small risk of developing cancer of the womb. For this reason, you should report any vaginal bleeding to your doctor.

Bone loss and pain: Some drugs may increase bone loss and cause pains and aches in your muscle or bone joints. As a result, bone density scans may be done before starting treatment and regularly during it. You should also stop smoking, take regular exercise, and take calcium in your diet. Ask your doctor about taking calcium supplements. Drugs may be prescribed if there is serious bone loss (osteopaenia or osteoporosis). There are also other ways to lessen the side-effects of hormone treatments.

Managing side-effects

Ask your doctor or nurse what side-effects you can expect and how to manage them. Usually these side-effects are mild and may reduce over time. If you continue to find them a problem, talk to your doctor or nurse. For more information about side-effects, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also find more information on our website, www.cancer.ie



To sum up

- Hormone therapy only works for women who have oestrogen-receptor positive (ER+) cancers.
- The choice of hormone therapy will depend on whether you have reached the menopause or not.
- Hormones tend to cause mild side-effects and often are not serious.
- The benefits of treatment with hormone therapies can last for years.

Chemotherapy

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

The aim of chemotherapy for secondary breast cancer is to stop the cancer from spreading. Chemotherapy is usually an option if you are not responding to hormone therapy or if your breast cancer is hormone negative. It might also be used for cancers that are growing quickly or affecting your liver or lungs.

Chemotherapy can relieve symptoms such as pain by controlling the growth of cancer, and improve your quality of life. For some people, chemotherapy can make the cancer smaller and keep it under control. When your medical team is deciding your treatment plan, your quality of life will be a very important consideration.

The benefits of treatment with chemotherapy can sometimes last for years.

How often will I have chemotherapy?

Chemotherapy is often 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 or through an intravenous infusion (drip). It may also be given in tablet form. Usually your treatment will be given in the chemotherapy day care unit.

You might receive your chemotherapy as part of a clinical trial. See page 45 for more details.

What kinds of drugs are used?

There are several chemotherapy drugs used to treat secondary breast cancer. Chemotherapy drugs can be used on their own or in combination with each other. If one type doesn't work, there are usually more options.

If you had chemotherapy to treat primary breast cancer, you will probably be given a different drug to treat your secondary cancer.

Your doctor or nurse will discuss your individual treatment plan with you.

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 by medication. Usually 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. For more information see page 53.
- **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.
- **Nausea and vomiting:** Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are very effective treatments to help prevent this. Your doctor can prescribe anti-sickness (anti-emetic) drugs for you.
- **Skin and nail changes:** Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle.
- **Hair loss (alopecia):** Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Before treatment your doctor and nurse will tell you if you are likely to have any hair loss.
- **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.
- **Constipation and diarrhoea:** Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).

- **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 and having a high or low temperature. Your hospital will let you know at what point you should contact them if you have a temperature. Other signs of infection include having a cough or pain passing urine.
- **Anaemia:** Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment.
- **Bleeding and bruising:** Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. You will have regular blood tests to count the number of platelets in your blood. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds, bleeding gums, vaginal bleeding or blood in your stool.
- **Changes in kidney function:** Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination or swelling of the hands or feet (oedema), as these can be a sign of kidney damage. It's important to drink plenty of fluids, about 1½ to 2 litres per day.
- **Changes in hearing:** Some chemotherapy drugs can cause buzzing or ringing sounds your ears. This is called tinnitus. These can be very distressing. Let your doctor know if there is any change in your hearing.
- **Sore eyes:** Some drugs can make you may feel as if you have grit in your eyes. Your doctor can prescribe suitable eye drops for you.
- **Feeling confused or memory problems:** You might feel 'vague' or mildly confused or have memory problems while having chemotherapy. This is sometimes called 'chemo brain' or 'chemo fog'. Tell your doctor or nurse if you feel this way.
- **Early menopause:** If you are a younger woman, you may experience menopausal symptoms during chemotherapy. For example, hot flushes, dry skin, dryness of your vagina and less interest in sex. For more information see page 58 and read advice on managing menopausal symptoms on our website, www.cancer.ie

- **Infertility:** Chemotherapy can cause infertility. This is more likely in women who are nearer their natural menopause. Infertility can be very hard to come to terms with. See page 58 for more.

If you have any symptoms that are troubling you or you feel 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*, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.



To sum up

- Chemotherapy is a treatment using drugs to kill cancer cells.
- Chemotherapy can be given in tablet form, directly into a vein as an injection or through a drip (infusion).
- The side-effects vary from person to person and depend on the drugs used.
- Some common side-effects are fatigue, nausea and vomiting, sore mouth and peripheral neuropathy.
- Most side-effects can be well controlled with medication.



Radiotherapy

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

Radiotherapy may help if your secondary breast cancer has spread to your bone, skin, lymph nodes or parts of your brain. It is a localised treatment, which means it only treats the area of your body that it is aimed at.

If cancer has spread to your bones, the aim of radiotherapy is to improve your mobility, decrease pain and prevent any possible fractures or spinal cord compression. It should also make you feel more comfortable.

If the cancer has spread to other parts of your body, it can shrink the tumour and relieve pain or swelling.

How is radiotherapy given?

With external beam radiotherapy, the radiation comes from machines which aim rays directly at your tumour or the tumour site. The machines are called linear accelerators. External radiotherapy does not make you radioactive. It is completely safe for you to mix with family and friends, including pregnant women and children.



Planning your treatment

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

An important part of the planning process is simulation. This involves using a CT scanner to pinpoint the area to be treated. 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.

Getting your treatment

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

The treatment normally takes several minutes and is painless. But you might find it uncomfortable to lie in the same position while the treatment is being given. If you think it might help, ask your radiation therapist if you can take a painkiller half an hour before your treatment. Most people receive radiotherapy as outpatients, travelling to the radiotherapy unit each day.

How much radiotherapy do I need?

Usually you will only need a short course of radiotherapy. You may have a single dose or a dose divided over a few days.

Side-effects of radiotherapy

Radiotherapy is given directly to the site of the cancer. This means any side-effects tend to affect the area of the body being treated. Because secondary breast cancer usually only needs a short course of radiotherapy most women have few side-effects. Some common side-effects are:

Nausea: Radiotherapy to your stomach area or brain may make you feel sick. This can be prevented or relieved by taking anti-sickness drugs before your treatment. Your doctor will prescribe these for you.

Fatigue: Fatigue or tiredness can build up over the course of your treatment. You may feel tired because of the treatment itself or perhaps you have to travel long distances for treatment. Rest as much as you need to. Regular gentle exercise such as walking can help to improve tiredness.

Skin changes: You may get some redness of your skin on the treated area. But it is rare to have skin reactions. Ask the radiotherapy staff in your treatment centre for skin care advice and how to feel more comfortable.

Hair loss: If you have treatment to your brain, you are likely to have hair loss to your head. The hair usually starts to grow back within 2 to 3 months of the treatment finishing. If hair loss happens in other parts of your body, it will only be on the treated area.

Pain: Radiotherapy for secondary bone cancer can cause a flare up of pain in the treatment area for a few days and you may need to take painkillers to help.

How severe these side-effects are will vary from person to person, depending on the amount of treatment received. Most side-effects develop during or shortly after your treatment and get better within a few weeks. Late side-effects may develop some time after treatment.

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



To sum up

- Radiotherapy uses high-energy rays to kill cancer cells.
- Radiotherapy is painless and each session only takes a few minutes.
- Side-effects of radiotherapy for secondary breast cancer depend on the area being treated. They include hair loss in the treated area, feeling sick (nausea) and skin changes.

Email cancernurseline@irishcancer.ie

Biological therapy

Biological therapies work with your body. They can help fight cancer, stop it spreading or control side-effects.

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

- **Cancer growth inhibitors** block the chemical signals that trigger cancer cells to divide and grow.
- **Monoclonal antibodies** trigger your immune system to attack cancer cells or target the cancer cells with drugs or a radioactive substance.
- **Angiogenesis inhibitors** interfere with the blood supply to the cancer cells.
- **Immunotherapy** boosts your body's immune system to fight cancer.

Some biological therapies fit into more than one of these categories.

The biological therapies used most often for secondary breast cancer are

- **Cancer growth inhibitors**, for example lapatinib (Tyverb®)
- **Monoclonal antibodies**, for example, trastuzumab (Herceptin®), bevacizumab (Avastin®) and pertuzumab (Perjeta®)

These drugs may be suitable if you have HER2-positive breast cancer. They target cancer cells that 'overproduce' or make too much of a protein called HER2. This protein is found on the surface of some cancer cells. The drugs work by attaching to the HER2 protein and slowing down or stopping the cancer cells growing.

A sample of breast cancer cells can be tested for the presence of HER2. It usually takes 3 weeks to get the results. About 1 in 5 women with breast cancer are HER2 positive. These cancers tend to grow faster than those that are HER2 negative and like many breast cancers can recur.

Remember if you had cancer before, the HER2 receptors on your cancer cells can change. Your doctor will not know if they have changed until they do a new biopsy.

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

New biological therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a biological therapy as part of a clinical trial (see page 45). Ask your doctor if there are any biological therapies available to treat your cancer or if there are any trials that are suitable for you.



Side-effects

Biological therapies only target the cancer cells and leave normal cells alone. This means you usually get fewer side-effects than with chemotherapy.

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

- Allergic reaction – fever and chills
- Headaches
- Flu-like symptoms
- Diarrhoea
- Nausea
- Fatigue

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

For more information on biological therapies and their side-effects, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.



To sum up

- Biological therapies use substances that usually occur naturally in your body to fight cancer.
- Unlike chemotherapy, biological therapies target cancer cells directly and do not harm normal cells.
- They only work if you have a particular type of cancer cell.
- The drugs can be given by tablet or into a vein through a drip.
- Some side-effects include fever and chills, headache, rashes.

Other treatments for secondary bone cancer

Bisphosphonates

If the secondary breast cancer is affecting your bones, you might be treated with a group of drugs called bisphosphonates. These can slow down or prevent bone damage and may reduce the spread of cancer.

Bisphosphonates can also be used to lower calcium levels in your blood if you have a condition called hypercalcaemia. This occurs when too much calcium escapes from the damaged bone into your bloodstream. High calcium levels can cause problems, such as nausea, vomiting, thirst, constipation and drowsiness.

Bone can be seriously weakened by cancer. In this case, bisphosphonates can help to strengthen the bone and reduce the risk of fractures. Bone pain can be reduced as well. In fact, the drug can help reduce pain that has not responded well to painkillers or is too widespread for local radiotherapy.

How are bisphosphonates given?

Bisphosphonates can be taken orally as tablets or as an injection into a vein. The tablets are taken one or twice a day, whereas the injection is given once a month. This happens in the hospital day ward and takes a couple of hours. Usually bisphosphonates are a long-term treatment and given as long as you are benefiting from them.

»»» It is extremely important to take bone-strengthening medications exactly as prescribed to get the best benefit.

What are the side-effects of bisphosphonates?

There are several side-effects to bisphosphonates but many women experience none. Some mild side-effects happen at the start of treatment. For example, bone pain and flu-like symptoms. The tablets can sometimes cause diarrhoea, constipation and heartburn.

Very rarely, bisphosphonates can cause jaw problems. Go to your dentist regularly and let them know that you are taking bisphosphonates.

»»» Tell your doctor or dentist immediately if you develop any problems with your teeth or gums, or swelling, pain, heaviness or numbness of your jaw while you are taking bisphosphonates.

For more about bone health, see our website www.cancer.ie. It has lots of information on bone-strengthening drugs, keeping bones healthy, avoiding falls, dental care and diet. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Biological therapies

A type of biological therapy called a monoclonal antibody can also be used to prevent fractures and other cancer-related bone problems. An example is Denosumab (Xgeva®, Prolia®).

For more information on biological therapies, see page 40.



To sum up

- Bisphosphonates can prevent bone damage in bones affected by secondary breast cancer.
- They can help reduce pain that has not responded well to painkillers or is too widespread for local radiotherapy
- Bisphosphonates can reduce high calcium levels in your blood.
- The long-term use of bisphosphonates reduces the risk of bone fractures and may delay the spread of the bone cancer.

Surgery

Surgery is generally not an option for most people with secondary breast cancer. It is unlikely to remove all the cancer, and drug treatments tend to be better options. Surgery is mainly used to help to control your disease and reduce your symptoms. Your doctor might advise having surgery in the following situations:

- **First diagnosis:** If secondary breast cancer is your first diagnosis, you might need surgery to remove a sample of breast tissue (biopsy) to confirm your breast cancer diagnosis. Your surgeon may remove the primary breast cancer if the tumour is small. Your doctor will tell you if surgery to the breast is likely to be helpful in your individual situation.
- **Bone:** If the cancer has spread to your bone, surgery can treat a fracture or replace a joint damaged by cancer.
- **Lungs:** If the cancer has spread to the lining of the membrane outside your lungs (pleura), or to the lungs themselves, there are different types of surgery to manage the cancer.
- **Brain:** If the cancer has spread to your brain, surgery can be used to remove small areas of cancer or drain fluid from your brain.
- **Liver:** If the cancer has spread to your liver, it may be possible to operate to remove a small cancer in a single area of the liver.
- **Other reasons:** Surgery can help if the cancer has grown out through your skin, or is pressing on nerves and causing pain or a blocked bowel.

What are the side-effects of surgery?

The side-effects of surgery will depend on the type of operation. Do ask your surgeon or nurse to explain why the surgery is recommended for you and what will be involved. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Clinical trials

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

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

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

More information

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

You can also visit Cancer Trials Ireland at www.cancertrials.ie for a list of current trials in Ireland.

- 6 Ask about drug trials, new combinations of drugs and research coming down the line. There is so much more hope for effective treatments now than when I was first diagnosed. I have friends on treatment for metastatic breast cancer for over ten years who are living energetic lives! 🍷

Sarah

How can my symptoms be treated?

Some symptoms of secondary breast cancer can be linked to the cancer itself or due to treatment. Your symptoms will depend on how the secondary breast cancer has affected you. You may experience symptoms such as:

- Pain
- Nausea and vomiting
- Breathing problems
- Difficulty in sleeping
- Swelling of the arm (lymphoedema)
- High calcium levels in blood
- Bone pain and weakened bones
- Constipation
- Fatigue

It is very unlikely that you will have all of these symptoms or even most of them. If you have any symptoms that are troubling you, let your doctor or nurse know. Sometimes radiotherapy and chemotherapy can be used to help symptoms. But there are other treatments that can help to make your life easier too.

Pain

Lots of people worry about pain. In fact, many people with secondary breast cancer do not have pain.

If you do get pain, it can be helped. Tell your doctor or nurse immediately if you are in pain. Your doctor will try to find out what is causing it so that you get the right treatment. Pain can also be due to other medical conditions that have nothing to do with your cancer.

Painkilling drugs

Your doctor will decide which painkiller is best suited to the type of pain you have. If the medication doesn't ease the pain, tell your doctor or nurse. There are lots of options, so if one medicine doesn't work, your doctor will try something else.

A palliative care specialist who manages pain and other symptoms may also be able to help you. They can arrange for you to try out different painkillers to see which suits you best.

Other drugs

Besides painkillers, several other drugs can be helpful in reducing pain. If the pain is due to secondary breast cancer in the bone, anti-inflammatory drugs can be helpful. Other drugs known as bisphosphonates can also help to relieve bone pain. See page 42 for more about bisphosphonates.

Radiotherapy

Radiotherapy is very good for treating bone pain from secondary breast cancer. It can be given as a single dose or divided over a few days. It usually takes at least 2–3 weeks to work.

Complementary therapies

Complementary therapies can be used on their own or with medical treatments. For example, gentle massage and aromatherapy may ease aches and pains; relaxation techniques may help you to feel more comfortable. See page 56.

More information on complementary therapies is available in a free booklet from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. Call our Cancer Nurseline on 1800 200 700 or call into a Daffodil Centre for a free copy. You can also read or download the booklet on our website, www.cancer.ie



Tips & Hints – pain



- If you are in pain, tell your doctor or nurse about it straight away. Be honest about the level of pain you are in.
- Describe the pain as clearly as you can. Is it a dull or sharp sudden pain? Is it always there or does it come over you in waves? Is it mild or severe? Do you wake up in pain during the night? It may help to write down the times you get pain and what makes it better or worse.
- Try to score your pain on a scale of 0 to 10, where 0 means no pain at all and 10 means the worst pain you can imagine.
- If you only have pain from time to time, take the painkillers when you need them. But if the pain is there most or all of the time, take your painkillers regularly.

- Discuss with your doctor or nurse if the pain is worse at night and wakes you up or if you have times when the pain 'flares up' and isn't controlled by your usual pain relief. You can get extra medication to help with this 'breakthrough pain'.
- If you are constipated from the painkillers, take a laxative every day. Drink plenty of clear fluids such as water and fruit juice to keep your bowel habit regular. Your doctor or nurse will give you something stronger if your bowels have not opened for 2 or 3 days.
- If you are feeling sick, your doctor may give you anti-sickness tablets. The nausea often improves as you get used to your medication. Do not drive or work machinery if you feel drowsy.

👉 Coping with side-effects often becomes a major challenge and you need to be very resilient in speaking clearly to the team involved in your care. Hospitals are such busy places and it can be difficult to get the help you require. Persevere, seek help from your GP and enquire about support centres. 🍷

Sarah

Nausea and vomiting

With secondary breast cancer, you might be sick (vomit) or feel sick (nausea) at some point during your illness. This can make everyday life very difficult to cope with. If you are having problems with feeling sick or vomiting, tell your doctor or nurse. There are ways to control sickness, depending on what is causing it. Nausea can be due to:

- The cancer itself
- Side-effects of drugs such as painkillers
- Constipation
- Too much calcium in your blood
- Treatments such as chemotherapy.

There are many anti-sickness drugs available to treat nausea and they work in different ways. If the drug you are taking is not working,

let your doctor know and a different treatment can be prescribed. You may need a combination of drugs to help prevent nausea and vomiting.



Tips & Hints – nausea

- Eat small amounts of food regularly.
- Avoid fatty foods.
- Avoid foods that make you feel sick.
- Avoid taking a lot of fluid just before you eat.
- Take ginger or peppermint to ease the nausea.
- Take plenty of fluids in small amounts throughout the day.
- Try a complementary therapy, like acupuncture. It may help nausea. Ask your doctor for advice first.
- Ask your doctor if you can take a regular anti-sickness drug.

Breathing problems

Shortness of breath can be very uncomfortable and distressing. This symptom may be caused by a tumour in your lung or in the lining outside it. There are ways to relieve the problem causing shortness of breath. For example, you may have extra fluid on your lung that is making it hard for you to breathe in a relaxed way. This is known as a pleural effusion. By removing this fluid, your lung can re-expand and breathing becomes easier. It is done by putting a small tube into your chest under a local anaesthetic. The tube can then be removed once all the fluid has drained.

If the drainage improves your symptoms but the fluid starts to build up again, your doctor may decide to do a pleurodesis. This is where medication is put into your chest through the chest tube to cause the linings of your lung to stick together. This prevents fluid building up again.

If cancer has spread to the tissue of your lungs, the painkiller morphine can be used to relieve the breathlessness. Another way to ease the shortness of breath can be through breathing exercises.

Your doctor may refer you to a physiotherapist who will teach you the exercises. For more information on breathlessness see our website, www.cancer.ie. You can also talk to a cancer nurse by calling our Cancer Nurseline on 1800 200 700 or visiting a Daffodil Centre.

Difficulty sleeping

During your illness, there may be times when you find it difficult to sleep. Often this is because you are anxious about treatment or worried about the future. Not being able to fall asleep when you have a lot on your mind may be the hardest part. If you find it difficult to sleep at night, tell your doctor or nurse. If you are feeling depressed, you may find that you wake early and then cannot get back to sleep.



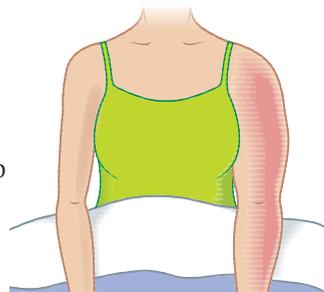
Tips & Hints – sleep problems

- Have a regular routine at bedtime.
- Take a warm milky drink before bed, but not coffee or tea.
- Have a warm bath with a few drops of lavender oil in it or sprinkle a few drops on your pillow.
- Listen to music or the radio if you cannot sleep. Or get up and watch TV or read a book.
- Play relaxation tapes, or audiotapes with stories, to help you get back to sleep.
- Complementary therapies may also help. For more information, see page 56.



Swelling of the arm (lymphoedema)

Lymphoedema is a swelling caused by a build-up of lymph fluid, when the lymphatic system isn't working properly to remove the fluid. This can happen if lymph nodes are removed during surgery or after radiotherapy to treat cancer.



If you notice swelling anywhere on your arm, hand or breast area, even if it comes and goes, you should tell your GP, oncologist or breast care nurse. This can happen soon after treatment or after some time. Other signs to watch out for are:

- A feeling of tightness when wearing clothing, bracelets, watches, or rings.
- A full, heavy, achy or weak feeling in the arm.
- A tight feeling in the skin.
- Dry, flaky, rough or scaly skin, or changes to your skin colour
- Trouble moving your arm.

Your doctor can refer you to a lymphoedema therapist who can recommend treatments to help keep it under control. The sooner you get treatment the better. Lymphoedema is easier to manage early on.

There is more information on lymphoedema and tips on managing the condition on our website, www.cancer.ie

You can also get information and advice from a cancer nurse by calling our Cancer Nurseline on 1800 200 700 or by visiting a Daffodil Centre.

High calcium levels in blood

With cancer in the bone, more calcium is absorbed into your bloodstream from your bone. A high level of calcium in your blood is called hypercalcaemia. It can cause excessive thirst, vomiting, drowsiness and confusion. To be treated, you will need to spend a day or two in hospital to get your calcium levels down. This is done by giving you intravenous fluids or drugs called bisphosphonates to stop further damage to your bone. Drinking plenty of fluids will help too. With treatment, you should feel much better after a few days.

Bone pain and weakened bones

Secondary cancer in the bone can cause bone pain. It also makes your bones weaker with a risk of fractures. Bisphosphonates and monoclonal antibodies can help to relieve bone pain as well as help strengthen them and reduce the risk of fractures. See page 42 for more information.

Radiotherapy is very good for treating bone pain due to secondary breast cancer. The treatment can be given as a single dose or divided over a few days. It can take 2–3 weeks to work.

If a bone is very weak, you may need surgery to strengthen it. This is done in hospital under a general anaesthetic. Your surgeon will put a pin into the centre of the weakened bone and might fix a metal plate to hold the bone firm as well. You will need to stay in hospital for a week or so to recover after this surgery.



Tips & Hints – taking care of your bones



- Take any medication prescribed for you
- Get regular exercise
- Make sure you are getting enough calcium in your diet. Good sources are cheese, yogurt, green leafy vegetables and sardines
- Stay a healthy weight
- Don't smoke
- Avoid caffeine and alcohol
- Take precautions around the house to avoid falls and accidents
- Take good care of your teeth and visit the dentist regularly.

Constipation

Constipation can be a common and distressing problem if you have secondary breast cancer, especially if you are taking painkillers. If you are suffering from it, talk to your doctor as soon as possible. They will want to assess it and find the cause before advising you on the best treatment.

Constipation might also be linked to a low-fibre diet, not drinking enough fluids, not eating enough, or being less active. Ask to talk to the hospital dietitian to help you plan a diet high in fibre with plenty of fluid. Gentle exercises can help to keep your bowel movements regular, so talk to your doctor or nurse for advice on what exercises you can do.

Fatigue

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

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

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

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. If you are not sleeping, talking to a counsellor may help.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy. You can also read the booklet on our website, www.cancer.ie

- 6 Try to keep living your life. Enjoy the times with your kids and family, get out and exercise, get fresh air, eat well. I found eating well a way for me to take control in a world that was out of control. It helped me with symptoms and eased my fatigue. 🍌

Marian



Tips & Hints – fatigue



- Build rest periods into your day. If you are going somewhere special, have a rest before you go out.
- Keep your energy for eating. Eat little and often and use ready-made meals or snacks.
- Wear clothes that are easy to put on and take off.
- Sit down when getting dressed or doing household jobs such as ironing.
- Do some exercise each day if possible. Ask your doctor or nurse for advice.
- Ask for help at work or around the house, especially with cooking, housework or childcare.
- Make sure your bedroom is quiet and not too hot or cold.
- Go to bed each night at the same time. Each morning get up at same time and do not lie in.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, cola or chocolate.
- Use relaxation techniques to get to sleep, like gentle exercise and relaxation

Early menopause

The nearer you are to the menopause, the more likely that chemotherapy will stop your periods permanently. An early menopause can also be a side-effect of hormone therapy or ovarian ablation if you are fertile. Your periods may become irregular or stop altogether. This can lead to uncomfortable menopausal symptoms, including:

- Hot flushes
- Night sweats
- Generalised aches and pains
- Vaginal dryness
- Lower sex drive
- Mood swings
- Poor concentration

As the early menopause has been caused by treatment, any symptoms may appear far more suddenly than if it were a natural menopause.

Some symptoms can be quite severe in some women and very mild in others. If you have a symptom and it concerns you, tell your doctor or nurse straight away.

Palliative care

During or after your anti-cancer treatment, your doctor may discuss palliative care with you.

The palliative care team are experts in managing the symptoms of advanced cancer, such as breathlessness, pain and nausea. Palliative care also offers emotional support and comfort to patients and their families. Palliative care includes end-of-life care, but your doctor may also recommend palliative care earlier in your illness, to help to manage your symptoms and improve your quality of life.

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 do not need health insurance.

Palliative care can be given in a hospice or community hospital or in your own home.

You go to a hospice for a day or two to get treatment for your symptoms or you may stay at the hospice in the later stages of your illness.

For more information on palliative care including a booklet called *Palliative care – Asking the questions that matter to me*, visit The Palliative Hub at www.adultpalliativehub.com

Talk to your doctor and nurse for more advice. Or if you do not feel well enough, your family can do so.

Cancer and complementary therapies

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

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

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

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

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

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

More information

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

“ A few weeks after diagnosis I joined a Living Well course run in ARC Cancer Support Centre. This was a life line. Everyone in the group had metastatic disease and I found it gave me a feeling of being more grounded and understood. It reduced the sense of isolation so many of us feel. ”

Sarah

Will treatment affect my sex life?

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have secondary cancer can take quite a while. It can be hard to relax as well when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment 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. Try other forms of closeness, such as touching, caressing and holding each other.

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. He or she may refer you for specialist relationships counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

There is no set time for you to be ready to have sex again. It varies from person to person. If you have any queries about how treatment may affect your sex life, do talk to your doctor.

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

Contraception

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

It's important to discuss contraception with your doctor or nurse. If your cancer is hormone sensitive, it is best not to use a hormone type of contraceptive, such as the pill.

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

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Don't be put off by thinking the question is small or trivial or that you'll be embarrassed. Your doctor and nurse are well used to talking about these matters and will give you advice. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at cancernurseline@irishcancer.ie

Treatment and fertility

Will treatment affect my fertility?

Chemotherapy and other treatments can damage your ovaries and reduce the amount of hormones made. This means that you cannot get pregnant. This infertility may be temporary or permanent. It will all depend on the type and dose of drugs used in your treatment and your age. Your periods may become irregular or stop altogether but continue to take contraceptive precautions during and after treatment.

Discuss any worries you have about infertility with your doctor before treatment starts. He or she can tell you if there are any options open to you at this time. For example, it may be possible to freeze your eggs before treatment begins. Rotunda IVF at the Rotunda Hospital in Dublin provides a service where eggs or sperm can be frozen for later use. It might also be possible to have a child before your treatment starts or to continue treatment during pregnancy.

Early menopause

Some treatments for breast cancer can affect the way the ovaries work. As a result, you may start your menopause earlier than expected, or have menopausal symptoms, such as hot flushes and vaginal dryness. For more information on the symptoms of an early menopause, see page 54.

You may find it helpful to get support from a counsellor who specialises in sexual issues. How you feel about yourself as a woman can be affected if you have menopausal symptoms. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse.

Coping with infertility

It is not easy to come to terms with infertility. It may be very distressing if you are already coping with secondary breast cancer. You may feel devastated if told that you can no longer have a child in the future. It can bring deep feelings of sadness, anger and loss of identity. You may find it helpful to talk openly to your partner or a friend about these feelings. It is important to talk to your doctor or nurse too. They may arrange for you to speak to a trained counsellor or a specialist, especially if you cannot deal with any strong emotions that you might have. Do seek professional help if infertility is likely to trouble you.

Treatment during pregnancy

Controlling the cancer or cancer symptoms during pregnancy can be a challenge for your doctor. Some treatments are not suitable if you are pregnant when diagnosed with secondary breast cancer. Do talk to your doctors about your options at this time and the timing of treatments.

The issue of pregnancy for women with secondary breast cancer is quite complex. You might worry about having a child for fear that you might not live long enough to raise the child. Or else you may believe that even if you do die, you can still give your child the love and care they need in the meantime. Talk to your doctor if you are concerned about this issue.

What follow-up will I need?

No matter what treatment you receive, you will still need to go back to hospital for regular check-ups. This is called follow-up. At each outpatient visit, your doctor will examine you and blood tests may be done. Follow-up often includes scans and X-rays. Ask your doctor if these are needed and how often they'll be done.

👉 My scans have remained stable. Treatment continues but the disease doesn't. Good news is an understatement. 🙄

Marian

The visits will allow your doctor to monitor your progress and follow up on any ongoing side-effects that you may have. He or she can also check for new side-effects that may develop. It is better to be aware of these as early as possible so that further treatment can be given.

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. That way you won't forget what you wanted to say.

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

Staying healthy

Many people want to make positive changes to their lives to stay as well as possible. Having a healthy lifestyle can help you to:

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

A healthy lifestyle includes:

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

Try to get 30 minutes of moderate activity 3–5 times a week. Ask your doctor about the type and amount of exercise that would be best for you. Some cancer support centres have exercise classes or groups. See page 77 for more about cancer support centres.

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

Exercise is very helpful in lots of ways. It can:

- Give you more energy
- Improve fatigue
- Boost your mood
- Reduce stress
- Keep you fit





Coping and emotions

How can I cope with my feelings?

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

Common reactions include:

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

Having advanced cancer has been described as ‘riding an emotional rollercoaster’ – sometimes you may feel very low, while at other times you may feel very positive and hopeful. Most people come through the initial shock and upset and find a way to cope. See page 66 for more about learning to cope.

- 🗨️ Life takes on new dimensions with this uncertainty, not all entirely negative. It makes many previously troublesome issues seem unimportant. Focus on living life in the present moment, just do those things you've always wanted to do! 🗨️

Sarah

- While some treatments can have some unpleasant side effects, people with advanced cancer sometimes find their daily lives are not affected very much.
- Often advanced cancer can be treated like a long-term illness, which causes problems from time to time.



Why me?

You may find the news that cancer has come back more upsetting than your original diagnosis. But remember nothing you have done is to blame. Even the experts don't fully understand what triggers some breast cancers to spread.

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

Anxiety and depression

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

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

👉 Get psychological support – talk to a counsellor as they can be invaluable. Ask for help. I found that hard but talking and getting help can be of huge benefit. 🙏

Marian

Counselling

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

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

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



Ways to get support

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

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

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

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

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

Talk things through: It can be a great weight off your mind to share your feelings and 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 Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre.

Learning to cope

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

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

In time, most people can adjust to life with secondary cancer.

“ I find information from conferences and literature a great crutch but I know others are more comfortable without detail. There is no correct way of coping. ”

Sarah

How can I help myself?

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

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

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

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

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

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

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

Try complementary therapies: Complementary therapies are treatments like acupuncture, yoga and aromatherapy that are given in addition to your standard treatment. They may help to relieve the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 56 for more information on complementary therapies.

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

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

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

Try to cope day by day: Secondary breast cancer can bring a lot of uncertainty into your life. It can be very difficult to face an uncertain future and feel you are no longer in control. Try to concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

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

Practical planning: It's very understandable that you might feel anxious or reluctant to talk to your family or friends about how you might like to be looked after if your cancer progresses, for fear of upsetting yourself or them. However, it can give you the chance to plan and deal with any practical concerns or worries you may have in your personal life. For more information see page 72. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice, information and support.



Positive emotions



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

How can my family and friends help?

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

Advice for carers

Caring for someone with secondary breast cancer can be difficult at times. Some patients manage well and need little practical support from family and friends. Others may need more support and care.

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

Caring for someone with cancer

Learn about cancer: Learn more about secondary breast cancer, any possible side-effects and the emotional effects it can cause. This will help you to understand how you can support your partner, relative or friend.

See our information on advanced cancer on our website, www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.

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

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

Support for you



Our cancer nurses are there to support you as a carer. Call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie for confidential support, advice and information. There is also information for carers on our website, www.cancer.ie

Looking after yourself

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

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

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

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

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

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

How to talk to someone with cancer

When someone close to you has secondary breast 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 Cancer Nurseline on 1800 200 700. Ask for a copy of our booklet *Lost for Words – How to talk to someone with cancer*. The booklet gives advice 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



Further information and support

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

Talking to children and teenagers

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

Saying nothing

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

How to tell your children

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



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

“ I am honest when talking to my family, but I don't overburden them with detail. ”

Sarah

Planning ahead

You can live for many years with secondary breast cancer and most people hope that this will be the case for them. But it can be hard to think about what might happen in the future when you have a diagnosis of secondary breast cancer. It might make you feel worried, scared or upset to think about the end of your life.

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.

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

Cancer Nurseline Freephone 1800 200 700

Support resources

Coping with the financial impact of cancer

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

Medical expenses

Medical expenses that you might have to pay include:

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

How much you pay towards your medical expenses depends on whether you qualify for a medical card and what type of health insurance you have, if any.

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

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

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

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

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

Benefits and allowances

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

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

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

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

If you have financial difficulties

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

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

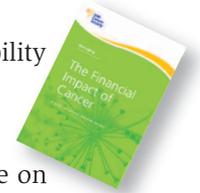
You can also call our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

More information

For more information please see our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:

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

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



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

Irish Cancer Society services

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

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

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

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

- Our **Daffodil Centres**. Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.
- Our **Living Life** programme. We provide a peer support programme for people who have recently been diagnosed with secondary cancer. The programme offers practical information, support and the opportunity to speak to trained volunteers who are living in a similar situation.

- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 77 for more information.
- **Patient travel and financial support services.** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
 - **Travel2Care** is a limited fund, made available by the NCCP, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
 - **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

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

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



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

Local cancer support services

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

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

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

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

Helpful books

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

You may find the following helpful:

Treatment and side-effects

Understanding Chemotherapy

Understanding Radiotherapy

Understanding Cancer and Complementary Therapies

Diet and Cancer

Coping with Fatigue



Coping and emotions

Understanding the Emotional Effects of Cancer

Lost for Words: How to Talk to Someone with Cancer

Who Can Ever Understand? Taking About Your Cancer

Talking to Children about Cancer: A Guide for Parents

A Time to Care: Caring for Someone Seriously Ill at Home

Managing the Financial Impact of Cancer. A Guide for Patients and their Families



What does that word mean?

Adjuvant treatment	Treatment for cancer given soon after surgery.
Ascites	An abnormal amount of fluid in your abdominal peritoneal cavity.
Alopecia	Loss of hair. No hair where you normally have hair.
Anti-emetic	A tablet, injection or suppository to stop you feeling sick or vomiting.
Benign	Not cancer. A tumour that does not spread.
Biological therapies	A treatment that uses your body's immune system to fight cancer and other diseases. Targeted therapies are one form of biological therapy.
Biopsy	Removing a small amount of tissue from your body to find out if cancer cells are present.
Cells	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
Chemotherapy	Treatment using drugs that cure or control cancer.
HER2	A protein on a cell that allows a growth factor to bind to the cell, causing the cell to grow and divide.
Hypercalcaemia	A high level of calcium in your blood.
Fatigue	Ongoing tiredness often not helped by rest.
Lymphoedema	Swelling in your arm that can sometimes develop after treatment for breast cancer.
Malignant	Cancer. A tumour that spreads.

Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
Metastasis	The spread of cancer from one part of your body to other tissues and organs.
Nausea	Feeling sick or wanting to be sick.
Neo-adjuvant treatment	Treatment such as chemotherapy or radiotherapy that is given before surgery to shrink a tumour.
Oncology	The study of cancer.
Palliative care team	A team of doctors and nurses who are trained in managing pain and other symptoms caused by cancer. They will also help cope with any emotional distress.
Prognosis	The expected outcome of a disease.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Radiotherapy	The treatment of cancer using high-energy X-rays.
Targeted therapies	A treatment that uses your body's immune system to fight cancer, for example, with antibodies. They belong to a wider group of drugs known as biological therapies.
Spinal cord compression	If the cancer spreads to the bones in your spine, it can press on your spinal cord and nerves. This can lead to paralysis, incontinence and numbness.
Staging	Tests that measure the size and extent of cancer.

Questions to ask your doctor

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

- What tests do I need?
- How long will it take to get the test results?
- What type of secondary breast cancer do I have?
- What treatment will I need?
- What is the goal of this treatment?
- Are there other treatment options?
- What can I expect to happen if I choose not to have this treatment?
- What side-effects will I get from the treatment?
- Am I a candidate for a clinical trial?
- Is there anything I can do to help myself during treatment?
- Can my symptoms be controlled?
- How will I know if the treatment is working?
- On average, how long does this treatment usually work?
- What happens if the treatment stops working?
- What problems should I report to you?
- How will this treatment affect my lifestyle (family, work, leisure, sex life)?

Your own questions

1

2

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10



Notes



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 is like to organise or take part in a fundraising event

Raise money

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

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

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

Did you like this booklet?

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

More information and support

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

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

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Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

