

NEOADJUVANT PATIENT

DECISION AID

A GUIDE FOR WOMEN WHO ARE CONSIDERING BREAST
CANCER TREATMENT WITH CHEMOTHERAPY AND/OR
HORMONE-BLOCKING THERAPY BEFORE SURGERY

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INTRODUCTION

Over the years the treatments available to women diagnosed with breast cancer have improved significantly. More treatment options are available to help cure more women of their cancer, or to keep women alive and well for longer. Treatment has also become more complicated, may be offered at different times and may continue for many months. Whenever possible, your treatment will be planned to best fit your personal situation and preference. Your treatment team is here to help you through this difficult time and to answer questions that you may have. This booklet is designed to help with some of those questions.

In certain situations, doctors may offer treatment with chemotherapy or hormone-blocking (systemic) therapy before surgery. You have been given this booklet, called a 'Decision Aid', because your doctor thinks that this option may be suitable for you.

The purpose of this decision aid is to help women to choose whether to have chemotherapy or hormone-blocking therapy before surgery (neoadjuvant) or after surgery (adjuvant). After reading the information, you may wish to weigh up reasons for and against having

neoadjuvant therapy using this decision aid. You can then discuss your thoughts with your doctor and make a decision.

As well as using this decision aid, you might like to talk to your doctor(s), family and friends and read other information that you may have. You may find additional paper and online resources to be valuable. A resource list is available at the end of this booklet along with space for you to make notes. These resources will give you extra information about breast cancer that you may find useful to help your decision about whether to have systemic therapy before or after surgery.

This decision aid booklet is for women who have recently been diagnosed with breast cancer, for whom chemotherapy or hormone-blocking therapy before surgery (neoadjuvant therapy) might be a treatment option.

WHAT TYPE OF BREAST CANCER DO I HAVE?

There are several different types of breast cancer. It is important to know which type you have when thinking about the pros and cons of treatment prior to surgery. Your doctor will be able to give you information about your type of breast cancer. There is also an explanation in the glossary on page 29. You may wish to mark which type you have, as a reminder (just tick the box that describes your cancer).

The main types of breast cancer are:

- Hormone receptor (oestrogen and/or progesterone positive: ER+/PR+), HER2 negative (HER2-)
- Hormone receptor (oestrogen and/or progesterone positive: ER+/PR+), HER2 positive (HER2+)
- Hormone receptor (oestrogen and progesterone negative: ER-/PR-), HER2 positive (HER2+)
- Hormone receptor (oestrogen and progesterone negative: ER-/PR-), HER2 negative (HER2-) (triple negative)

Women with any of these types of cancer may be offered chemotherapy, surgery and radiotherapy. If you have

hormone receptor positive breast cancer, you may also be offered hormone-blocking medication such as tamoxifen, anastrozole (Arimidex®) or letrozole (Femara®). Similarly, if you have HER2 positive breast cancer, you may be offered drugs such as trastuzumab (Herceptin®), neratinib and pertuzumab. If a clinical trial is an option for you, other types of medications might also be used.

Treatment options may also depend on other factors, including the grade of the tumour (how much tumour cells look like normal cells), stage of the tumour (describes the size and location of cancer), and whether there are cancer cells in the lymph nodes under your arm.

Testing positive for mutations in the BRCA (BReast CAncer) gene can also influence treatment. These genes help control how cells grow. If there are changes in the genes, it could make you more likely to get certain types of cancer including breast cancer. The changes can often be passed down through families so people with a family history of breast cancer may have this.

You can make notes about the important features of your cancer here:

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WHAT TREATMENTS MIGHT BE GIVEN FOR MY BREAST CANCER?

Your doctors and nurses will explain the details about the exact treatments that you could receive. There are two main types of breast cancer treatment: Local and Systemic.

LOCAL TREATMENTS: Treat cancer cells in the breast area only

SURGERY

Surgery involves removing any visible cancer. The whole breast can be removed (a mastectomy) or just the cancer and the area around it (a lumpectomy, or breast conserving surgery). You would also have surgery to check whether the lymph nodes (glands) in your armpit have any cancer in them. This may be done as a sentinel node biopsy at the same time as your breast operation. If there is cancer in the lymph node(s) that were removed, you may also have an operation to remove some more lymph nodes from under the arm (axillary dissection). If the lymph nodes appear to be involved before surgery, an axillary dissection may be done at the time of the initial breast surgery. Sometimes a second operation is needed because some cancer has been left behind in the breast. Having chemotherapy before surgery does not make this more or less likely to occur.

RADIOTHERAPY

If you have breast conserving surgery, then you are likely to be offered radiotherapy. You may also be offered radiotherapy after a mastectomy, depending on the size of the cancer, whether any lymph nodes are involved, or other factors that your doctors think are important. Radiotherapy kills cancer cells in the area it is aimed at and is similar to the rays that are used when you have a chest X-ray.

SYSTEMIC TREATMENTS: Using drugs that can reach all parts of the body

CHEMOTHERAPY

Chemotherapy is a medicine that is given to kill cancer cells throughout the body. For breast cancer, it is usually given intravenously (though a drip or injection into the vein) every 1-3 weeks, for a total of 12-24 weeks. There are many different types of chemotherapy, and your doctor will be able to describe the risks and benefits of the treatments that are most suitable for you.

TARGETED THERAPY

Targeted therapies work by targeting specific characteristics of cancer cells, like a protein that allows the cancer cells to grow in a rapid or abnormal way. This helps to stop the

growth and spread of cancer while affecting normal, healthy cells less than other types of cancer treatments, potentially reducing side effects.

In HER2 positive breast cancer, drugs such as trastuzumab (Herceptin®) and/or pertuzumab (Perjeta®) target the HER2 receptors on tumor cells. This is typically administered intravenously once every three weeks for a total of one year. This may include the time treatment is given before surgery.

CDK4/6 inhibitors, such as ribociclib (Kisqali®) and abemaciclib (Verzenio®), are used for high-risk hormone positive breast cancers. These treatments work by blocking proteins called CDK4 and CDK6, which are important for cell division and growth. For patients with BRCA mutations, PARP (Poly ADP Ribose Polymerase) inhibitors like olaparib (Lynparza®) are used. These drugs target the PARP protein that helps repair damaged DNA in cells, thus causing the cancer cells to die.



IMMUNOTHERAPY

This is a treatment that helps the immune system attack cancer cells, and may be given together with chemotherapy.

HORMONE-BLOCKING THERAPY

Hormone-blocking (endocrine) therapy is a tablet that is taken every day, for women with oestrogen (ER) and/or progesterone (PR) receptor positive breast cancer. For premenopausal women, a medication such as goserelin (Zoladex) may be used to stop the ovaries from making oestrogen, or the ovaries may be removed surgically. Hormone-blocking therapy works by interfering with the signal that oestrogen sends to cause this type of breast cancer to grow. Hormonal treatments are usually given for 5 years or longer.

WHY MIGHT IT BE NECESSARY TO HAVE SYSTEMIC TREATMENTS?

Systemic treatments are given to some women with early breast cancer, to reduce the chance that the cancer will return in the future.

HOW SOON DO I NEED TO HAVE TREATMENT?

You might think that treatment for breast cancer needs to start within a very short time. However, research has shown that most breast cancers take several years to grow to a size that can be seen on a mammogram. So most of the time there is no harm in taking one or two weeks to make a decision about which treatment is right

for you. After you have made a decision, surgery or chemotherapy may take days to a couple of weeks to commence, depending on local scheduling at the hospital where you are planning to have treatment. Again, there is no evidence to suggest that waiting those few weeks makes any difference to the success of your treatment.

WHAT ARE MY OPTIONS FOR THE TIMING OF CHEMOTHERAPY AND SURGERY?

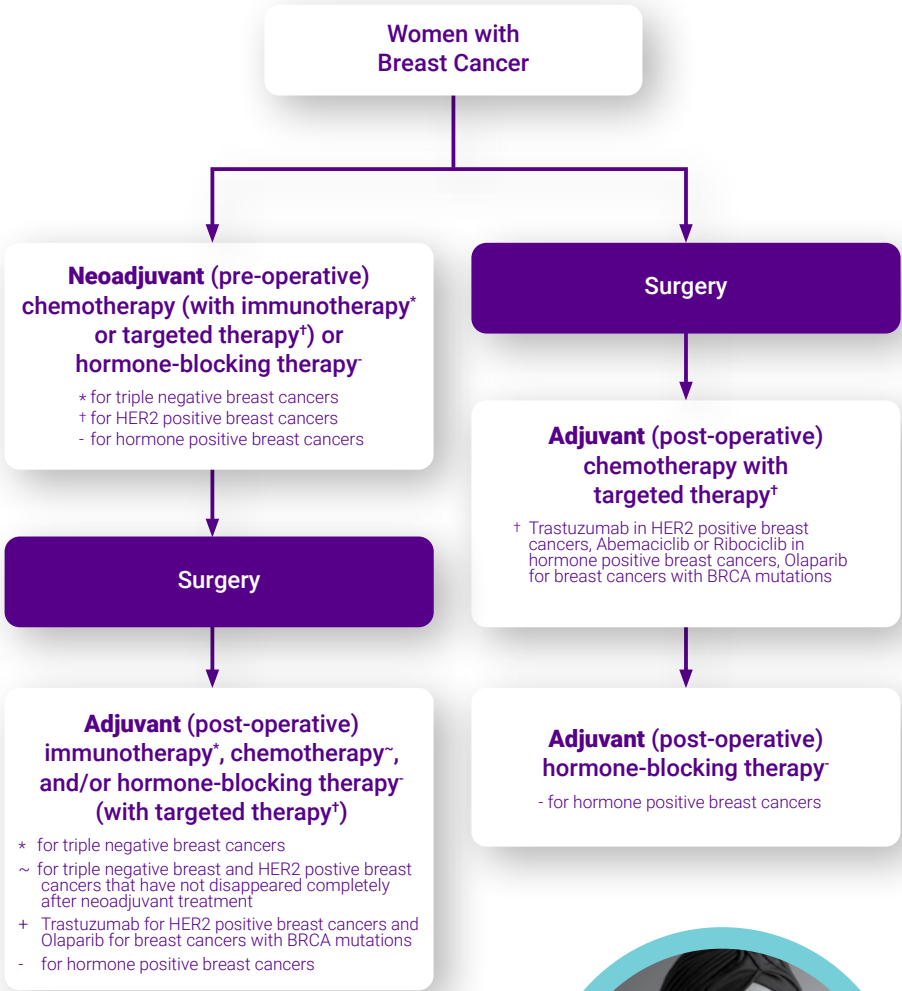
Neoadjuvant: This means you will start with chemotherapy, targeted therapy or hormone-blocking therapy, and then have surgery, usually after several months of treatment. This means you will start with chemotherapy, immunotherapy, targeted therapy or hormone-blocking, and then have surgery, usually after several months of treatment. These treatments may also continue after surgery depending on the results of surgery. You may also need radiotherapy,

which is usually given after surgery. This option does not usually mean that you will receive more therapy or receive treatment for a longer time, just that the timing is different.

Adjuvant: This means you will have surgery first. You will then be offered further therapy that may include chemotherapy, targeted therapy, hormone-blocking therapy and radiotherapy depending on the stage and type of cancer you have.



YOUR OPTIONS FOR THE SEQUENCE OF TREATMENTS



NEOADJUVANT THERAPY

Neoadjuvant therapy (treatment begins before surgery) has been commonly used around the world for many years. Breast cancer clinical trials have shown that treatments given to women before surgery is just as effective as having treatment after surgery in terms of the cancer coming back elsewhere in the body (distant recurrence), and survival.

If you have been offered neoadjuvant therapy, it does not mean that your cancer is worse than cancer treated with adjuvant therapy. Neoadjuvant therapy has in the past

been given to women who have larger breast tumours than average, but more recently this type of treatment has been given to women with moderately sized tumours, and tumours that are more likely to respond well to chemotherapy.

Regardless of which treatment you choose, your doctor will ensure that you receive the best possible care.

NEXT, we describe the pros and cons of neoadjuvant therapy, and then the pros and cons of adjuvant therapy.

WHY MIGHT I CHOOSE TO HAVE TREATMENT BEFORE SURGERY?

There are several reasons why your doctor might have raised the possibility of treating your cancer before it is removed surgically.

These reasons include:

- To reduce the size of the tumour so that you can have breast conserving surgery (rather than a mastectomy - removing the whole breast).
- To reduce the size of the tumour so that a smaller operation is possible.
- To reduce the number of lymph nodes that need to be removed
- To be eligible to participate in a neoadjuvant clinical trial.
- To give time for more information to become available, such as the results of genetic testing, which can influence the type of surgery and treatment you may choose to have.
- To be able to see or feel how effective the chemotherapy is against your cancer.

- To give you a better idea of your prognosis (the chance of your cancer coming back).
- To help decide if extra therapy is needed after surgery

These reasons are explained in the following pages. There are other reasons why your doctor may have

suggested treatment before surgery, and your doctor will explain these to you, if relevant.

There is space for you to make notes at the end of this booklet. If you think of a question, concern or comment please write them in the back of the booklet as soon as possible. You can take this list with you to your next visit.

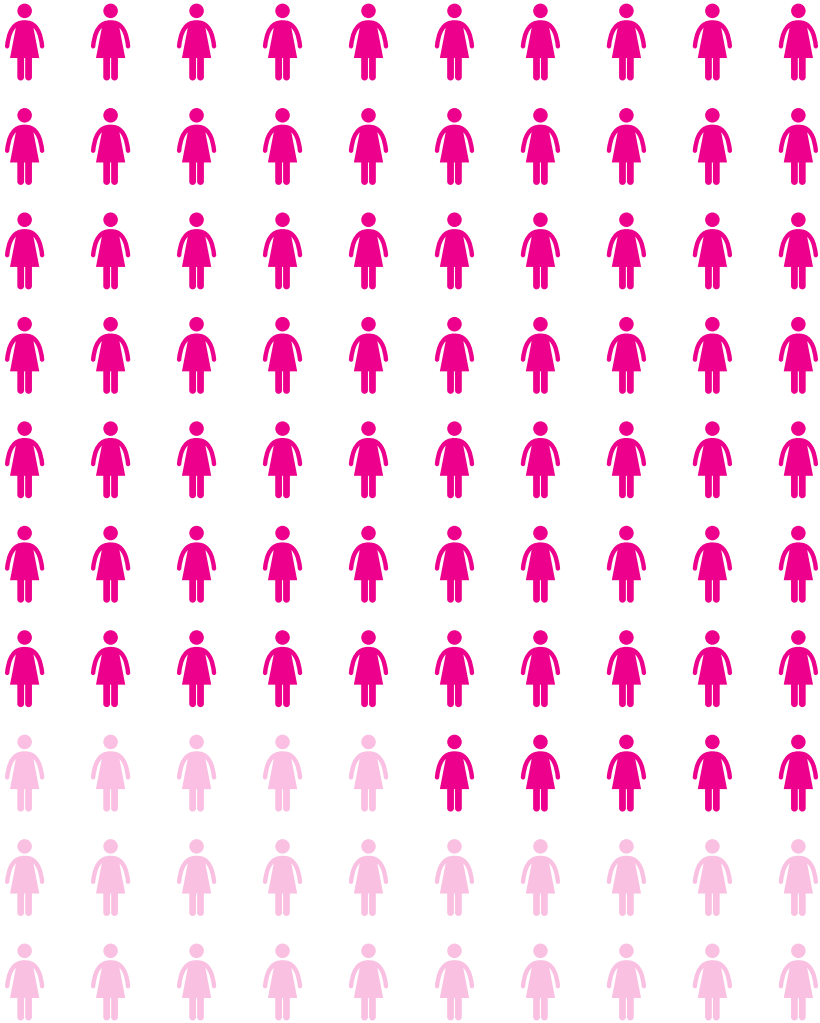
REDUCING THE SIZE OF THE TUMOUR SO YOU CAN HAVE BREAST CONSERVING SURGERY RATHER THAN A MASTECTOMY

Your surgeon may have told you that you need a mastectomy (removal of the entire breast). This may be due to the size of the tumour, the type of breast cancer, the size of your breast, or for other reasons.

Neoadjuvant therapy can reduce the size of the cancer in some patients, so that they may safely have breast conserving surgery (removal of only the part of the breast containing the tumour). The breast cancer is more likely to shrink if it is triple negative or hormone receptor negative/HER2 positive and thus women with these types of breast cancer are more likely to be able to have breast conserving surgery after neoadjuvant therapy.

If you were going to need a mastectomy, but you choose neoadjuvant therapy before the surgery, you have around a 25% chance of having breast conserving surgery after these treatments. In other words, 25 out of every 100 patients treated in this way will be able to avoid a mastectomy, but 75 in every 100 patients will still require a mastectomy. The diagram on the following page shows this.

Even if your surgeon has told you that you can have breast conserving surgery now, then neoadjuvant therapy may shrink the cancer further. This may mean that less breast tissue will need to be taken and your breast is more likely to retain its natural shape.



If each of the 100 figures above is a woman who was going to need a mastectomy, then after neoadjuvant therapy about 25 women will be able to have breast conserving surgery (light pink figures). About 75 women will still need to have a mastectomy (solid pink figures).

REDUCING THE SIZE OF THE CANCER TO MAKE SURGERY EASIER SO THAT LESS BREAST TISSUE NEEDS TO BE REMOVED

If scans (ultrasound or MRI) or physical examination show your tumour is more than 2cm in size, then neoadjuvant

therapy might shrink the tumour enough so that less breast tissue needs to be removed at the time of surgery.

REDUCING THE NUMBER OF LYMPH NODES THAT NEED TO BE REMOVED

Neoadjuvant therapy also works on any cancer cells that might be in the lymph nodes under your arm. Having neoadjuvant therapy means that these cancer cells might be killed before they are removed. Thus,

only a sentinel node biopsy might be needed rather than an axillary clearance, reducing the chance of lymphoedema (swelling, tightness, pain and reduced movement in the arm on the side of the cancer).

PLANNING SURGERY

In some cases, it may be worthwhile to delay surgery on the breast. You may wish to delay surgery if:

- you are waiting for the results of **genetic testing**. If you are found to have an inherited breast cancer gene, you may wish to think about having a double mastectomy (both breasts removed) to reduce your risk of developing breast cancer again. Having the results before surgery means that you can have one operation, rather than two;
- **breast reconstruction** is planned, and you wish to allow time for both your breast cancer surgeon and your reconstruction surgeons to be

available to perform their specific surgeries at the same time;

- you wish to delay decisions about surgery, and **take one decision at a time**;
- your doctors feel that it is important to start neoadjuvant therapy first because your cancer appears to be fast-growing.

Research has shown that if chemotherapy is required, you will get the same survival if you have it before surgery, as having it afterwards. If surgery is delayed for any reason, you might want to get the chemotherapy over and done with and have surgery afterwards.

TAKING PART IN A BREAST CANCER CLINICAL TRIAL

In some cases, neoadjuvant therapy is given as part of a clinical trial (research study). Your doctors will discuss this option with you if there is a trial available that is suitable for you. This may involve a new drug or combination of drugs, or a new way of using currently available therapies. In a neoadjuvant clinical trials, we have immediate feedback on how effective the medications are against

your cancer, especially at the time of surgery when the cancer is looked at under the microscope. The alternative, if surgery is done first, is that we do not know if the medications have had any effect on any remaining cancer cells for a long time, often years. For more information about breast cancer clinical trials, visit a registry such as www.clinicaltrials.gov, or ask your doctor(s).

OBSERVING THE EFFECT OF THE NEOADJUVANT THERAPY

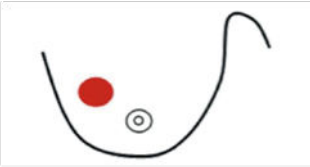
If you have neoadjuvant therapy, it is possible to check whether it is shrinking your cancer. This occurs for about 90% of women (90 out of every 100 cases treated in this way).

If you have surgery first, there is no way of knowing whether the cancer has shrunk in response to the treatment, because there is no cancer in the breast left to observe.

The reason this is important is discussed on the following pages.



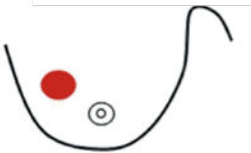
POSSIBLE RESULTS OF NEOADJUVANT THERAPY



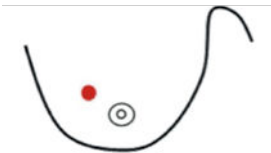
Breast cancer before treatment



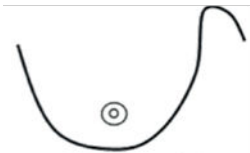
Neoadjuvant chemotherapy (with immunotherapy or targeted therapy) or hormone-blocking therapy



Cancer remains the same size, or (rarely) grows



Cancer shrinks



Cancer disappears entirely



Surgery

CHANCES OF THE TUMOUR DISAPPEARING COMPLETELY

As shown on the previous page, there is a chance that neoadjuvant therapy will completely clear the cancer from your breast and from the lymph nodes under the arm. In that case, you should still have an operation, as otherwise the cancer may grow back. Your doctor may organise for a special metal 'clip' to be injected into the breast

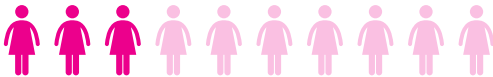
cancer before you start or during neoadjuvant therapy so that your surgeon knows where the cancer was and can remove tissue from that area.

The number of patients with no cancer visible on surgery after neoadjuvant therapy depends on the type of breast cancer:

**HORMONE RECEPTOR POSITIVE, HER2 NEGATIVE:
1 OUT OF EVERY 10 WOMEN**



**HORMONE RECEPTOR POSITIVE, HER2 POSITIVE:
3 OUT OF EVERY 10 WOMEN**



**HORMONE RECEPTOR NEGATIVE, HER2 POSITIVE:
5 OUT OF EVERY 10 WOMEN**



**HORMONE RECEPTOR NEGATIVE, HER2 NEGATIVE (TRIPLE NEGATIVE):
6 OUT OF EVERY 10 WOMEN**



The solid figurines show the number of women (out of 10) who do not have any tumour visible at the end of treatment. Some clinical trial treatments can give a higher chance of the cancer disappearing entirely. However, this cannot be guaranteed.

PROGNOSIS

(HOW LIKELY IS THE CANCER TO RETURN?)

The survival benefit from chemotherapy for breast cancer is the same, whether you have it before or after surgery. If you have neoadjuvant therapy before surgery, your cancer may shrink. In some cases, the cancer can disappear entirely. Whether or not this happens tells us something about your chances of doing well. If neoadjuvant therapy completely clears the cancer from your breast and lymph nodes, you will have gained some “good news” – that your breast cancer is responding to the treatment and is less likely to come back. On the other hand, if your cancer doesn’t shrink, or even grows, you will have gained some less good or even “bad” news – that your breast cancer is not so responsive and is more likely to appear elsewhere in your body. Even if your cancer does grow while on treatment, it does not mean that it will definitely spread elsewhere, and may still be cured by surgery and other treatments that your doctors may offer.

The following information is about women who are alive and free of cancer five years after being diagnosed with breast cancer. For some women the cancer comes back before 5 years, for some it comes back after 5 years, and for most women it never comes back.

However, the statistics are often described using the 5 year mark.

For women who have had neoadjuvant therapy, the prognosis depends on the type of cancer:

- Hormone receptor positive, HER2 negative: **85 out of every 100 women** whose cancer has **disappeared entirely** are alive and free of breast cancer 5 years after diagnosis, compared with **75 out of 100 women** whose cancer **did not disappear entirely**.
- Hormone receptor positive, HER2 positive: **90 out of every 100 women** whose cancer has **disappeared entirely** are alive and free of breast cancer 5 years after diagnosis, compared with **65 out of 100 women** whose cancer **did not disappear entirely**.
- Hormone receptor negative, HER2 positive: **85 out of every 100 women** whose cancer has **disappeared entirely** are alive and free of breast cancer 5 years after diagnosis, compared with **78 out of every 100 women** whose cancer **did not disappear entirely**.
- Triple negative: **95 out of every 100 women** whose cancer has

disappeared entirely are alive and free of breast cancer 5 years after diagnosis, compared with **82 out of every 100 women** whose cancer **did not disappear entirely**.

The chance of your cancer disappearing completely also depends on which type of cancer you have. This is explained in the following pages.

If the cancer does not shrink or disappear during treatment, it means your cancer is more resistant to the treatment that you were given. It does not mean that the cancer will

definitely come back. If you have a hormone positive cancer, not all the work is done by the chemotherapy, hormone-blocking treatment is an important part of the treatment of this type of breast cancer.

Even if the cancer cannot be seen on scans and cannot be felt by you or your doctor after neoadjuvant therapy, surgery is still recommended to make sure that all cancer is removed. Looking at the cancer under the microscope after surgery can also give you additional information on the chances that your cancer will return.

TREATMENT OPTIONS AFTER SURGERY

If chemotherapy before surgery does not work very well, it may be worth having additional, or different treatments after surgery. For some types of cancer, these treatments can help remove any resistant cancer cells because they work in a different way to the treatment that was given before surgery.

This is most relevant if you have a HER2-positive, triple negative or breast cancer with a BRCA mutation. After your breast and lymph node surgery, the tissue that has been

removed is sent to the laboratory for analysis. As described above, sometimes there will be cancer cells that the neoadjuvant therapy has not eradicated. Your medical oncologist may then offer additional or different treatment, as there is research showing that these treatments help to get rid of any breast cancer cells that may still be elsewhere in your body. Importantly, these treatments have been shown to increase the chance of your cancer being cured, and therefore of long-term survival.

SOME OTHER ISSUES WITH HAVING NEOADJUVANT THERAPY

THERE IS NO INCREASE (OR DECREASE) IN PROBLEMS WITH SURGERY

Having neoadjuvant therapy does not increase or decrease the chance of having problems from surgery, such as an infection or delayed wound healing.

RADIOTHERAPY

If you have breast conserving surgery, radiotherapy is usually offered. If you have a mastectomy, radiotherapy may or may not be needed. A good response to neoadjuvant therapy does not mean that radiotherapy (and its side effects) can be avoided.

WHAT IF THE CANCER DOES NOT GET SMALLER?

As discussed above, there is a chance that the cancer may not seem to be getting any smaller during neoadjuvant therapy. This can cause worry that the treatment is not working. If the cancer does

not get any smaller, it does not necessarily mean that the treatment is not working, and you and your doctor may decide to continue with treatment as planned.

In some cases you may still be able to feel a lump in your breast after you have started neoadjuvant therapy. What you can feel or see may only be scar tissue and no cancer is left. On the other hand, even if the cancer can no longer be felt, there is still a possibility that some cancer cells remain. So what we can see and feel from the outside does not tell the whole story. Scans and pathology are needed to make a decision on whether the treatment is working.



WHAT IF THE CANCER GETS BIGGER?

Some people might worry about their cancer getting larger or spreading elsewhere, while receiving treatment prior to surgery. It is uncommon for this to happen. It happens in about 3% (3 in 100) of patients, and in almost all these patients (90%) surgery can still be successfully performed to remove the cancer, with outcomes remaining the same as if they had had surgery before adjuvant treatment. The following pages show this risk.

WHAT IF THE CANCER COMES BACK IN THE BREAST?

Some studies have shown that over the long term, there is a slightly higher chance of the cancer coming back within the breast (local recurrence) after neoadjuvant therapy, while other studies have shown that there is no difference. Overall survival and the chance of the cancer coming back somewhere else in the body is the same whether systemic therapy or surgery is first. With modern scans, surgical techniques and radiotherapy, the difference in local recurrence is very small.

WHAT IF I CAN'T HAVE SURGERY?

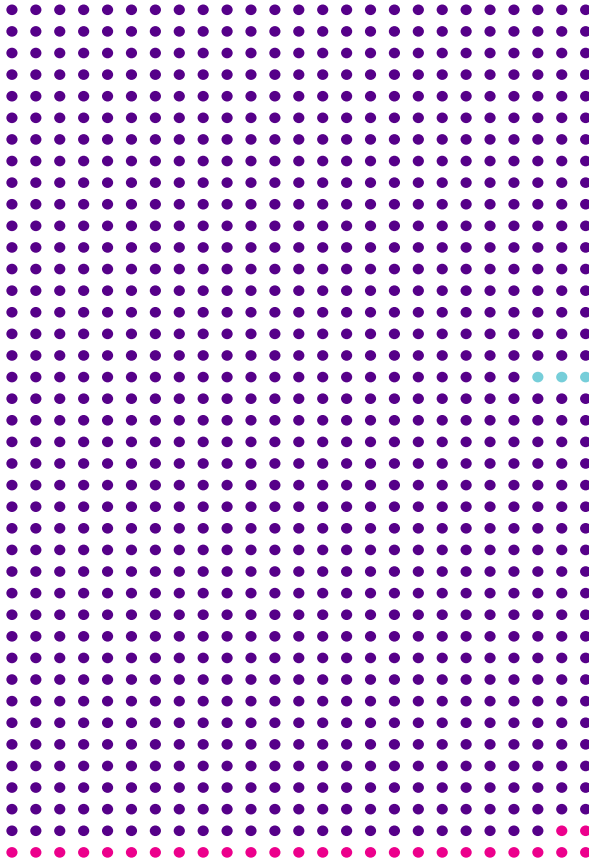
Less than 3 in every 1,000 patients (0.3%) who have neoadjuvant therapy are not then able to have surgery because the cancer became too large, or because cancer became visible elsewhere in the body (metastatic breast cancer).

In the rare situations that this occurs, it means that surgery **would not have cured the cancer anyway**, even if an operation was done first. This is because there was already cancer

that had spread beyond the breast and lymph nodes, which would not have been completely removed by surgery and systemic therapy.

Your doctor will check regularly with physical examination and scans such as ultrasound or MRI to see whether the cancer is smaller, larger or the same size. If it does grow, your surgery may be moved to an earlier time, before your planned neoadjuvant therapy is finished.

THE CHANCE OF CANCER GROWING WHILST RECEIVING NEOADJUVANT THERAPY (3%).



PURPLE dots show the patients whose tumour will either shrink or stay the same size after neoadjuvant therapy

BLUE dots show the patients whose cancer will get bigger or spread elsewhere in the body, and surgery will not be possible

PINK dots show the patients whose tumour got bigger during neoadjuvant therapy, but could still have surgery

Of 1000 people who have neoadjuvant therapy (the purple dots), 30 will have their cancer grow while having treatment (the pink dots). 27 of these 30 people are almost certainly still able to have surgery aimed at cure. 3 out of every 1000 (0.3%) would not be able to have surgery, however surgery would not have cured these 3 if done before systemic therapy (blue dots).

THE PROS AND CONS OF ADJUVANT THERAPY (SURGERY FIRST)

The chance of the cancer coming back elsewhere in the body is the same if you have chemotherapy first or surgery first.

If an operation is possible now, then you may prefer to have surgery

first, and then make a decision about any other treatments such as chemotherapy, targeted therapy, hormone-blocking therapy and radiotherapy, once surgery is complete.

ADVANTAGES OF SURGERY FIRST

INFORMATION ABOUT THE CANCER

A possible advantage of having surgery first is that you may have more precise knowledge of the type and stage of the cancer before decisions are made about any further treatment. If the cancer is removed in an operation before systemic therapy is given, the pathologist can look at the cancer cells under a microscope and provide information about it. This helps you and your doctors to make decisions about the best treatment options for you. Sometimes this shows that chemotherapy is not needed after all, because the pathologist can see the whole cancer, rather than just a small part of it. One of the best ways of knowing whether the cancer is likely to return is whether or not there is cancer in the lymph nodes near the breast and it also guides whether radiotherapy is needed. If neoadjuvant therapy has made the cancer shrink or disappear

from the breast or lymph nodes, then some of that information may no longer be available.

IMMEDIATE REMOVAL OF THE CANCER

Some women may be uncomfortable leaving the cancer in place for several months whilst having neoadjuvant therapy. The idea that the cancer is still in their body can cause some women to feel more anxious and stressed. There is a possibility of anxiety about whether the cancer is growing or not. If the cancer is removed first, then the small chance that it might grow is taken away.

RADIOTHERAPY

If you have a mastectomy, then you are less likely to need radiotherapy after surgery. Radiotherapy might still be needed in some situations, such as if there is cancer in your

lymph nodes under the arm, or if your cancer is large. If you have breast conserving surgery, then radiotherapy is usually offered.

MANY WOMEN HAVE SURGERY FIRST

Having surgery first is common, particularly for small breast cancers where breast conserving surgery is

already possible, or in cases where neoadjuvant therapy may not be needed. Some women might prefer having a treatment that many others have. The use of neoadjuvant therapy is not rare, but in many places it is less common than having surgery first.

DISADVANTAGES OF SURGERY FIRST

HIGHER CHANCE OF NEEDING A MASTECTOMY

A possible disadvantage of having surgery first is that you may need a mastectomy, when you could have the option of breast conserving surgery if you had neoadjuvant therapy to shrink the cancer.

NO WAY TO SEE IF SYSTEMIC THERAPY IS WORKING

Another disadvantage is that you will not be able to see the effect that the neoadjuvant therapy is having on your cancer and so you may have less information about the chance of your cancer coming back. This is discussed in detail

in the sections about neoadjuvant therapy titled 'Observing the effect of chemotherapy' and 'Prognosis'.

INFECTION AFTER SURGERY

Sometimes after surgery, an infection may develop in the breast, or the wound may be slow to heal, which could delay the start of adjuvant chemotherapy. While it is usually OK to wait for a short time before starting chemotherapy, it is generally should start within 2-3 months to give the chemotherapy a chance to work. In other words, if an infection causes a delay of more than 2-3 months between surgery and starting chemotherapy, the chemotherapy may be less effective.

REMEMBER:

Being offered treatment before surgery does not necessarily mean that there is anything unusual or worse about your type of breast cancer. Neoadjuvant therapy was previously given for larger breast tumours, but more recently this type of treatment is being given to women with moderately sized tumours.

Treatment before surgery is commonly used around the world. Having chemotherapy before

surgery is just as effective as having chemotherapy after surgery in terms of the chance that the cancer will come back (recurrence) and survival.

The decision to have neoadjuvant or adjuvant therapy is one that you, your surgeon and your medical oncologist can make together. Your doctors will ensure you get the best care regardless of the decision you make.



ARRIVING AT A TREATMENT DECISION

The previous pages have outlined the main options available to you now. The following steps may help you to make a decision whether or not to have systemic therapy before surgery.

The decision-making process may be easier if you follow these seven steps:

1. Understand your diagnosis and your risk of breast cancer recurring (coming back) as fully as you can.
2. Understand your options for treatment and the risks and benefits of these options.
3. Review the pros and cons of those options.
4. Assess the importance to you of the pros and cons.
5. If you are offered neoadjuvant treatment through a clinical trial, prioritise the pros and cons of the trial for you (and your family).
6. Get more information from your doctor or breast care nurse if you are unsure of anything or have more questions.
7. Discuss your preferred treatment option with your surgeon, medical oncologist, family doctor, your family and other significant people in your life.

You have already gone through steps 1-3. To help you complete steps 4-7, and come to the decision that suits you best, we have prepared a worksheet on the following pages.



WORKSHEET

After reading this booklet you may feel you understand more about treatment options for your breast cancer. You may wish to weigh up the positives and negatives, to help you work out which treatment option is right for you. You may not come to a decision now, but this may assist you at your next visit with your medical oncologist or surgeon.

The next two pages list reasons that are relevant to the decision about whether to receive systemic therapy, either before or after surgery for your breast cancer. Indicate which issues are important to you. That will help you work out which way you are leaning.

I want to have breast conserving surgery if at all possible
"I would like to avoid a mastectomy"

Not at all important

Fairly important

Very important

I have reasons to delay surgery
Eg. Genetic testing, planning surgery

Not at all important

Fairly important

Very important

I think it is important to see whether neoadjuvant therapy has shrunk the cancer or not
"It may give me information about my prognosis"

Not at all important

Fairly important

Very important

Other:

Not at all important

Fairly important

Very important

Favours neoadjuvant (pre-operative) treatment

Waiting for surgery would worry me
"Even if I am having treatment, leaving the tumour there would be stressful"

No
concern

Small
concern

Big
concern

I am worried about the tumour growing or spreading before surgery
"It is rare, but concerning"

No
concern

Small
concern

Big
concern

**I want to know as much as possible about the cancer before considering
adjuvant chemotherapy**

"It may help my decision about chemotherapy"

No
concern

Small
concern

Big
concern

Other:

Not at all
important

Fairly
important

Very
important

Favours adjuvant (post-operative) treatment

Any further questions? Write down any questions you want to ask your surgeon or medical oncologist (there is more space at the end).

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Which way are you leaning? Circle the star which best indicates whether you are leaning towards neoadjuvant therapy or adjuvant therapy. The closer the star is to either option, the more certain you feel about that option.

WHERE ARE YOU LEANING?

Neoadjuvant therapy ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ Adjuvant therapy

WHAT HAPPENS NOW?

Your treating doctor, often your surgeon, will have brought up the possibility of neoadjuvant therapy. Your doctor has given you this booklet to help you find out more about the option of receiving neoadjuvant therapy to assist you to make a decision about whether it is right for you.

Your doctor and other health care professionals (such as a breast care nurse) will continue to support you through the decision-making process, and will be able to answer any questions you might have. You

may be referred to see a medical oncologist to discuss the matter further. A referral to a medical oncologist does not mean that you must proceed with treatment before surgery. Neoadjuvant therapy may be the recommended option, it may be presented to you as a “genuine choice” for you to make, or your medical oncologist may recommend against it, with immediate surgery being the preferred option.

Once you and your doctor(s) have made a decision, treatment will be arranged for you.

GLOSSARY

Adjuvant: treatment that is given after surgery, with the intent of cure.

CDK4/6 Inhibitor: Cyclin-dependent kinase 4 and 6 (CDK4 and CDK6) are enzymes that have an important role in cell division. CDK4/6 inhibitors are drugs designed to interrupt the growth of cancer cells. CDK4/6 inhibitors are used in combination with hormone-blocking therapy to treat some hormone receptor-positive breast cancers.

Chemotherapy: A medicine used to kill cancer cells throughout the body. It is usually given through an intravenous (IV) drip.

Clinical trial: Research that is testing a new way of treating a disease.

Decision aid: a document that contains information to help people make a decision about medical treatment.

Early breast cancer: breast cancer that is only on the breast, or in breast and lymph nodes under the arm on the same side of the body.

Endocrine or hormonal therapy: tablets that are taken daily for at least 5 years for hormone receptor positive breast cancer, such as tamoxifen, anastrozole (Arimidex®) or letrozole (Femara®). Ovarian function suppression is also a form of hormonal therapy, through either injection of a medication, or surgical removal of the ovaries.

HER2 receptor: a protein on the surface of cells that helps them grow and divide.

HER2 positive (HER2+) breast cancer: a type of breast cancer that has a larger number of HER2 receptors on the cells than usual. It can be treated with drugs such as trastuzumab (Herceptin®).

Hormone receptor: either the oestrogen receptor or progesterone receptor, which indicates that hormonal treatments such as tamoxifen may be used.

Hormone receptor positive breast cancer (ER+/PR+): a type of breast cancer that has hormone receptors on the cells. These receptors are special proteins that the hormones estrogen and progesterone bind to, causing the cancer to grow. Hormonal therapy can be used for this type of breast cancer.

Immunotherapy: A treatment that stimulates the body's immune response to attack the cancer cells.

Inflammatory breast cancer: breast cancer that affects a large area of the breast, but may not be felt as a distinct lump. It is a less common type of breast cancer; your doctor will be able to tell you if you have this type.

Local therapy: treatment that affects part of the body, eg. surgery or radiotherapy.

Metastatic (secondary or advanced) breast cancer: breast cancer that has spread beyond the breast and lymph nodes, to other parts of the body, such as bones, liver or lungs.

Neoadjuvant: treatment that is given before an operation to remove the breast cancer.

PARP Inhibitor: PARP is a protein (enzyme) found in our cells, it stands for poly-ADP ribose polymerase. It helps damaged cells to repair themselves. As a cancer treatment, PARP inhibitors stop the PARP from doing its repair work in cancer cells and the cell dies.

Pathological complete response (pCR): when no cancer can be seen by the pathologist in the breast or lymph nodes that have been surgically removed, after neoadjuvant chemotherapy or hormonal therapy has been given.

Systemic therapy: treatment that affects the whole body, eg. chemotherapy or hormonal therapy

Triple negative breast cancer: breast cancer that does not have oestrogen (ER), progesterone (PR), or HER2 receptors on its surface.

FURTHER INFORMATION AND SUPPORT

Breast cancer information

BreastCancer.org: www.breastcancer.org (USA)

Susan G Komen: www.komen.org (USA)

Dr Susan Love Research Foundation: www.drSusanLoveResearch.org (USA)

Breast Cancer Network Australia: www.bcna.org.au (Australia)

Cancer Australia: www.canceraustralia.gov.au (Australia)

Macmillan Cancer Support: www.macmillan.org.uk (United Kingdom)

Breast Cancer Care: www.breastcancercare.org.uk (United Kingdom)

Clinical trials information

Breast Cancer Trials: www.breastcancertrials.org.au

Clinical trials: www.clinicaltrials.gov

Australia and New Zealand Clinical Trials Registry: www.anzctr.org.au

I-SPY trials: www.ispytrials.org

Local contact information:

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