

# Breast Cancer Treatment and Aftercare Plan



# Hello!

My name is Cathriona, in 2020 I met with people just like you that were diagnosed with breast cancer, together we developed this guide.

Hearing you have breast cancer is the beginning of a long and emotional journey.

This plan will help you navigate your journey and help answer those questions. It contains information to help you better understand your disease, tests, and treatment. It has sections for you to record your test results and the treatments you receive. A diary to keep track of your appointments and a place to record key information about you and your healthcare team.

All journeys need signposts, so we have included details of services that you can contact for support, information to support your wellbeing, hints and tips and questions to ask your healthcare team.

Knowledge is power.

Remember..."You are braver than you believe, stronger than you seem, smarter than you think, and twice as beautiful as you'd ever imagined".

All our love,

Cathriona and team.

First Edition: September 2020 Cover Artwork: ©Riona Kearns 2020





#### Compiled by Dr Cathriona Kearns, PhD, AMRSB.

This project has received funding from the European Union's Horizon 2020 Research and innovation Programme under the Marie Skłodowska-Curie Co-funding of regional, national and international programmes Grant agreement No: 713279.



#### Designed with love by Kay McKeon.

Owner and Creative Lead at Letter Eleven Design, Breast Cancer Survivor and Cancer Patient Advocate.

# **Contents**

Se	ction 1 - Breast Cancer Explained	07
Giv	es you information about breast cancer.	
Se	ction 2 - Key Information & Treatment Plan	17
typ It a hea	s is your treatment plan. It helps you keep a record of your e of cancer, treatments you receive and aftercare you need. Iso is where you keep key contact information for your althcare team and your own essential information such as o to contact in an emergency, health cover, etc.	
At (	each step fill in your results with your medical team. Step 1 Fill in after your diagnosis tests. Step 2 Fill in at each stage of your treatment. Step 3 Fill in at the end of your hospital treatment.	
Se	ction 3 - Appointments Diary	47
	ır appointments diary, radiotherapy, chemotherapy, and ow-up appointment trackers.	
Se	ction 4 - Diagnosis and Results	59
	Information on tests for diagnosing your cancer and helps explain your results in <b>Step 1 of your treatment plan</b> Hints, tips and questions to ask your medical team at this stage.	
Se	ction 5 - Treatments	73
	Information on how breast cancer is treated and treatments you may receive. This section helps explain <b>Step 2 of your treatment plan.</b> Hints, tips and questions to ask your medical team at this stage.	
Se	ction 6 - Aftercare	91
	Information on aftercare and helps explain  Step 3 of your treatment plan.  Some useful resources.	

# Layout of your plan

This plan is a guide to your breast cancer diagnosis (how it is identified), treatment, and aftercare. It will help you keep track of your results and be a personal diary of your health care and wellbeing.

If English is not your main language or you do not understand ask for an Interpreter or someone to help you at the hospital.

Your cancer diagnosis and treatment will happen in stages. The plan calls these steps. Each step has a section in the plan.

# Step 1

Is about the tests that you may need to diagnose your cancer.

# Step 2

Is about the treatments that you may get to treat your cancer.

# Step 3

Is about your aftercare and wellbeing.

# Look out for these symbols

This symbol gives you questions you can ask your medical team.





This symbol gives you a tip or a reminder.

**Each section has a pocket** where you can insert leaflets. You can also add leaflets or more notes to the file by punching a hole in them and clipping them into it.

You should take this file with you to all healthcare or wellbeing appointments that you attend.

Don't be afraid to **ask the medical professionals to write things down for you** if you do not fully understand them. Medical professionals will be happy to help.

Notes	

# Section 1

# **Breast Cancer Explained**

Everyone's breast cancer is slightly different.

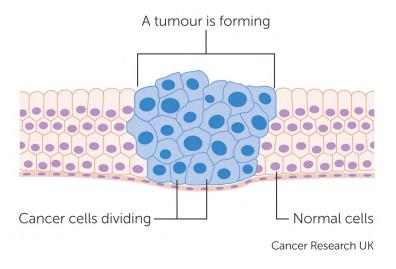
This section will help you and your loved ones answer some of the questions you may have on; what is breast cancer, how does it spread, are there different types, and why breast cancers are not all the same.

It will help you understand some of the medical terms you may hear mentioned at your hospital visits.

#### What is breast cancer?

Cells make up the organs and tissues of our bodies. We need cells for our bodies to grow, heal and repair. We do not know it or feel it, but our cells are always dividing to make new cells.

When we get cancer, the cells start to grow and multiply out of control and they can sometimes attack and destroy the healthy cells in our tissues or organs. They can lump together (like the blue part in the diagram below) and that lump is called a **tumour.** 



This type of tumour is called **malignant** because the cells that make it are not normal cells but are harmful cancer cells. The tumour (lump) can grow into nearby tissue. Sometimes bits of it can break off and travel through the blood or the lymphatic system in our body to other parts of the body where it grows another tumour. When this happens, the new tumour is called a **secondary cancer** or a **metastasis**.

#### Where does the cancer start?

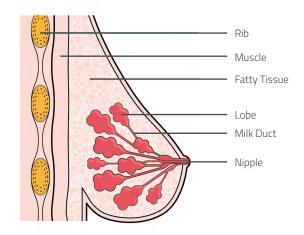
Your breast is made up of three main parts, they are called: **Lobules, Ducts** and **Fatty tissue**.

The lobules (sometimes called lobes) are the glands that make milk.

Milk is carried to the nipple through fine tubes called ducts.

The fatty tissue surrounds and holds everything together.

Most breast cancers begin in the milk **ducts** or **lobes**. (See diagram below).

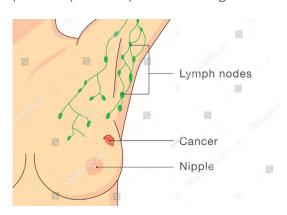


# How can breast cancer spread?

Your breast tissue joins into your lower armpit which has **Lymph Nodes** (sometimes called lymph glands) in it under the skin. These nodes or glands are part of a system in your body called the lymphatic system, that protects you from infection and disease. The lymphatic system is like a drainage system for your body. It collects fluid and waste material from your body tissues and drains it through your veins back into your blood. The lymph nodes look like small beans and they filter out the germs and disease from the fluid.

The lymph nodes in your armpit closest to the breast are known as **axillary nodes**. The first lymph node that the breast drainage (lymphatic) system drains into is called the **sentinel node**.

If the cancer cells have spread outside your breast, it is likely that they will travel through the sentinel node first before moving to other lymph nodes. You will usually have tests to check if there are any cancer cells in these lymph nodes. If there are no cancer cells found in the lymph nodes it is less likely that your cancer has spread to other parts of your body. (See the diagram below)



# How do I know what type of breast cancer I have?

There are many things about your cancer that you and the doctors need to know to help you get the best treatment.

- Where abouts in your breast is the tumour (lump)?
- Have the cancer cells spread outside your breast?
- How fast is the tumour growing?
- What is helping the tumour grow?

The tests that you will have done will help answer some of these questions.

# What are the main types of breast cancer?

There are different types of breast cancer. The most common types are as follows:

#### **Ductal Carcinoma In Situ (DCIS)**

This is the earliest type of breast cancer. It is not invasive meaning the cancer cells are in the ducts of the breast, but these cells have not spread into your normal breast tissue.

#### **Invasive Breast Cancer**

This means the cancer cells have moved outside where they started to grow in the breast ducts or lobules into nearby tissue in your breast. Invasive breast cancer has the potential to spread to other parts of the body.

# **Invasive Lobular Breast Cancer**

This type of invasive cancer is where the cancer cells started in the lobules of the breast, but they have spread from there to nearby tissue in your breast.

#### Invasive Ductal Breast Cancer

This is where the cancer cells grow outside the ducts in the breast into other parts of breast tissue.

## **Triple Negative Breast Cancer**

Triple negative breast cancer is a type of cancer that does not have any of the receptors commonly found in breast cancer.

Some cancer cells have proteins called receptors on them that hormones or a protein called HER2 can attach to and encourage the cells to grow. There are many treatments that can be given to block these receptors. Triple Negative breast cancer does not have any of these usual receptors meaning some treatments, like hormone treatment, will not be useful for this type of cancer.

# **Inflammatory Breast Cancer**

This is when cancer cells grow and block the lymph vessels in the skin of the breast. The breast then becomes inflamed and swollen

#### Angiosarcoma

This is a rare breast cancer that starts in the cells that line blood vessels or lymph vessels.

# How big and fast growing is my cancer?

To answer this question the cancer specialists will need to know information on your cancers Stage, Grade and Receptors. They get this information from the tests that you have done at the hospital.

# Stage

The stage of a cancer describes the size of the cancer and how far it has spread. Your breast cancer may be described as Stage 1, Stage 2, Stage 3, or Stage 4. They will be written as Stage I, Stage II, Stage III, or Stage IV. To decide what stage your cancer is at the specialist looks at the size of your **T**umour and scores it between 0-4 (0 = small).

They also look to see if there are cancer cells in your lymph N odes and score them between 0-3 (0 = no lymph nodes have cancer cells).

They also look to see if the cancer has **M**etastasised (spread to other parts of your body).

This is called **TNM** staging. Based on these TNM results your cancer will be given an overall stage between 1 and 4.

# Stage I cancer is usually called 'Early stage cancer'.

The tumour is generally small, and most times has not spread beyond the breast. If cancer cells are found in the lymph nodes, they are usually in small numbers

# Stage II cancer is also usually called 'Early stage cancer'.

The tumour size may be slightly bigger than stage 1 and is usually between 2 cm but no more than 5 cm in size.

The cancer can be found in the breast or sometimes there is no tumour in the breast, but cancer cells are found in the nearby lymph nodes, or it can be in both the breast and in nearby Lymph nodes.

**Stage III cancer is usually called 'Locally advanced cancer'.** This means the cancer has spread to more lymph nodes than in Stage II and sometimes it has spread to other areas of the breast such as nearer the skin. Sometimes the tumour size is bigger than 5 cm.

**Stage IV usually means the cancer has spread to other parts of the body.** This is sometimes called 'Advanced cancer' or 'Secondary breast cancer' or 'Metastatic breast cancer'.

#### Grade

The grade gives an idea of how slowly or quickly the cancer might grow. The grade is based on how the cancer cells look under a microscope compared with your normal cells.

# **Grade 1** (low-grade cancer)

The cancer cells look like your normal cells. They usually grow slowly. These cancer cells are less likely to spread.

**Grade 2** (moderate or intermediate-grade cancer) The cancer cells look more abnormal and grow slightly faster than grade 1 cells.

# **Grade 3** (high-grade cancer)

The cancer cells look quite different from your normal cells. They generally grow more quickly than grade 1 or 2 cells.

# **Receptors**

Some breast cancer cells have receptors (proteins) that hormones or a protein called HER2 can attach to and help the cancer cells grow. When you have your biopsy, the laboratory will test to see if these are present. If the test is

positive that means your cancer cells have these receptors and your doctor may recommend treatments that block them to help slow down the growth of the cancer.

The main hormone receptors involved in breast cancer are:

**'Oestrogen receptor' sometimes written as ER+ or ER-**Oestrogen is a hormone that plays an important role in the female reproductive system. It helps to control the menstrual cycle. Sometimes breast cancer cells contain oestrogen receptors, if they do this is known as oestrogen receptor positive (ER+) breast cancer, if they do not it is known as oestrogen receptor negative (ER-) breast cancer.

It is written ER because the American spelling of Oestrogen is Estrogen. You may be offered hormone (sometimes known as endocrine) therapy (treatment) to block the effect of oestrogen and slow down the growth of breast cancer if your result is positive.

# Progesterone receptor sometimes written as PR+ or PR-

Progesterone is also another hormone in the body but we have it in smaller amounts than oestrogen. Sometimes tests are done to see if there are any progesterone receptors. If progesterone receptors are there this is known as progesterone receptor positive (PR+) breast cancer.

The benefits of hormone therapy are less clear for people whose breast cancer is progesterone receptor positive (PR+) but oestrogen receptor negative (ER-). Very few breast cancers fall into this category but if this is the case your specialist will discuss with you whether hormone therapy is appropriate.

# Human epidermal growth factor receptor 2 sometimes written as HER2 positive or HER2 negative

Some breast cancer cells have a higher than normal level of a protein called HER2 on their surface which also helps the cancer cells to grow. If HER2 is found on the cancer cells this is known as HER2 positive breast cancer, if it is not then it is known as being HER2 negative breast cancer. Around one in five invasive breast cancers are HER2 positive.

Cancer that does not have receptors for HER2 or oestrogen or progesterone is called triple negative breast cancer. This type of cancer affects up to 1 in 5 women with breast cancer and is more common in younger women.

# **Summary**

After you have a biopsy or surgery samples are taken and sent to the laboratory to get a description of your tumour based on stage, grade, and receptors. This is called getting the **histology** of your tumour.

Knowing this helps decide the best treatment for you.

When you visit your cancer doctor or nurse and get a test result ask them to fill in Step 1 on your treatment plan form.

This will be your record. You may need it later.

# Section 2

# Key healthcare contacts and my treatment plan

It is important to keep a record of your type of breast cancer, what treatment you received and what support you need and all your healthcare contacts.

# **Key healthcare contacts**

Keep a record of all your healthcare contacts here.

Key Contacts	Name	Telephone
General Contacts		
Hospital		
Cancer clinic		
Oncology day ward		
Out of hours		
Family doctor (GP)		
Daffodil Centre		
Radiotherapy Conta	acts	

Radiotherapy Contacts		
	ts	

Key Contacts	Name	Telephone		
Medical Contacts				
Consultant (Oncologist)				
Nurse specialist				
Surgery Contacts				
Surgeon				
Surgeon secretary				
Nurse specialist				
Other Contacts				
Psych-oncologist				
Social worker				
Support groups				
Physiotherapist				
Occupational Therapist				
Dietitian				

# **My Treatment Plan**

#### **About this form**

It is important to keep a record of your type of breast cancer, what treatment you received and what support you need.

Ask your medical team to help fill in the form with you.

The form is divided into three parts called Steps

Step 1 is about your diagnosis (your type of cancer).

Start filling in this part of the form once you start getting tests at the breast clinic.

- You fill in the section **Personal Information** on this form.
- Your contact details and essential information.
- Medical History record any medical conditions you have.
- My Medication record any tablets or medication you take.
- Family History of Cancer record any family member that had cancer.
- Ask your cancer doctor or nurse to fill in the section on 'Diagnosis' when you start to get results back from your tests.

# Step 2 is about treatments that you will receive for your cancer.

Fill in this part of the form with your breast care team when you start any treatments for your cancer.

Step 3 is about your aftercare.

You will see questions on the form that you can ask, they will have this symbol beside them.



Personal and Contact Information			
Title:	First name:	Last name:	
Address:			
Home ph	one number:		
Mobile:		Work phone:	
Email:			
Date of b	irth:	Country of birt	th:
Main lang	guage spoken:		
Relations	hip status (please tick)	Single	Married
	Widowed	Divorced	Separated
Do you ha	ave children? Yes	No 🗌	
Age/s of o	children:		

Person to contact in Emergency		
Name:		
Relationship to you:		
Home phone:	Work phone:	
Mobile:		
Second contact person (in c	ase first cannot be contacted)	
Name:		
Relationship to you:		
Home phone:	Work phone:	
Mobile:		
Health cover details		
Private health insurance		
Company:	Policy number:	
Level of cover:	Date joined:	
Medical card number:	Date of Expiry:	
·		

# Hospital record numbers

If you know your record numbers for treatment hospitals you have attended, include them here.

Hospital name:
Hospital record number:
Name of my breast clinic:

# **Medical History**

Use this section to record information about any past and current health conditions that you have – such as arthritis, high blood pressure, asthma, diabetes, heart trouble, angina, depression etc. or any other medical conditions. Include any past surgery you had or if you have been to counselling.

Medical history		

Medical history continued

# Medication

Use this page to write down the names of any tablets or medication that you have been prescribed or take regularly, include any vitamin tablets you take regularly. Also write down what you are taking them for.

Reason for taking it	Prescribed by	Frequency and Dose

# Family history of cancer

Most people who get breast cancer do not have a family history but some people have a higher risk of getting breast cancer because there may be a faulty gene running through their family.

The chance of there being a family link is bigger when several of your family members have been diagnosed with breast cancer or with other cancers like ovarian cancer or bowel cancer.

The most common genes that can change and cause breast cancer are called BRCA1 and BRCA2. You may be offered a test (called a genetic test) to see if you have these genes if there is a strong family history of cancer.

At the clinic you may be asked about first and second-degree relatives and if any of them had cancer. A first degree relative is your parent, brother or sister, or your child. Second degree relatives are aunts, uncles, nephews, nieces, grandparents, and grandchildren.

Women with triple negative breast cancer are sometimes offered genetic testing. This is offered even if they do not have a family history of breast cancer because most breast cancers caused by a change in the BRCA1 gene are triple negative.

Make a note of family members that had cancer and how they were related to you on next page.

Name of relative	How are they related to you?	Type of cancer they had?

# **Step 1 – Diagnosis**

Ask your doctor or nurse to fill in this section with you. Go to **Section 4 -Step 1** to get an explanation of the tests used to diagnose breast cancer to help you understand your results.

# At the first visit to the clinic which of these did I get done?



Procedure		Result	
Mammogram		Yes	No
Ultrasound		Yes	No
Biopsy		Yes	No
In layman terms what	t do my results r	nean:	
Cancer Type/Histolog	y Subtype:		
Diagnosis Date:			

	Expert
What type of cancer do I have?	
Invasive breast cancer	
Invasive lobular breast cancer	
Triple negative breast cancer	
Ductal Carcinoma In Situ (DCIS)	
Inflammatory breast cancer	
Angiosarcoma of breast	
Other rare type	
	Ask The Expert
<b>Location:</b> Which breast is the cancer in?	
Left Right	
Both breasts	



# **Stage:** What stage is my cancer?

Overa	all Sta	ge						
I		II		Ш		IV		
Breal	kdown	of st	aging.	Tumo	ur size	(T)		
ТО		T1		T2		T3	T4	
Node	s-in ly	mph	nodes	(N)				
NO		N1		N2		N3		
Metastasis <b>(M)</b> – Spread to another part of body								
Yes		No						
							Ask T	
							Expe	
Grad	e: Wha	at Gra	de is r	ny car	ncer?			
1. Lov	v grade	<u> </u>						
2. Inte	ermedi	ate gr	ade					
3. Hig	h grad	е						

# **Hormone Receptor status:**

Is my cancer ER positive or ER negative?
Is my cancer HER2 positive or HER2 negative?

Oestrogen				
Positive (ER+)	Negative (ER-)			
Not known/Not applicable				
Progesterone				
Positive (PR+)	Negative (PR-)			
Not known/Not applicable				
Human epidermal growth factor receptor 2 (HER2)				
op:200:1101 8:01101 100				
HER2 Positive	HER2 Negative			
_	HER2 Negative			
HER2 Positive	HER2 Negative  ent			
HER2 Positive  Familial Cancer Risk Assessm Breast and or ovarian cancer	HER2 Negative  ent			
Familial Cancer Risk Assessm  Breast and or ovarian cancer in 1st or 2nd degree relatives:	HER2 Negative   ent  Yes No			

30

Ask The

Expert

Notes	
	—

# **Step 2 – Treatment**

Ask your doctor or nurse to fill in this section with you as you get each type of treatment. **Section 5 – Step 2** helps explains your treatment and your results.

Ask The Expert
Surgery: What type of surgery will I have?
Surgery: Yes No
Surgery Date(s):
Type of Surgery:
Mastectomy Lumpectomy
Ask The
Do I need treatment before surgery? If so, what type will I need?
Neo adjuvant treatment (treatment before surgery)  Yes  No
Treatment type:
Start date: End Date:

# **Surgical procedure/findings:**



Was there cancer in my lymph nodes? What type of procedure did I get?

Lymph Node Removal						
Positive Negative	N	ot knowr	n/Not	appli	icable	
Axillary Dissection						
Positive Negative	N	ot knowr	n/Not	appli	icable	
Sentinel Biopsy						
Positive Negative	N	ot knowr	n/Not	appli	icable	
<b>Oncotype DX test:</b> Am I eligible for the Onco	otype D	)X test?			sk The expert	
Eligible for Oncotype D	K test:	Yes		No		
Recurrence Score:						
Advised to get chemothe	erapy:	Yes		No		

What type of radiation did I receive?
What is meant by the dose/fractionation?
(ask your radiation consultant or radiation therapist)

	Ask The	
	Expert	
1		

Radiation:	Yes	No	
Start date:		End date:	
Туре			
External Beam (EBF	RT)	Brachytherapy	
Other			
Dose/fractionation:	:		
Area treated:			

What types of treatment did I receive?
What are the most likely side effects of the treatment? How long will the treatment take? (ask your consultant). Am I eligible for a clinical trial?

Systemic Therapy:

Yes

No

<b>Systemic Therapy:</b> Yes		No	
Start date:		End date:	
Туре			
Chemotherapy		Hormonal therapy	
Other			

Name of treatment	Duration	Any side-effects YOU had to drug note here

Notes		
Ongoing Treatmen	nt	
Name of treatment	Duration	Any side-effects to look out for

# Should I take additional vitamins or supplements with my cancer treatment?

	Ask The	
. 7	Expert	
?	7	

Yes		No	
tamin D		Other	
suppleme	ents pre	scribed:	
	tamin D	tamin D	

# Complementary and alternative therapies

Some people with cancer find it helpful to try complementary therapies. Some methods can be used safely with your standard treatment others can interfere with it. Always discuss with your medical doctor before you change your treatment or add on any methods of your own.

					Experi	
Complementary a	nd alto	ernative	thera	oies	-	
Is the patient using alternative treatme			Yes		N	0
Туре:						
Diet therapy 🗌	Megav	vitamin t	herapy		Herbalisı	m 🗌
Other please list						

39

Tell your cancer doctor if you have any side effects. Some have been listed below but discuss any others you might have.

Ask The Expert

# Persistent symptoms or side effects at completion of treatment:

Fatigue	Yes	No
Menopausal symptoms	Yes	No
Numbness	Yes	No
Pain	Yes	No
Psychosocial/Depression	Yes	No
Other (please list below):		

Notes	

# Step 3 – Follow up and after care

Ask your doctor or nurse to fill in this section with you. Go to **Section 5 – Step 3** to get suggestions on looking after yourself after your treatment.

You will need to come back to the hospital to have check-ups and to have some scans.

Ask The Expert

# **Schedule for Clinical Visits**

Type of test	How often	Who with	Where do I get it

		Ask The Expert
Breast follow up screening		
Annual Mammogram	Yes	No 🗌
Annual MRI Other	Yes	No 🗌
Bone density	Yes	No 🗌
GP check-up	Yes	No 🗌
Other	Yes	No

Breast cancer survivors may experience issues with the areas listed below. Sometimes it can be hard to talk to the people closest to you. It is important to get help.

It is normal for people that get a cancer diagnosis to face emotional or mental health, parenting, work/ employment, financial, and/or insurance issues.

If you experience any of the following discuss with your cancer doctor or breast care nurse and ask who to contact if you need or would like additional help.

Issue	Contact	Expert
Anxiety or depression		
Emotional and mental health		
Memory or concentration loss		
Fatigue		
Fertility		
Sexual Functioning		
Physical functioning		
Lymphoedma		
Weight changes		
Financial advice or assistance		
Insurance		
Parenting		
Work /School		
Other		

Several lifestyle/behaviours can affect your ongoing health, including the risk of the cancer coming back or developing another cancer.

Discuss with your breast care nurse or doctor how you can stay healthy and who to contact if you need or would like additional help or information in any of these areas:

		Expert
Issue	Contact	
Alcohol use		
Diet & eating healthy		
Management of my medications		
Management of my other illnesses		
Physical activity		
Sunscreen use & protection from the sun		
Tobacco use/stop smoking		
Dental care		

like support wit	h list below:
	like support wit

# Section 3

# My Appointment Diary and Trackers

It is important to keep a record of your appointments and meetings.

# **My Diary**

Appointments and meetings				
Date	Where	Reason		
-				

Appointments and meetings				
Date	Where	Reason		

# **Radiotherapy Tracker**

Total number of radiotherapy sessions			
Date	Where	Reason	

Total number of radiotherapy sessions		
Date	Where	Reason

# **Chemotherapy Diary**

Chemotherapy is given in cycles with a rest in between each cycle. It is a good idea to keep track of the days and which cycle you are on.

Total number of chemotherapy cycles I had:	
Name of drugs I was given:	

Date & Day	Cycle number	Notes
1st January 2020 Day 1	1	Felt a bit sick nurse give me anti- sickness tablet and felt much better afterwards

Date & Day	Cycle number	Notes

# **Follow-up Diary**

You are responsible for keeping a record of all your follow-up appointments after your treatment finishes.

You need to let your cancer clinic know if you change your GP.

Year	Mammogram		GP Ch	eck-up
	Date	Result	Date	Result

Mammogram		GP Cho	eck-up
Date	Result	Date	Result

Year	Mammogram		GP Cho	eck-up
	Date	Result	Date	Result

My Notes	Medical Advice
·	
Six Month Review	
	team about any areas needing support
Six Month Review Talk to my medical My Notes	team about any areas needing support  Medical Advice
Talk to my medical	

# Nine Month Review Talk to my medical team about any areas needing support

My Notes	Medical Advice

#### **Twelve Month Review**

Talk to my medical team about any areas needing support

My Notes	Medical Advice

# Section 4

# Step 1 Diagnosing Your Breast Cancer

This part of the plan tells you about the tests that you may have to get done to identify what type of breast cancer you have.

You may not have to get all the tests mentioned.

Fill in the **Step 1 part of your treatment plan** with your cancer doctor or nurse to keep track of your results.

At the end of this section are questions you might want to ask your cancer doctor or breast care nurse

# First stage diagnosis sometimes called the 'Triple Assessment'

You have been referred to the hospital to have some tests to see if you have breast cancer.



Bring a friend or family member with you to the clinic if you can for support.

The tests you have will confirm whether you have cancer. These tests will tell if your cancer is invasive (has spread or the potential to spread), the **Grade** of your cancer and whether there are **Receptors** present.

At the breast clinic in the hospital you will see a specialist breast doctor or a nurse practitioner. They will ask you about your signs and symptoms and ask you about your past medical history.

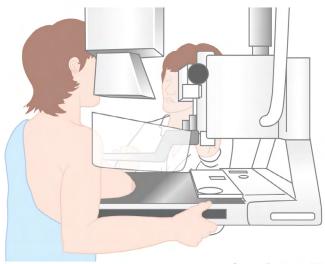
The doctor or nurse will examine your breasts and the lymph nodes in your armpits and around your neck. They will then explain what type of tests you will need.

You may have many of these tests on the same day. You may get some results on the day, but other test results take longer.

Tests that you may have to get are explained in this section.

# Mammogram

A mammogram is an X-ray of the breasts. This test takes a photograph of the inside of your breast and shows if there are any abnormal looking areas.



Cancer Research UK

# What happens during a mammogram:

You will be asked to take off your clothes from the waist upwards and you might be asked to put on a hospital gown.

The radiographer (the person taking the X-ray) will position your breast between 2 flat plates on the machine. The plates press on your breast so an X-ray image (like a photograph of the inside of your breast) can be taken from the top and the side of your breast.

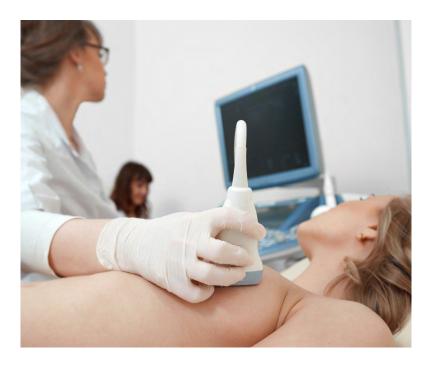
You will feel some pressure, and this can be uncomfortable, it only lasts a few minutes and does not harm the breast. You can get dressed straight after the mammogram. Some

women can experience some tenderness in their breast for up to a few hours afterwards.

Mammograms are usually only used for women over the age of 40. They are not as helpful in younger women, or in women who are on hormone replacement therapy (HRT) because the breast tissue is denser, and it is more difficult to find abnormalities. If you are under 35, your specialist is likely to suggest that you have an ultrasound instead of a mammogram. Some women may need to have both an ultrasound and a mammogram.

#### **Ultrasound**

An Ultrasound is another way of taking an image of the inside of your breast.



# What happens during an Ultrasound:

You will be asked to take off your clothes from the waist upwards you may be asked to lie down. A gel is applied to your breast, this may feel a bit cold. The person taking the ultrasound will then pass a wand-like device over your breast. This is what takes the picture of the inside of your breast.

Breast ultrasound is painless and only takes a few minutes. You can get dressed straight afterwards. It is not unusual to have both a mammogram and an ultrasound.

# **Breast Biopsy**

If the X-ray/scan shows abnormal cells you may need to have a biopsy.

This is where a small sample of cells or tissue is removed from your breast and sent to the laboratory where a specialist doctor called a **pathologist** will examine the sample to check for cancer cells.

The biopsy may be done on the same day as the X-ray/ Scans. Biopsy tests are used to tell whether your cancer is invasive or not, the grade of cancer you have and whether the cells have receptors.

There are several different types of biopsy. Your specialist doctor or nurse will explain which one they will use to get the sample. Almost all biopsies will create some bruising that will go away in a few days.

Before a biopsy you may get a local anaesthetic. This is an injection that will numb the area, this is so you feel no pain and you will be awake.

# The different types of biopsy are listed below.

## Fine needle aspiration (FNA)

This is a quick, simple test. The doctor or specialist nurse puts a very fine needle into your breast and takes a sample of cells into a syringe.

# **Needle (core) biopsy**

Your doctor or nurse uses a hollow needle to take the sample. You will first get an injection of local anaesthetic into the area in your breast to numb it. Sometimes the specialist may use an ultrasound or mammogram to guide where to take the sample. They will then insert a needle and withdraw a sample of cells. You may feel a sensation of pressure for a short time during the biopsy.

# Vacuum-assisted biopsy (VAB)

This type of biopsy removes a bigger sample than the previous needle biopsies. You will have to remove all your upper clothing and you will have a mammogram to pinpoint the area to sample.

You will get an injection of local anaesthetic into the area in your breast to numb it. When it is numb the specialist will make a small cut in your breast skin and put a needle through the cut which is attached to a suction device. This may make a small vibrating noise as it draws out the sample of cells. It may be a little uncomfortable, but you should feel no pain. If you feel pain let the specialist know. You may need a paper stitch where the cut was made.

#### A punch biopsy

You may have a punch biopsy if your breast is red or inflamed and the doctor thinks you could have inflammatory breast cancer.

You will have to remove all your upper clothing and lie down on a couch. You will be given a local anaesthetic to numb the skin. When the area is numb the doctor will take a small circular area of your skin using a small cutting device. You may feel some pressure on the breast, but it should not be painful, if you feel pain let the doctor know. You may need a paper stitch where the cut was made.

# **Excision biopsy (surgical biopsy)**

Occasionally, the doctor may decide to remove the lump or abnormal area. To do this you will need to have an operation that is usually done under general anaesthetic but can sometimes be done under local anaesthetic. You will have to come back a different day for this procedure.

# Wire guide biopsy.

If the doctor cannot see on the X-ray images a clear lump, but there is an abnormal area in the breast, they may use this type of biopsy.

This involves putting a wire into the breast tissue to show the surgeon which piece to remove. You will have a local anaesthetic to numb the area and the wire is inserted under the skin in your breast and the end is taped to your skin to stop the wire coming out. You will have to come back a different day for this procedure.

On the day of your operation you will have a general anaesthetic and the surgeon will remove the abnormal area. You may have a paper stitch over the wound. You can usually go home later in the day. Your nurse will tell you how to look after the wound.

#### **Getting your test results**

Waiting for test results is always an anxious time. It can take from a few days to a couple of weeks to get the results.

You may find it helpful to talk with your partner, family, or a close friend. You may want to contact a cancer support group in your local area to talk with others going through a similar experience.



It is normal to feel anxious, upset, and worried about what will happen next.

If you want to talk to someone in confidence after you leave the hospital you can call the **Irish Cancer Society Cancer Nurse line Freephone 1800 200 700**. This service is free and is confidential or If you prefer you can visit the Daffodil Centre at the hospital.

# Next stage of diagnosis – additional tests

If the biopsy results show there are cancer cells, you will need more tests before you start treatment. The results of these tests are used to tell you more about the cancer such as the **Stage** of the disease.

## Types of tests you may need are:

#### **Blood samples**

To check your general health and how well your kidneys and liver is working.

#### MRI scan

An MRI scan may be done to find out the size of the cancer and help doctors decide which operation you should have.



# What happens at an MRI scan?

An MRI scan is painless and takes about 30 minutes. You may be given an injection of dye into your arm before the scan to help give a better image. You will lie on a couch (like

in the picture above) and when the scan starts the couch will move inside the tunnel-like machine. The machine will take pictures as you move through it. The machine is quite noisy, but you will be given earplugs / headphones to wear during it and you can listen to music to block the noise out.

Once you are in the right position, your radiographer leaves the room before starting the machine. They can always see you through a window and you will have an intercom so you can talk to each other. The scan is painless, but it can be difficult to stay still.



Closing your eyes when you are in the tunnel can help you relax.

#### Bone scan

You may be offered a bone scan.

# What happens at a Bone scan?

You will have a small amount of a radioactive substance injected into a vein. You will need to wait for 2 to 3 hours after the injection before you can have the scan.

You will be asked to lie down on an X-ray table. A camera will then scan your entire body. Abnormal bone absorbs more radioactivity than normal bone, so these areas will show up on the scan as 'hot spots'. The scan can also show bone changes like arthritis. The scan is painless, and you will be able to go home afterwards.



Having someone with you or bringing a book or magazine or music to listen to can help pass the time.

If you are planning on going through an airport in the days following this type of scan bring your appointment letter with you. Some airport scanners may detect any small amounts of radiation in your body.

#### CT scan or PET scan

You may be offered a CT or a PET scan. These scans also help identify if the cancer has spread to other parts of your body by giving a more detailed picture of the tissues in your body.

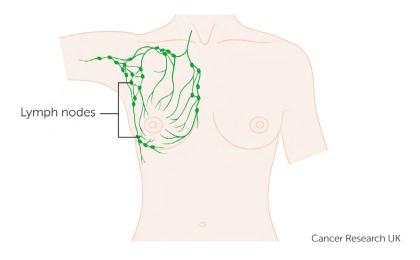
# What happens at the scan?

You may be given a drink or an injection of a dye (radioactive sugar in the case of a PET scan), which helps make the images clearer. This may be given to you about an hour before the scan if it is a PET scan.

You lie on a couch that passes forwards and backwards through a large doughnut-shaped machine. The scan is painless, but you will have to lie as still as possible. The radiographer leaves the room before starting the machine. They can always see you through a window and you will have an intercom so you can talk to each other. The scan takes 10–30 minutes.

## Lymph node ultrasound scan and biopsy

You may be offered an ultrasound scan of your armpit to check the lymph nodes in this area. The scan is painless and only takes a few minutes. A gel is applied to your armpit and a wand-like device will be passed up and down your armpit. Sometimes this is done at the same time as the breast ultrasound.



## Lymph node biopsy

If the lymph nodes look abnormal, a biopsy (tissue sample) will be taken to see if the cancer has travelled to the lymph nodes.

## What happens at the biopsy?

To do this you will first get a local anaesthetic to numb the area and when it is numb a thin needle is inserted to take the tissue sample.

It may be a little uncomfortable, but you should feel no pain. If you feel pain let the specialist know. You usually can go home afterwards. You will have a small dressing over the biopsy area.

## **Summary**

**Step 1 is now finished.** You should ask your nurse or doctor to fill in the details in the Step 1 part of your treatment plan form. This is your record of the results.

After the tests have been completed the medical team will meet to discuss your test results and they will suggest a plan for your treatment.

## Ask The Expert

## **Questions to ask**

- How long until I get my results?
- How will I get the results that I will not be given today?
- What pain relief can I take if my breasts get sore when I go home?
- Ask your nurse or doctor for their name and phone number and write it in your key contacts
- Ask your nurse or doctor to fill in any results you got in the Step 1 part of your treatment plan form under 'Diagnostics'
- If you do not understand what the doctor or nurse is saying about your results, ask them to write it in layman terms for you at the top of the Step 1 form.

Notes		

## Section 5

# Step 2 Treating Your Breast Cancer

This part of the plan tells you about the types of treatments (sometimes you will see them referred to as therapy, which means a course of treatment) used to treat breast cancer.

#### **Breast cancer treatments include:**

- Surgery
- Radiotherapy
- Chemotherapy
- Hormone therapy
- Immune type therapy or a combination of these.

The type of treatments you will get will depend on your type of cancer.

Fill in the **Step 2 part of your treatment plan** with your cancer doctor or nurse to keep track of your treatments and results.

### **Treatments**

Surgery is often the first treatment for breast cancer. Some people may be given a treatment (chemotherapy or hormonal therapy) before they can have surgery. This may be needed for example, to reduce the size of a large tumour. This is called getting a **Neoadjuvant treatment.** 

Treatments that are given before surgery are called 'neoadjuvant'. Treatments given after surgery are called 'adjuvant' you may hear these terms when treatment of your cancer is being discussed.

The reason you may get a treatment after surgery is to help prevent the cancer returning.



Some treatments for cancer can affect your **fertility.** If you are considering getting **pregnant** now or in the future **before** you start treatment, ask your doctor if your treatment will affect this.

See questions at the end of this section to ask your healthcare team before starting treatment.

## Surgery

For most people breast cancer involves some type of surgery to remove the cancer from the breast. There are two main types of surgery (lumpectomy and mastectomy). The type of surgery you have depends on the size of your cancer, where it is in the breast, and what type of surgery that you prefer. Your surgeon will explain these to you in more detail.

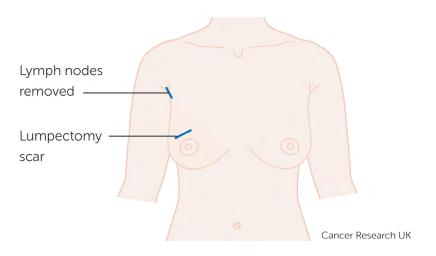
## **Breast-conserving surgery** (lumpectomy)

## What is a lumpectomy?

This is where the part of the breast containing the cancer and some normal tissue that surround it is removed. Some normal tissue is removed to check if there are any cancer cells around the edges (margins) of the tumour.

If there are no cancer cells around the edges, your report will say that there is a healthy or clear margin. If cancer cells are found in the margins you may have to go back to have more surgery.

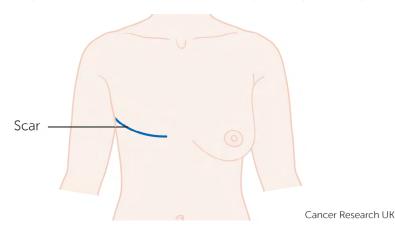
You will usually be offered a course of radiotherapy after you have this type of surgery. This is to reduce the risk of cancer coming back in the same area.



## Mastectomy

## What is a mastectomy?

This is where the whole breast is removed. Some people like to have breast reconstruction at the same time as having their breast removed. A breast reconstruction is where the surgeon creates a new breast shape by using an implant and/or tissue from another part of your body.



It is your choice if you want a breast reconstruction or not. You can have the reconstruction done at the same time when the breast is removed or you can think about it and decide to have it done at a later stage (months or years later) or you do not have to get it done at all, it is entirely up to you.

If you do not want a breast reconstruction or are not having one straight away your breast nurse will offer you a **prosthesis**. This is an artificial breast shape that you can put inside your bra to create the shape of a breast.



Artificial breast shapes are sometimes called 'softies' or 'cumfies'

You might also be offered radiotherapy after this surgery if your doctor thinks there is a risk of the cancer coming back around the scar. In this case, your surgeon might discuss delaying breast reconstruction until after the radiotherapy treatment.

You will also usually have some of the **lymph nodes in your armpit** removed to check them for cancer cells.

## **Checking lymph nodes during surgery**

## (Sentinel Lymph Node Biopsy)

Even if your lymph nodes look normal on the ultrasound, your surgeon will check them again during your surgery. The surgeon usually removes the **sentinel lymph node** and maybe 1 to 3 other nodes to check if there are any cancer cells in them.

## How are the lymph nodes checked?

This is usually done by having an injection of radioactive liquid into your breast, close to where the cancer is, before your operation. This lets the surgeon see which group of lymph nodes the dye goes to first. If the cancer cells have moved into the lymph nodes, they are also likely to go to this group first.

If cancer cells are found in the sentinel nodes, you will need to have another operation to remove most or all the lymph nodes under your arm. This is generally done about 2 weeks after you get the results from the sample taken during surgery. This is called **axillary lymph node dissection** or sometimes it is called axillary lymph node clearance.

Some people are offered radiotherapy to the armpit to destroy any remaining cancer cells instead of surgery.

Lymph node removal can cause a condition in some people called Lymphoedema. **Lymphoedema** is a swelling that can develop in your arm, hand, breast, or chest area due to a build-up of fluid. Sometimes this can happen after surgery or radiotherapy or it can appear months or even years after your treatment.

If you notice any swelling tell your doctor straight away. You can be referred to a Lymphoedema therapist to get it treated.



Sometimes the blue dye injection you get to show up the lymph nodes can make a blue stain on your breast. This will fade away In a few weeks. It also can turn your urine green for a few days.

## **Summary**

## Lumpectomy is known as breast-conserving surgery

- Only part of the breast is removed.
- You may need more than one operation if the margins are not clear.
- You will need radiotherapy after this surgery.

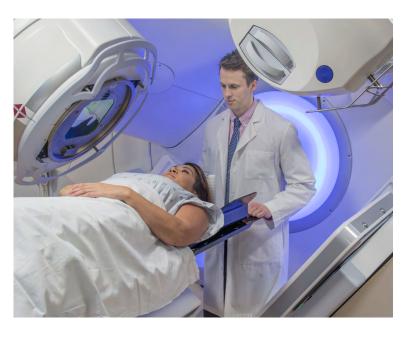
## Mastectomy is where all the breast is removed

- After breast surgery you will be offered a prosthesis to put in your bra.
- You can have a breast reconstruction which is a more permanent breast shape matching the shape of the other breast. Sometimes this can be done at the same time as your surgery. Discuss your options with surgeon or breast care nurse **Before** surgery.

## **Radiotherapy**

## What is radiotherapy?

Radiotherapy uses high-energy X-rays to destroy cancer cells. You may have radiotherapy before surgery if the tumour is big to help reduce it or you may have it after surgery to reduce the risk of cancer coming back. Radiotherapy can also be given to help reduce pain if the cancer is at an advanced stage or if it has come back.



The person who operates the machine is called a **Radiographer.** They will give you information and support during your treatment.

The person who will give you the radiotherapy is called a **Radiation Therapist**. The doctor who is the specialist in radiotherapy for cancer patients is called a **Radiation Oncologist.** 



Remember to make a note of the radiation therapist and radiation doctor name and telephone. You may need to call them at a later stage.

## There are two types of radiotherapy.

## 1) External

Sometimes called external **beam radiotherapy**. This type of radiotherapy can be given before or after your breast surgery. You lie on a bed and a large x-ray machine sends a beam of radiation onto where the cancer cells are located (like in the picture on previous page).

You may have a course of this treatment (sometimes called sessions) every day from Monday to Friday with a break over the weekend for about 3 to 6 weeks.

## 2) Internal

Sometimes known as **'brachytherapy'.** This is where the radiation is put inside your body (this is called an implant) and may be left there for a few days. You normally stay in hospital for this type of treatment.

## Radiotherapy can cause side-effects

You may feel tired, have a shortness of breath and a dry cough, some skin irritation (e.g. itchy skin or a rash) and this can last for a few weeks after the treatment has finished.

Other side-effects can happen after radiotherapy treatment has finished. For example, breast swelling and pain, lymphoedema, hardening of breast tissue (called fibrosis), change in the appearance of your breast for

example spidery marks on the skin of your breast, or weakened bones.

Your cancer doctor, specialist nurse or radiographer will tell you what to expect and what to do if you experience any of these side-effects.

## Chemotherapy

## What is chemotherapy?

Chemotherapy is a treatment that uses drugs to kill the cancer cells by disrupting the way the cancer cells grow.

Chemotherapy can be given before surgery or radiotherapy to reduce the size of the tumour, or it can be given after surgery to reduce the risk of the cancer coming back. It can also be given if the cancer is advanced (spread to other parts of the body or has come back) or is of a high grade (grade 3).



Chemotherapy can be the first treatment for some cancers like inflammatory breast cancer, triple negative breast cancer and sometimes for HER2 type breast cancers.

## How is chemotherapy given?

The drugs are usually given into a vein by an injection or by a drip. Some can be given as tablets. There are many types of chemotherapy drugs. Chemotherapy is often given as a few sessions of treatment in the hospital that last a few hours each time. Having a session of chemotherapy followed by the break is known as a cycle of treatment.

## How long will I be on chemotherapy?

The length of a cycle is usually 1 to 3 weeks but will depend on the type of chemotherapy drugs you will need. You may need many cycles and the course could last anything from 3 to 6 months. Your cancer doctor or specialist nurse will tell you how many cycles you are likely to need.

Chemotherapy can be given on its own or with other treatments for example If you have HER2 breast cancer, you may be offered a drug treatment called Herceptin with your chemotherapy.



It is a good idea to keep track of how many days and cycles of chemotherapy you have. Keep track in your chemotherapy diary in Section 3.

## What are the side-effects of chemotherapy?

Chemotherapy has many unpleasant side-effects that can affect your quality of life.

Some side-effects like feeling sick and hair loss will stop after the treatment has finished, others can last for months or even appear years later. Different chemotherapy drugs can cause different side-effects. It is important that you ask your doctor what the side-effects are before you begin this treatment.

If you start chemotherapy it is also a good idea to keep a note of your side-effects in your chemotherapy diary to tell your specialist doctor or nurse as they can give you some medications and suggestions to help ease these side-effects.



Your taste and smell might change when on chemotherapy making some food taste bitter, bland, or salty. The following can help:

- Add herbs and seasoning to food.
- Add sauces to moisten food.
- Rinse your mouth regularly.

Make homemade soups and stews on days you feel a bit better and put in the freezer for days you are not up to cooking.

Chemotherapy can make you constipated. Increase your fluids and eat food high in fibre like beans, peas, or fruit.

Chemotherapy can cause a dry mouth. Sip fluid throughout the day to keep your mouth moist. Ice-cream and milk shakes are gentle on your gums if they are sore.

## **Oncotype DX test**

## What is the Oncotype DX test?

Some breast cancer genes can affect how cancer cells grow. Oncotype DX is a test used to see how active certain genes are in the cancer tumour. This is known as a genomic test. It can only be used on some types of early stage breast cancer.

## What type of breast cancer is eligible for the Oncotype DX test?

You can ask to have this test done if your cancer is: Early stage (Stage I or II), is Oestrogen-receptor-positive (ER+), is HER2 negative (HER2-) and if there is no cancer in the lymph nodes.

## Why it is useful?

If you have this type of breast cancer the Oncotype DX test results will help you and your doctor, make the decision on whether to have chemotherapy. The results of the test give a score (called a **recurrence score**) that gives you an estimate of the likelihood of your cancer returning in the next 10 years and whether chemotherapy treatment is likely to be of benefit for you.

The recurrence score is between 0 to 100, the lower the score the lower the risk of your cancer returning, and you are less likely to benefit from chemotherapy. The higher the score the more likely you are to benefit from chemotherapy.

If you have a low score you will be offered hormone therapy. If you have a high score you will most likely be offered hormone therapy + chemotherapy.

#### How is the test done?

If you are eligible for the test a sample of your breast cancer tissue that was removed during surgery will be sent away for testing. The results usually take 10–14 days to come back.

## Hormone therapy

Hormones help control how cells grow and what they do in the body. The hormones oestrogen and progesterone can help breast cancer cells grow. Hormone treatments (tablets) are given to slow this down. They only work for breast cancer that is oestrogen-receptor-positive (ER+) or progesterone positive (PR+). Some hormone therapy drugs like **Tamoxifen** do this by blocking the receptors on the cancer cells.

## When is hormone therapy given?

Usually hormone therapy is given after surgery or chemotherapy. It can also be given if surgery is not possible or sometimes before surgery to help reduce the size of the tumour.

## What type of hormone therapy would I be given?

The type of hormone therapy you will be offered will depend on whether you have been through the menopause or not, the risk of your cancer coming back and how the side-effects are likely to affect you.

Women that have not reached menopause will usually be offered tamoxifen or sometimes they may be offered ovarian suppression or ablation.

- Ovarian suppression stops the ovaries making oestrogen and causes a temporary menopause.
- Ovarian ablation means removing the ovaries and causes a permanent menopause.

Women who have been through the menopause will usually be offered a treatment called an **aromatase inhibitor** such as **Anastrozole**, **Letrozole**. These slow down oestrogens that is produced naturally in our body fat. Some hormone treatments need to be taken for years. If aromatase inhibitors are taken over a long period, they can cause your bones to thin (this is called osteoporosis).

Your doctor may prescribe drugs called **bisphosphonates** and suggest taking Calcium and Vitamin D supplements to help protect your bones. You will normally have a scan called a **DEXA Scan**, to check your bone health.

#### Side-effects of hormone treatment

The most common side-effects of hormone treatments are hot flushes and feeling tired. They can also give you irregular periods or sometimes your period may stop while you are on treatment. Ask your consultant about the likely side-effects.

## **Immune Type Therapy** (Targeted therapy)

Targeted therapy works by blocking the growth and spread of cancer by interfering with the biology of the cancer cells. They are called targeted therapy because they only target the cancer cells and leave normal cells alone. This type of treatment can be used to treat HER2 positive cancer and for some types of metastatic breast cancers.

## How is targeted therapy given?

It is given usually into a vein through a drip or as an injection, but some other types may be given as a tablet. Herceptin is an example of this treatment. For this drug you usually get it every 3 weeks for a year. You may have a heart test before starting treatment and then regular heart tests every couple of months over the year.

#### What are the side-effects?

Common side-effects of targeted therapy are flu-like symptoms like a headache, sweats, feeling tired and joint/muscle pains. Some targeted treatment can affect the way your heart works. If you have a heart or blood pressure problem, you may not be able to have this treatment.

## **Clinical Trials**

Clinical trials are research studies that test new treatments and ways of diagnosing cancer on patients. For example, a clinical trial may test a new drug against the usual treatment to see how good or bad it is in comparison. The drug has already been carefully tested before it goes into the clinical trial but is not available yet through the health service.

## Why would I consider a clinical trial?

- If you are interested in the chance of getting access to new treatments.
- If you are diagnosed at an advanced stage.
- If you are not responding to other treatments.
- If you want to help future cancer patients and contribute to research.

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask if there are any clinical trials suitable for you.



Contact your local **Daffodil Centre** and ask if they are having any chemotherapy education talks. These talks explain chemotherapy and give you tips on how to get through it.

The **Irish Cancer Society** website has videos and more information on chemotherapy and all breast cancer treatments. The links to the website are below. Ask some of your family or friends to copy this link into the internet so you can see this information if you are not sure how to do this.

www.cancer.ie/cancer-information-and-support/cancer-types/breast-cancer

#### **Tips on Hair Loss**

Provided by Joyce at Wigworld www.wigworld.ie

- Hair loss can vary from mild shedding to total loss.
- It is a good idea to have a consultation with a wig supplier before you start treatment.
- If you decide to go for a wig get a letter from your cancer clinic if it is not already in your hospital pack. You will need this letter to give to the wig supplier. Don't be afraid to ring and ask wig suppliers questions.
- Your hair will grow back after the treatment but don't colour it for about 6 months.
- You can also get some nice scarfs to wear.
   Bamboo headwear are light and ideal for sensitive skin.
- You may also lose the hair on your eyebrows or some of your eyelashes. These will grow back after treatment. You can use stencils for eyebrows and line your lower eye with a light pencil. If you want to have something more permanent, you could try an eyebrow tattoo, but it is best to have this before treatment.

## **Summary**

- Before you start treatment if you are considering getting pregnant now or in the future ask your cancer doctor if your treatment will affect your ability to have children.
- Breast cancer treatment usually will involve surgery. You may have some or all of your breast removed.
- You will have your lymph nodes checked and if any have been removed you are at risk of getting lymphoedema.
- Not everyone gets chemotherapy, many of the side effects can be helped with medication.
- Hormone therapies only work for breast cancers that are hormone positive. These treatments have sideeffects that include menopausal symptoms, brittle bones (osteoporosis), blood clotting and bone pain.
- Clinical trials are another possible treatment option.
   Ask your cancer doctor or nurse specialist to fill in with you the Step 2 Form in your treatment plan to have a record of your treatment.

#### Questions to ask your medical team

- What type of treatment do I need?
- Why is this treatment the best one for me?
- How long will my treatments take?
- What are the side-effects of this treatment?
- What can I do to help myself during treatment?
- Would I benefit from a clinical trial?

## Questions about the effect of treatment on your fertility

- Will the treatment affect my ability to have children?
- Can anything be done to preserve my eggs before the treatment begins?
- What will happen if I become pregnant?
- Some drugs cause your period to stop, ask will this be permanent, or will my period come back after treatment has stopped?
- How will I know if I am fertile after treatment has finished is there a test that I can have?

## Questions if you are having breast mastectomy

- What type of reconstruction surgeries are there?
- Are there any side-effects from getting a reconstruction?
- When can I get a reconstruction done?

## Questions if you are having chemotherapy

- What is my risk of developing secondary cancer by having chemotherapy?
- Will I lose my hair and when is this likely to happen?
- Are wigs free on prescription or will I have to pay?
- Will my teeth and bones be affected by the treatment?
- If you feel you would benefit from talking to a counsellor, ask to be put in touch with one.

## Ask The Expert

## Section 6

## Step 3 Your Follow-Up and Wellbeing

Many women are relieved or excited to be finished with breast cancer treatment, but it can also be a time of worry. Some women are concerned about the cancer coming back or feel lost without seeing their cancer care team as often.

It is important to sit down with your cancer doctor and discuss a care plan going forward. Use **Step 3** of your treatment plan to help with this.

## Follow-up clinical visits

After your treatment has ended you will have regular check-ups with your doctor. This is called follow-up. At first you will see your cancer consultant every 3 to 6 months then it will be once per year.

You will also have a mammogram every year (check with your cancer doctor how many years you will have this for )and a GP check-up once per year.

You need to keep a note of the dates and results of your follow-up visits. Use your follow-up tracker in section 3.

## **Emotional help**

People react differently to a cancer diagnosis. Some people feel fear and anxiety, sorrow, angry or denial. It can also be difficult for some women to accept the change in their body after having cancer surgery.

If you feel that you are having low moods that are getting the better of you or you are finding it hard to cope it is important to get help.

Refer to this check-in list throughout your treatment to help you recognise your struggles/needs at different stages.

Check-in list		
1	Is cancer affecting me Mentally/Emotionally?	
2	Is anxiety/uncertainty interfering with my daily life?	
3	Is body disfigurement /hair loss effecting my self-image or social confidence?	
4	Am I sleeping well?	
5	Has cancer interrupted my hobbies or passions?	
6	Has cancer caused a financial burden?	
7	Are physical ailments affecting my quality of life?	

Check-in list		
8	Do I suffer with memory loss?	
9	Am I content with my sexual wellbeing?	
10	Have I fertility concerns?	
11	Am I worried about returning to work?	
12	Despite cancer can I still find joy in my life?	
13	Do I feel my loved ones need support?	
14	Any other issues that are affecting my daily life?	

Would you benefit from talking to a counselling service? Ask your medical oncologist (doctor) or breast care nurse to give you details of how you can get in touch with these services.

Free counselling is available at some of the local cancer support centres.

The **Irish Cancer Society** will be offering specific workshops to help with practical advice along with support for emotional and mental health wellbeing. Check their website for details.

A list of counsellors is also available on the Irish Cancer Society website at www.cancer.ie or call the Cancer Nurseline Freephone 1800 200 700

## How to help yourself recover

To help you recover consider the following:

## Involve family and friends

If you can talk to family and friends about how you feel this may help your recovery. Ask someone close to go with you to medical appointments. Often family and friends want to help but don't know how and you will benefit from their support.

If you are feeling alone but need to talk to someone, you can contact the **Cancer Nurseline Freephone 1800 200 700** for a chat or visit your Daffodil Centre in your local hospital where volunteers can give you support.

## Learn about your cancer

Learning about your cancer can help you better understand your treatments. Ask your medical team questions, pick up leaflets about breast cancer or go onto some of the cancer charities websites that have lots of information and videos explaining breast cancer.

#### Eat well

After treatment, you may find you have gained some weight. This can happen with chemotherapy and hormonal therapy. When you are feeling better, it is a good idea to get to a healthy weight.

Keeping to a healthy weight reduces the risk of some other cancers, heart problems and other illnesses such as diabetes. If you need help on how to do this ask your breast care nurse or your medical oncologist or your GP where to get more information to help you.

#### Get some exercise

Exercise is a great way to boost your mood and can help with weight loss. Tell your doctor or nurse what type of exercise you like. Getting out for a walk is free and a great way to start. If you like boating groups like the Plurabelle paddlers which are a breast cancer Dragonboat club may be a good way to get fit and active.

www.plurabellepaddlers.com / www.corkdragons.ie

#### Try to relax and not stress

Some people like yoga, meditation or art therapy to help them relax. Ask at your cancer support centre if they run any of these classes. Doing something you like to relax for example taking time to yourself, having a walk outdoors or listening to music can help if you are feeling stressed.

## **Support groups**

Self-help or support groups offer a chance to talk to other women who understand what you are going through. Call into your local Daffodil Centre in your hospital and ask what support groups are in your area or ask your family GP.

Many people get support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer.

## Transport and financial concerns

The **Irish Cancer Society** runs a Volunteer Driver Service which provides transport for cancer patients to and from hospital appointments. Contact the **Irish Cancer Society Volunteer Driver Service team on (01) 231 0522** for more details.

#### Work

It is a good idea to talk to your manager early on when you have been diagnosed with cancer. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

#### When will I be ready to return to work?

You are usually the best judge of when you will be ready to return to work. Your healthcare team can also give you guidance on this. You may decide to return to work during or after chemotherapy or may feel you cannot return to work at all. It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work

#### Information on benefits and allowances

During treatment and recovery, most women who are working will need to take time off work and some women may decide to leave work. Your partner or another family member may also need to take time off to help care for you. This may cause a financial strain.

Start by asking your employer if you are eligible for Statutory Sick Pay

#### What happens if I am not entitled to sick pay?

If you are not entitled to sick pay from your employer, you can apply for Illness Benefit if you have enough social insurance (PRSI) contributions. If you do not have enough contributions, you should contact your local social welfare office for advice.

If you have been employed for 2 years or more and have the relevant social insurance contributions, you may be entitled to receive Illness benefit from the Department of Employment Affairs and Social Protection.

More information on benefits and allowances can be got by contacting:

- The medical social worker in the hospital
- Citizens Information Tel: 0761 07 4000
- Department of Social Protection (DSP) – Tel: 1890 662 244
- Money Advice and Budgeting Service Helpline Freephone 0761 07 2000

#### Resources checklist

A checklist to ask yourself with suggestions of resources to lookup to help.

	Area's Affecting Me	Programs and Contact
1	Is cancer affecting me Mentally/Emotionally?	Counselling Arc House Mindfulness course
2	Is anxiety/uncertainty interfering with my daily life?	Mindfullness Course
3	Is body disfigurement /hair loss effecting my self-image or social confidence?	Wigworld.ie Browtique Look good feel better Belissima

	Area's Affecting Me	Programs and Contact
4	Am I sleeping well?	Remedies
5	Has cancer interrupted my hobbies or passions?	Bravehearts Dragonboat clubs
6	Has cancer caused a financial burden?	Social Worker for entitlements Citizens information
7	Are physical ailments affecting my quality of life?	The lymph clinic Menopause advice Dietician advice Physiotherapy
8	Do I suffer with memory loss?	Mindfulness helps concentration
9	Am I content with my sexual wellbeing?	BodyGra.ie Dysparenia Remedies for vaginal dryness Psychosexual therapy
10	Have I fertility concerns?	Talk with your medical team

Area's Affecting Me		Programs and Contact
11	Am I worried about returning to work?	Talk with your GP or hospital medical team. Contact you employer to see if you can return on phased return
12	Despite cancer can I still find joy in my life?	Take time for yourself, do something you enjoy.
13	Do I feel my loved ones need support?	CLIMB Program. Counselling Arc house. Support groups
14	Any other issues that are affecting my daily life?	

#### Leinster

#### Carlow

## Eist Cancer Support Group

Tel: 059 913 9684 or 085 144 0510 Email: info@eistcarlowcancersupport.ie

#### **Dublin**

#### Aoibheann's Pink Tie

www.aoibheannspinktie.ie

## **ARC Cancer Support Centre**

www.arccancersupport.ie

## Balbriggan

Balbriggan Cancer Support Group Tel: 01 841 0116 / 087 353 2872

Email: balbriggancancersupportgroup@hotmail.com

### Tallaght Cancer Support Group

Tel: 086 400 2736

Email: ctallaght@yahoo.ie

## The Bella Rose Foundation

www.bellarose.ie

#### Kildare

## Newbridge Cancer Support Group

Tel: 083 360 9898

Email: newbridgecancerhealinghelp@gmail.com

#### Kilkenny

## Cois Nore - Kilkenny Cancer Support Centre

Tel: 056 775 2222 Email: info@coisnore.ie

## Littleway Cancer Support Service

Email: clane@little-way.org

## North Kildare Community Cancer Caregivers

Email: info@communitycancercaregivers.com

#### Laois

#### The Cuisle Centre

www.cuislecentre.com

Tel: 057 868 1492

Email: info@.cuislecentresupportcentre.ie

#### Louth

### Cara Cancer Support Centre

Tel: 087 395 5335

Email: info@ccscdundalk.ie

## Gary Kelly Cancer Support Centre

Tel: 041 980 5100

Email: info@gkcancersupport.com

## Offaly

## **Dochas Offaly Cancer Support**

Tullamore branch Tel: 057 932 8268

Birr branch Tel: 087 277 7728

www.dochasoffaly.ie

Email:info@dochasoffaly.ie

#### Westmeath

## Athlone Breast Cancer Support Group

LoCall 1850 719 719 / 044 937 1971

Email: info@larcc.ie

#### Lakelands Area Retreat & Cancer Centre

LoCall 1850 719 719 / 044 937 1971

Email: info@larcc.ie

## Midland Area Cancer Support Group

Tel: 044 937 1971

#### Cancer Support Sanctuary LARCC

Tel: 044 937 19711

Email: info@cancersupport.ie

#### Wexford

## Hope Cancer Support Centre

Tel: 053 923 8555

Email: info@hopesupportcentre.ie

#### Wicklow

## **Arklow Cancer Support**

Tel: 085 1100 066 or 040 223 590 Email arklowcancersupport@gmail.com

## Angels of Hope

www.angelsofhope.org.uk

## Purple House Cancer Support Centre Bray

Tel: 01 286 6966

Email: info@purplehouse.ie

www.purplehouse.ie

#### Wicklow contd.

## **Greystones Cancer Support**

Tel: 01 287 1601

Email: info@greystonescancersupport.com

www.greystonescancersupport.com

#### Rathdrum Cancer Support Group

Tel: 086 066 0175

Email: rathcan@gmail.com

## Wicklow Cancer Support Centre

Tel: 040 432 696

Email: wicklowcancersupport@gmail.com

#### Connacht

#### Galway

#### **Athenry Cancer Care**

Tel: 091 844 319 or 087 412 8080 Email: athenrycancercare@gmail.com

## **Ballinasloe Cancer Support Centre**

Tel: 090 964 9767 or 085 716 5266 Email: ballinasloecancer@gmail.com

## East Galway and Midlands Cancer Support

Tel: 090 964 2088

Email: info@egmcancersupport.com

## Gort Cancer Support Group

Tel: 086 172 4500

Email: info@gortcancersupport.ie

### Galway contd.

#### Hand in Hand

Tel: 091 483 694 or 087 660 0103

Email: info@handinhand.ie www.cdshelpinghands.ie

#### Tuam Cancer Care Centre

Tel: 093 28522

Email: support@tuamcancercare.ie

#### **Cancer Care West**

Tel: 091 545 0040

Email: galwaysupport@cancercarewest.ie

## Cancer Care West Support Centre

72 Seamus Quirke Road

Westside, Galway Tel: 091 540 040

info@cancercarewest.ie

#### Mayo

## Cara Iorrais Cancer Support Centre

Tel: 097 20590

Email: caraiorrais@gmail.com

## Mayo Cancer Support Association

Tel: 087 924 6875

Email: mayocancer@gmail.com

www.mayocancer.ie

#### Roscommon

## Roscommon Cancer Support Group

Tel: 090 662 5898

Email: info@roscommoncancersupport.ie

#### Sligo

## Sligo Cancer Support Centre

Wine street Sligo branch Tel: 071 917 0399

Tubercurry branch Tel: 089 448 0527

Email: scsc@eircom.net

www.sligocancersupportcentre.ie

#### Munster

#### Cork

## Cork ARC Cancer Support House

www.corkcancersupport.ie

Tel: 021 427 6688

#### Cork Cancer Care Centre

Tel: 021 494 9090

Email: corkcancercarecentre@gmail.com

#### Clare

#### Slainte an Chlair

Tel: 087 691 2396

www.clarecancersupport.com

#### Kerry

## Kerry Cancer Support Group

Tel: 066 719 5560

Email: kerrycancersupportgroup@eircom.net

www.kerrycancersupport.com

## Recovery Haven

Tel: 066 719 2122

Email: reception@recoveryhavenkerry.com

#### Limerick

## Mid-Western Cancer Information & Support Centre

Tel: 061 210 979 Email: info@mwcf.ie

#### **Tipperary**

## **CARE Cancer Support Centre**

Tel: 052 618 2667

Email: cancercareclonmel@gmail.com

www.cancercare.ie

#### Circle of Friends

Tel: 062 33550

Email: circleoffriendstipp@gmail.com

## Suaimhneas Cancer Support Centre

Tel: 067 37403

Email: suaimhneascancersupport@eircom.net

## Suir Haven Cancer Support Centre

Tel: 0504 21197

Email: suirhaven@gmail.com

#### Waterford

## Solas Cancer Support Centre

Tel: 051 304 604

Email: info@solascentre.ie

www.solascentre.ie

## Youghal Cancer Support Group

Tel: 024 92353

Email: youghalcancersupportgroup@hotmail.com

#### Ulster

#### Cavan

#### Cavan

## Cuan Cancer Social Support and Wellness Group

Tel: 086 455 6632 or 049 851 1021

Email: cuan@cavan.ie

## Donegal

#### **Cancer Care West**

Tel: 074 960 1901

Email: donegalsupport@cancercarewest.ie

## Donegal Cancer Flights & Services

Tel: 074 953 2949

Email: ionadnp@gmail.com

#### The Forge Cancer Support GroupPettigo

Tel: 071 986 1924

Email: theforgefrc@eircom.net

#### **Cancer Care West**

Tel: 091 545 000

www.cancercarewest.ie

### Monaghan

## Crocus Monaghan Cancer Support Group

Tel: 087 82565

Email: crocusmonaghan@gmail.com

#### **Other Useful Websites**

## **Irish Cancer Society**

www.cancer.ie

#### Europa Donna Ireland

www.europadonnaireland.ie

#### **Marie Keating Foundation**

www.mariekeating.ie

#### Irish Oncology and Haematology Social Workers Group

www.socialworkandcancer.com

#### **IPPOSI**

www.clinicaltrials.ie

#### **Cancer Trials Ireland**

www.cancertrials.ie

#### Can Teen Ireland

www.cancer.ie

#### Macmillan Cancer UK

www.macmillan.org.uk

#### Cancer Research UK

Cancerresearchuk.org

#### Sources

## Factual information on cancer diagnosis and treatment has been taken from the following sources:

- Irish Cancer Society
- Macmillan Cancer Charity UK
- ©Cancer Research UK, 2002
   All rights reserved. Information taken 20/08/20

#### Images have been taken from the following sources:

- ©Cancer Research UK, 2002
   All rights reserved. Information taken 20/08/20
- Flicker photos
- WikiMedia Commons
- Shutterstock
- iStock Photo

## The contents of the document have been informed by the following:

- Breast cancer patients and survivors
- Members of The Patient Voice In Cancer Research (UCD)
- Members of the Breast Disease Specific Group of Cancer Trials Ireland a multi-disciplinary group of medical professionals dealing in breast cancer care in Ireland.
- Irish cancer charities and input from members of the National Cancer Control program
- Tips on foods to help with chemotherapy were given by Therese Cahill
- Tips on hair loss were given by Joyce O'Carroll at Wigworld

The document was compiled by **Dr Cathriona Kearns.**