

A decision aid for choice regarding surgical treatment

to help patients diagnosed with breast cancer
make an informed and values-based decision

There are various options for breast cancer surgery, and each carries its own benefits and risks.

This decision aid seeks to help women diagnosed with breast cancer decide whether to undergo breast-conserving surgery or mastectomy, and whether or not to undergo breast reconstruction after undergoing mastectomy.

It also helps them understand why the surgical method proposed by surgeons is suitable for them.





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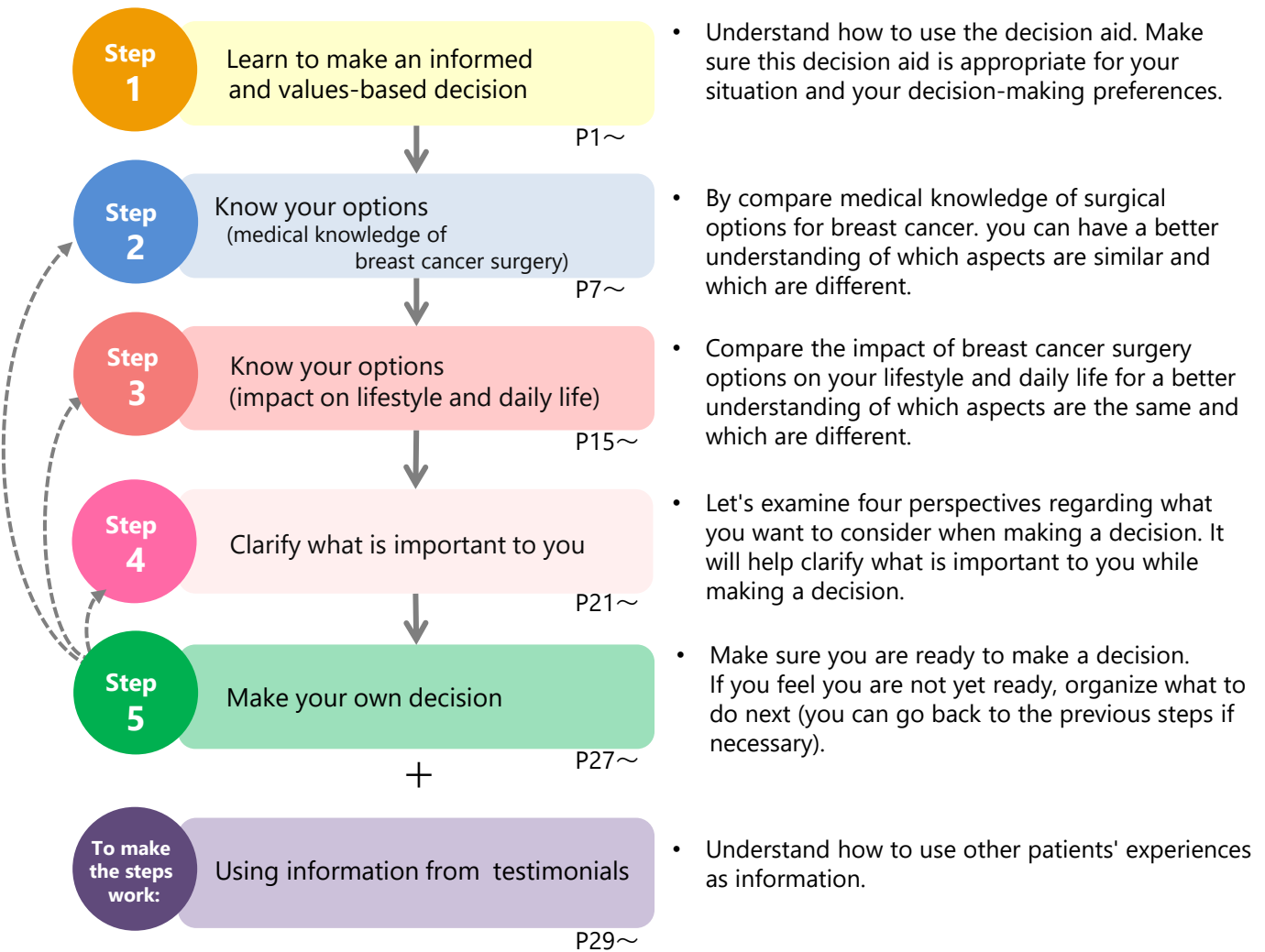


● What is the decision aid for choice regarding surgical treatment for breast cancer?

There are benefits and risks associated with breast cancer surgery.

This decision aid is for people who have been diagnosed with breast cancer and want to decide convincingly which breast-conserving and mastectomy options is appropriate for them, whether to undergo breast reconstruction after mastectomy, and to understand why the surgical options proposed by their surgeon is appropriate for them Created for. It is designed to assist those who want to gain a better understanding of why the surgical procedure proposed by their doctor is appropriate for them.

The steps in this decision aid are as follows. When you first read it, follow the order of the steps.



This decision aid includes stories from people who have undergone surgery for breast cancer (experiences of decision making process and making a decision) at each step of the process.

● How to use the decision aid for choice regarding surgical treatment of breast cancer**■ Make sure this decision aid is useful to you.**

The decision aid for choosing a breast cancer surgery procedure is not intended to recommend which option is best for you. It is designed to help you choose an option that is appropriate for you and that you are comfortable with, by reading the information included, comprehending accurate information, and examining what is important to you when making a decision, and by facilitating communication with doctors, nurses, and other medical professionals, family members, acquaintances, and breast cancer survivors.

This decision aid is designed for people mentioned below

Who can use this decision aid?

- Those who have been diagnosed with breast cancer and are planning to undergo breast-conserving surgery or mastectomy.
- Those who have been diagnosed with breast cancer and have almost decided to undergo mastectomy, but are reconsider whether to have reconstruction.
- The surgeon has recommended breast-conserving surgery or mastectomy, but you would like to know why the doctor recommended that method and whether it is suitable for you.

However, it does not contain information for those who, should be informed and are discussing their individual situations with their doctor.

You need to discuss your individual situation with your doctor if**(You need more information other than what is in this decision aid)**

- You found out that you have breast cancer during your pregnancy
- You have a strong genetic background
- Your doctor has recommended treatment options other than surgery (e.g., Stage IV breast cancer).

* If you are planning your pregnancy, inform and discuss with your healthcare professionals about your desire to become pregnant or have a baby before starting treatment. You may be able to obtain information about the effects of anti-cancer drug treatment and hormone therapy on pregnancy ahead of starting treatment, so that your doctor can decide your treatment plan.

■ Identify what role you would like to play in your treatment decisions.

You have identified that this decision support tool is suitable for your breast cancer situation.

Another important thing to consider is what decision-making role you prefer.

There are three main types of roles in decision-making.



When deciding, check what role you prefer.

- You want to "make an informed decision for yourself"
- You want to "share your decision with your healthcare professionals and family"

If either or both of the above apply to you, you may find this decision aid helpful.

If you would prefer someone else, such as a doctor or a family member, to make the decision for you, you may not find the information in this section useful. For example, you could read this decision aid with your family and use it to check whether your doctor has made the right decision for you.

■ You can use this decision aid to read, write and discuss the contents.



● Preparing for informed values-based choice

■ You need time to think about your surgical options.

When you are diagnosed with breast cancer, it is natural to want to eliminate the cancer as soon as possible. However, if you are diagnosed with early-stage breast cancer, there is no medical urgency to have immediate surgery. Time is also needed to carry out a full examination to decide the appropriate surgical procedure. It may take between one and three months from the time of diagnosis to surgery (depending on the medical facility).

Talk to your doctor about the time you have to think about your surgical options. This will give you sufficient time to calm down, obtain information and consider the best option.

It is crucial to know how much time you have to think carefully.

If the doctor suggests that you have to decide immediately or that this is definitely the better option, there must be a reason. Ask your doctor why you need to do so. If you wish, you can get a second opinion.

■ You are not alone.

Your surgeons and nurses can help you to better understand your medical condition and assist you to consider carefully about what is important for you before you take any decision. When you are feeling distressed, you may not be able to comprehend the information well, it may take you a long time to understand it or you may not be able to think clearly.

Don't put up with the hard feelings. Emotional support is also important for you. Talk to your surgeons and nurses.



● How long did other breast cancer survivors take to decide on the surgical procedure?

When I underwent a comprehensive medical examination, my breasts needed to be re-examined. I then underwent a full breast examination. I was informed that I have breast cancer by the doctor at the hospital where I had the full breast examination. The doctor referred me to a hospital where I could get admitted and undergo surgery. It took about three months before I underwent surgery. (Ms. B)



It was about a month-and-a-half from the diagnosis of breast cancer to the surgery. It took a month to make a definitive diagnosis. When I was diagnosed with breast cancer, I wanted to have surgery immediately.

However, I contacted several hospitals for a second opinion. I underwent surgery at the hospital where I got the second opinion. (Ms. C)

My decision was made rather early on. I had pre-operative chemotherapy, so I had enough time before I underwent surgery for breast cancer. The surgical method was going to change depending on how well the pre-operative chemotherapy worked, so I took care to control my emotions so that I would be okay with either surgical method. (Ms. F)



● Tell us about your feelings after the breast cancer diagnosis.

I behaved like a typical cancer patient. I thought "No way, not me" when I was diagnosed with breast cancer. I started to learn about breast cancer soon after my diagnosis and have collected information from books and professionals. I was extremely depressed soon after diagnosis until my course of treatment was decided. (Ms. G)



When I was diagnosed with breast cancer, I was not shocked and I accepted it without emotion.

I knew I was at a high risk of cancer because I lost my mother to cancer. (Ms. D)



The year I was diagnosed with breast cancer, I had a lot of things to attend to at my children's wedding and at work. I had to deal selflessly with hospitalization and treatment.

I read many books and used the internet to gather information. Before the surgery, I was imagining what would happen after surgical procedure. (Ms. H)



When I was diagnosed with breast cancer, I couldn't believe what had happened to me. I was really sad and felt miserable.

Naturally, I had no knowledge of breast cancer. I could hardly understand what the doctors were telling me. (Ms. J)



● How did other breast cancer survivors decide?

I had early stage breast cancer, so I followed my doctor's recommendations. I only had to read books about cancer. (Ms. B)



I had sufficient time between diagnosis and surgery. However, I was extremely scared to learn about breast cancer.

My surgeon explained about the treatment. My husband accompanied me to appointments with my surgeon and did some research about breast cancer and treatment on the internet for me. Subsequently I made a decision. (Ms. I)



Before I underwent surgery, I received a second opinion.

I chose to have my surgery at the first hospital because the explanation from the doctor at the first hospital corresponded with the explanation I received at the second opinion, and also because it was easy to access post-operative treatment. (Ms. D)



When I was diagnosed with breast cancer, I was single. My parents were elderly and it was difficult to talk to them about it.

I have always made my own decisions. I used the internet to gather information about breast cancer treatment on my own. I visited other hospitals because the procedure I wanted (one-stage breast reconstruction) was not offered at the first hospital.

Although a lot of information was available online, I was confused because of my lack of knowledge about the treatment and the procedure. I asked the doctors several questions about what I did not know and what I did not understand.

Ultimately, I chose the surgical procedure and underwent treatment after understanding the potential risks, with my main concern being that I would not feel any loss and that I would be able to return to my normal life as soon as possible. (Ms. M)

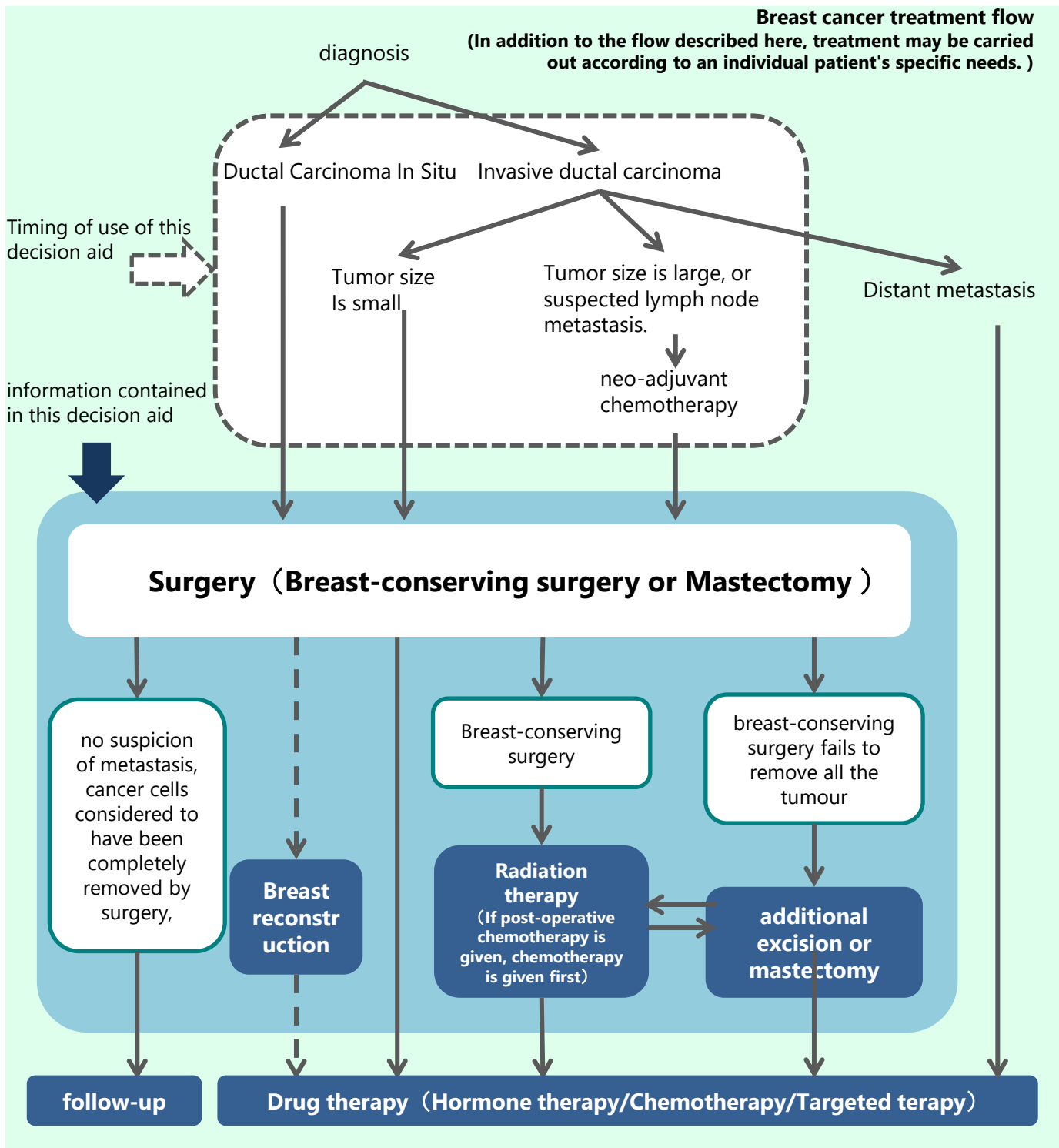


From the diagnosis of breast cancer to surgery and subsequent treatment, the schedule proposed by the surgeon was followed. My surgeon seemed very busy, so I gathered information from the internet and books. I approached my treatment considering what was best for me. (Ms. E)



● Breast cancer treatment flow

This decision aid focuses on the treatment flow for breast cancer, particularly the decision on the surgical method and whether to undergo breast reconstruction. The decision aid is designed to be used for patients diagnosed with cancer and required to undergo surgery.

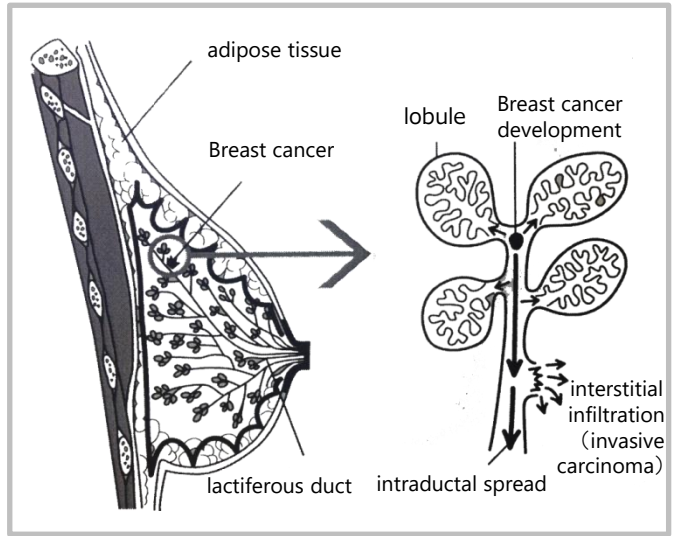


Choosing an appropriate treatment requires a proper understanding of the medical characteristics of the options. Learn about the options from a medical point of view. Then compare the different types of surgical procedures and the differences between them.

● What is breast cancer?

The breast consists of mammary glands that produce milk, the ducts that carry the milk and the fat that supports them. Each mammary gland is divided into lobules, which are connected by duct-like structures called milk ducts.

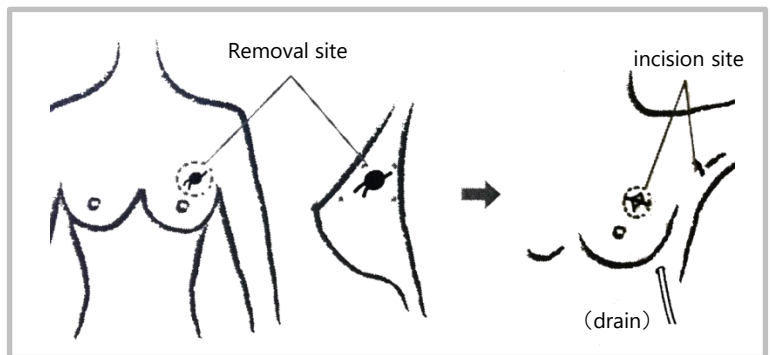
About 90% of breast cancers originate from these ducts and are called ductal carcinomas. About 5–10% of breast cancers arise from the lobules and are called lobular carcinomas³. Treatment of breast cancer includes surgery (surgical treatment), radiotherapy and drug therapy (e.g., hormone therapy, targeted therapy and chemotherapy).



● Basic knowledge about surgery

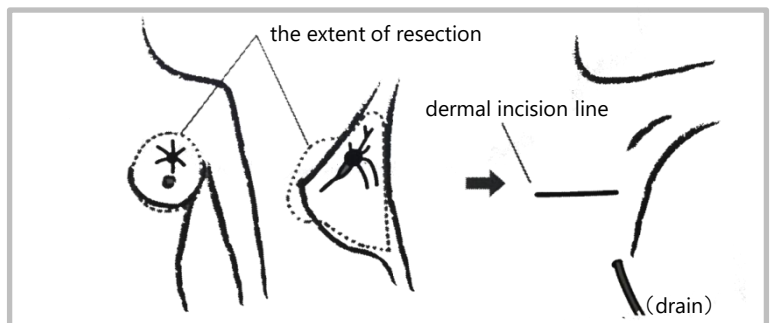
■ Breast-conserving surgery
(Partial mastectomy)

Breast-conserving surgery (partial mastectomy) is a procedure in which only the part of the breast which is cancerous is removed⁷.



■ Modified radical mastectomy
(Mastectomy)

The breast is removed, leaving the pectoralis muscle, including part of the skin⁴. Mastectomy is a surgical procedure in which the nipple, nipple areola and breast bulge are generally removed in their entirety. It is also called a total mastectomy.

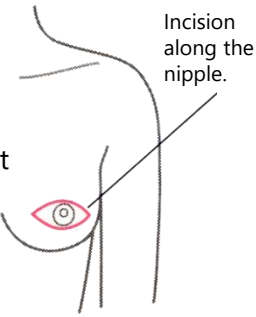


Subcutaneous mastectomy

The two methods listed on the previous page are the most commonly performed procedures, but the following two methods are also being increasingly used. However, there are conditions for the indications. If you want reconstruction after surgery, you may consult your doctor to see if this type of surgery is possible⁷⁾.

Skin-sparing mastectomy

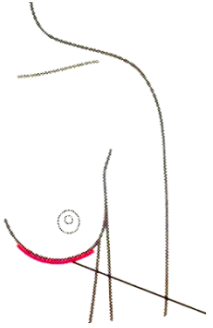
The nipple areola and mammary gland are removed, leaving as much skin as possible. The extent of the resection is determined according to the spread of the cancer⁷⁾.



Incision along the nipple.

Nipple-sparing mastectomy

The nipple areola is left intact and the mammary gland is removed. It is not yet a standard treatment as it has not yet been fully evaluated for safety and long-term survival. Indications need to be carefully considered⁷⁾.

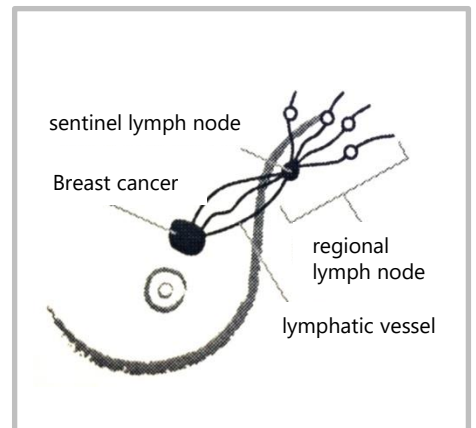


Incision under the breast.

Axillary lymph node surgery

Sentinel lymph node biopsy

The sentinel lymph node is where lymph is assumed to first arrive from breast cancer. Sentinel lymph node biopsy is a surgical procedure in which only these sentinel lymph nodes are removed to check for the presence of metastatic cancer cells. If there are no cancer cells in the sentinel node, it is assumed that no other lymph nodes have metastasized, and lymph nodes other than the sentinel node are not removed. Sentinel lymph node biopsy is 95–97% accurate in identifying metastases⁵⁾.



Axillary dissection

This is indicated for patients who have obvious metastases on pre-operative examination or who have been found to have metastases on sentinel lymph node biopsy. The lymph nodes in the axilla are buried in fatty tissue. The removal of these in one lump to a defined extent is called dissection⁵⁾.

■ Breast reconstruction

This is a surgical procedure to reconstruct a new breast that has been lost as a result of breast cancer surgery. There are two types of reconstruction: an artificial breast implanted under the muscle (artificial breast reconstruction) or a portion of fat or muscle from the back or abdomen transplanted into the breast (autologous tissue reconstruction). It can be performed following breast cancer surgery (one-stage reconstruction) or again months or years later (two-stage reconstruction)⁵⁾.

If you are considering reconstruction, you should inform your surgeon and plastic surgeon about your preference, gather information and discuss with them.

● When mastectomy is considered more suitable than breast-conserving surgery

In the case of early-stage breast cancer, the medical outcome (outcome in terms of survival) is the same regardless of whether breast-conserving surgery or mastectomy is chosen²⁾.

However, mastectomy may be more appropriate in some cases considering following factors.

■ Mastectomy is more suitable than breast-conserving surgery.

The following are some reasons why mastectomy may be more suitable than breast-conserving surgery

- ❑ If the lump is large compared to the size of the breast
- ❑ If the cancer has spread widely
- ❑ If there are two or more lumps separated by more than one in the breast
- ❑ If you are pregnant or for any reason it is considered inappropriate or unsafe to have radiotherapy
- ❑ If the cancer is so close to the nipple that the nipple must also be partially or completely removed.

There are other cases not listed here where the doctor considers a mastectomy to be suitable.

● Comparison of the benefits (pros) and risks (cons) of the surgical options
from a medical point of view

Let's compare the benefits and risks of each options from a medical point of view.

Depending on your medical condition, you may be able to compare all the options before you, or you compare two options: mastectomy only or mastectomy plus breast reconstruction.

	Breast-conserving surgery followed by radiation therapy	Mastectomy	Mastectomy with reconstruction
Survival rate	The survival rate remains the same regardless of which surgical procedure is chosen. By undergoing surgery, one can live longer than if one does not undergo surgery.		
Risk of recurrence in the breast	Marginally higher than with mastectomy (about 10% over a 10-year period ⁵⁾ .	Marginally lower compared to breast-conserving surgery (around 3% over a 10-year period).	The risk of recurrence in the breast is the same as for those who undergo mastectomy only.
Risk of cancer being left behind	There is a minor risk of the cancer being left behind. In this case, the surgery is performed again.	There is little risk of leaving behind cancer.	There is little risk of leaving behind cancer.
Treatment required in addition to surgery	Radiotherapy is usually required after breast-conserving surgery. Radiotherapy is given on five consecutive weekdays for five minutes each session for three to five weeks.	Radiotherapy may not be necessary in some cases. If lymph node metastases are found as a result of the surgery,	Same as for mastectomy. There is a risk that complications from reconstruction may require surgery.
Need for chemotherapy or other drug therapy	This is not related to the different methods of surgery. The decision is made after examining the characteristics of the cancer cells removed by surgery and the risk of recurrence.		

A comparison helps to understand which of the benefits and risks of each are the same and which are different.

The decision aid contains basic medical information about surgery, but it is not all-inclusive. You should understand the basics here and use it while discussing surgical procedures with your healthcare professionals. If you feel the need to gather information on your own, you can do so through books.

Whether or not you will be treated with medication after surgery, and what type of medication will be used, will be determined by examining the characteristics of the breast cancer tissue removed surgically, but we have not included information regarding this in this decision aid.

● Which option did you choose? What did you discuss with your surgeon?

When I had to make a decision about surgery, I told my surgeon "I would like to undergo breast-conserving surgery if it can help preserve my breast shape." I underwent breast-conserving surgery after I had received an adequate explanation of not only the advantages, but also risks involved from my surgeon. (Ms. A)



My surgeon showed me MRI and CT images and explained that breast-conserving surgery was not possible because of the large size of the tumor and that a mastectomy would be more suitable. (Ms. K)



I chose breast-conserving surgery on my own after my surgeon explained to me that there were two options—breast-conserving surgery and mastectomy—and their benefits and risks. (Ms. D)



The surgeon provided information about the benefits and risks of both breast-conserving surgery and mastectomy.

However, the surgeon recommended mastectomy because it would be difficult to preserve the shape of my breast considering the number of lumps and the location of my cancer. (Ms. I)



For some breast cancer survivors who provided their stories, the doctor decided whether breast-conserving surgery or mastectomy was appropriate and only one method was explained to them.

If the surgeon recommends one or the other to you, the best method in terms of medical and standard of care is chosen and information provided.

If you feel that you are not convinced or do not understand, you can ask why that particular method is suitable for you and why the other option is not.

● What did you think when comparing the benefits and risks of each option?

Comparison of the benefits and risks helped me choose my option.

Knowing the disadvantages of each option allowed me to consider carefully about my options. I will be satisfied with my decision even if something unexpected happens.
(Ms. M)



The surgical method was determined by the size of the tumor and other factors rather than a comparison of benefits and risks. (Ms. F)



I chose breast-conserving surgery. I believe I made a good choice because I did not feel the sense of loss of having lost a breast.

However, I have concerns about the risk of cancer recurrence.
(Ms. E)



In order to make the best choice for me, I made a comparison by writing down the advantages and disadvantages of each option in a notebook.

By writing, rather than thinking about it in my head, I was able to calmly sort out my feelings and go into the surgery satisfied.
(Ms. J)



There are benefits and risks to both choices, and there is no right answer, but I think it was important to spend time worrying (comparing) until I was satisfied with my choice.
(Ms. A)



I had to make my choice in a hurry. So I don't think I was able to compare them properly.
(Ms.H)



I attended a seminar on breast reconstruction prior to my surgery. I was able to see pictures of breast-conserving surgery, mastectomy only, mastectomy plus breast reconstruction at the seminar.

I was able to see pictures of both good and not-so-good outcomes at the seminar and identify the benefits and risks of each method.
(Ms. J)



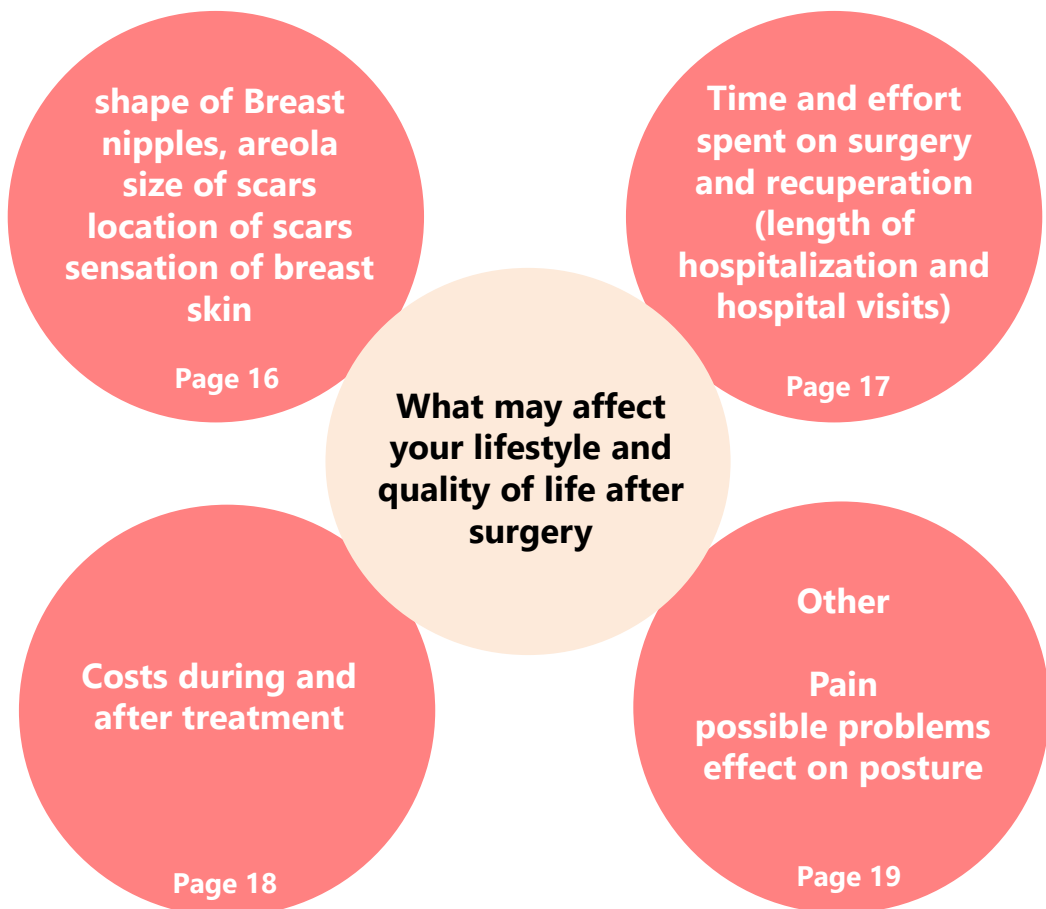
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Surgery to remove the cancer is not the end of the process. Life continues long after surgery. It is important to revamp your lifestyle and the impact on your daily life and to choose your treatment wisely.

For early-stage breast cancer, the medical outcome (outcome regarding survival) is the same regardless of which surgical procedure you choose²⁾. It is important to learn about both the effects of surgery and the impact on quality of life after surgery.

Let's look at the similarities and differences between the surgical options in four points that may affect your lifestyle and daily life.



● **Shape of breast, nipple/areola, scar size, location and post-operative breast skin sensation**

The table below shows the similarities and differences between the different options in terms of shape of breast, nipple/areola, scar size, location and post-operative breast skin sensation.

	Breast-conserving surgery followed by radiation therapy	Mastectomy	Mastectomy with reconstruction
shape of breast, nipple/areola	<p>The appearance of the breast may be the same as before surgery or it may be deformed due to the location, size and spread of the cancer.</p> <p>Whether the breast deformity is minor or major depends on the balance between the original breast size and the size of the cancer.</p> <p>A dimpling may occur after the tumor has been removed, or there may be a left-right difference in the position or orientation of the nipple.</p>	<p>There are several types of mastectomy.</p> <ul style="list-style-type: none"> ● Removal of the entire breast, nipple and areola. ● The nipple and areola are left in place and the mammary glands are removed. ● The nipple, areola, and the mammary glands are hollowed out. <p>You will have a flat chest after your breast is removed. The possible options depend on individual' situations.</p> <p>It is important to discuss this with your doctor.</p>	<p>Breast reconstruction can create a breast shape. If you have had your nipple or areola removed, reconstruction can also be used to create a nipple or areola.</p> <p>When and how to reconstruct</p> <p>-Timing-</p> <ul style="list-style-type: none"> ● At the same time as breast cancer surgery. ● After a period of time following breast cancer surgery. <p>-Methods-</p> <ul style="list-style-type: none"> ● Reconstruction using an artificial breast ● There are advantages and disadvantages depending on the timing/method of reconstruction using autologous tissue (using part of the fat or muscle from the patient's abdomen or back). It is important to discuss this with your surgeon or plastic surgeon.
scar size location	<p>The size and location of the scar will depend on the location, size, and spread of the cancer.</p>	<p>The size and location of the scar will depend on the method used to perform the mastectomy.</p>	<p>The size and location of the scar will differ depending on the method of reconstruction. In the case of reconstruction using autologous tissue, the scar is larger than that of an artificial breast, and it is located where the skin, muscle, and fat are removed.</p>
post-operative breast skin sensation	<p>There will still be sensation of the breast skin.</p>	<p>You may lose sensation of the skin in the area where the surgery was performed. Sensation may or may not recover over a year or two.</p>	<p>This is similar to mastectomy.</p>

● Time and effort spent on surgery and recuperation

The table shows the similarities and differences in the time and effort spent on surgery and recuperation by different surgical procedures.

	Breast-conserving surgery followed by radiation therapy	Mastectomy	Mastectomy with reconstruction
Length of hospitalization	<p>The length of hospitalization depends on the medical institution where you are being treated and on your progress after the surgery.</p> <p>If the post-operative course is favorable, the patient may be discharged within a few days to a week.</p> <p>If the post-operative course is favorable, the hospital stay is usually shorter than for mastectomy or mastectomy plus breast reconstruction.</p>	<p>The length of hospitalization depends on the institution where the patient is treated and the course of the post-operative period.</p> <p>A relatively longer stay than for breast-conserving surgery is common.</p>	<p>The length of hospitalization depends on the treating medical institution and the course of the post-operative period.</p> <p>As a rough guide only, it can take from a day to a few days for artificial breasts (implants) and from about two weeks to a month for autologous tissue.</p> <p>Consult your doctor or plastic surgeon about the length of hospitalization due to reconstruction, regular visits to the hospital and how long you will need to stay.</p>
Length of time to recovery	<p>The time it takes to be able to perform your original activities may vary greatly from person to person.</p> <p>Recovery time after surgery may be shorter than with mastectomy or mastectomy plus breast reconstruction, if the patient is doing well after surgery.</p> <p>The time and effort of daily visits to the hospital for radiation therapy for 3 to 5 weeks are required.</p>	<p>The length of time until the patient is able to return to normal activities may vary greatly from person to person.</p> <p>Recovery time after surgery is generally somewhat longer than with breast-conserving surgery, even if the postoperative course is favorable.</p>	<p>The length of time until you are able to do your original activities may vary greatly from person to person.</p> <p>Your recovery time may vary depending on the different methods of reconstruction.</p> <p>Consult your surgeon or plastic surgeon for recovery time after reconstruction.</p>

● **Costs**

The table shows the similarities and differences between the options about costs.

	Breast-conserving surgery followed by radiation therapy	Mastectomy	Mastectomy with reconstruction
Costs	<p>Costs related to standard treatment, including surgery for breast cancer, are covered by health insurance (public medical insurance).</p> <p>In some cases, a high-cost medical care reimbursement system may also be available. Some coverage depends on the type of medical insurance that an individual has. If you have chemotherapy after surgery,</p> <p>you will also have to pay for a wig. Wigs are not covered by health insurance and are self-paid.</p>		
	<p>After surgery, there may be costs for pads and bras to compensate for the appearance of the breasts (if the breasts retain their shape, there is no need to be purchase new ones).</p> <p>You will have to pay for transport to and from hospital (every weekday for 3–5 weeks) while undergoing radiotherapy.</p>	<p>After surgery, you may have to pay for pads, artificial breasts and bras to compensate for the shape of your breasts.</p>	<p>Since 2013, some methods of reconstruction with artificial breasts are being covered by health insurance (autologous tissue has been covered by health insurance for some time).</p> <p>Some methods are covered by health insurance and some are not.</p> <p>Before reconstruction, talk to your plastic surgeon or surgeon about the costs as well.</p>

Inform your healthcare professionals regarding any concerns you may have about your life after surgery.

By informing your healthcare professionals, you will be able to discuss with them specifically the best treatment options, together with the effects of the treatment and your life after treatment.

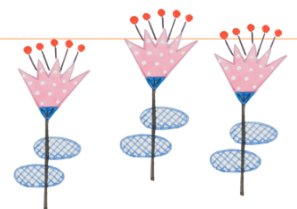


● **Other (pain, possible other problems, effect on posture)**

The table also shows other similarities and differences between the options about pain, possible problems and postural effects.

	Breast-conserving surgery followed by radiation therapy	Mastectomy	Mastectomy with reconstruction
Pain	<p>You may experience pain at the surgical site shortly after surgery, which can be relieved with painkillers. You may experience heat and pain due to post-operative radiotherapy.</p> <p>You may still experience discomfort etc. after a period of time. Mammography is required for regular check-ups after surgery. Some pain may be felt during these procedures.</p>	<p>In the immediate post-operative period, you may experience pain at the surgical site, which can be relieved with painkillers.</p> <p>After some time, discomfort may still be experienced.</p>	<p>In the early post-operative period, pain at the surgical site may be experienced, but can be relieved with painkillers.</p> <p>For reconstruction with an artificial breast, pain may occur while the expander is creating a bulge.</p>
Other possible problems	<p>Some people may feel depressed because of the change in the appearance of their breasts.</p> <p>Post-operative radiotherapy is required. Radiotherapy after surgery causes skin changes.</p> <p>If reconstruction is desired due to changes in the appearance of the breast, there is a risk that the radiotherapy will reduce the elasticity of the skin, making reconstruction difficult or causing problems after reconstruction.</p>	<p>Some people lose their breasts and become depressed. If lymph node metastases are present, additional radiotherapy may be recommended.</p> <p>You will need to ask your doctor's opinion on this.</p>	<p>-Reconstruction at the same time as mastectomy-</p> <ul style="list-style-type: none"> ● It may be burdensome to think about both surgery and reconstruction. ● There is little or no loss of the breast. ● You may not have time to think carefully about reconstruction options. <p>-Reconstruction afterwards-</p> <ul style="list-style-type: none"> ● You may feel depressed by the temporary loss of your breasts. ● You can consider about reconstruction more gradually. ● You will have more surgeries. <p>Some people are happy with their breasts after reconstruction, others are not. There is a risk of problems associated with reconstruction.</p>
Effect on Posture	<p>Compared to a mastectomy, the effect on postural balance may be marginal, but some patients may feel that their postural balance has been compromised.</p> <p>The extent to which postural balance is affected may vary from person to person.</p>	<p>Losing one breast to a mastectomy can cause postural imbalance and neck and shoulder pain in some patients.</p> <p>The extent to which postural balance is affected may vary from person to person.</p>	<p>Compared to a mastectomy, postural balance may be less affected, but some patients may feel that their postural balance has been compromised.</p> <p>There are individual differences in the effects of postural balance.</p>

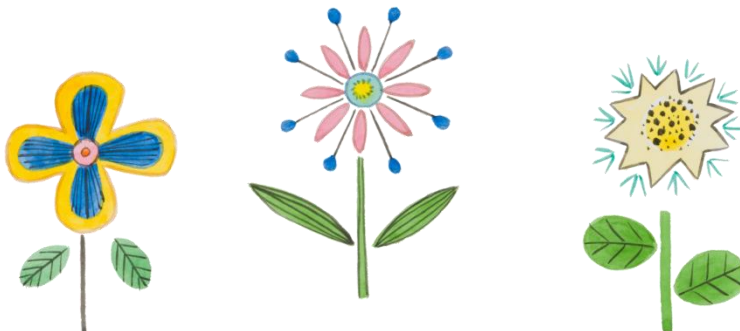
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You have learnt about your options from two aspects: the medical aspect and the impact on your lifestyle/day-to-day life. It is important that your decision is well informed and based on your values. Once you are clear about your values, you are more likely to discuss your surgical choices with your surgeon.

Pages 22–25 provide four perspectives to help you clarify what is most important to you, so you can weigh up or check your concerns. As you gather information, talk to healthcare professionals and discuss with your family, your initial ideas about what you want to care for may change.

As long as you do not feel burdened, you may take some time in the run-up to your surgery to review and re-evaluate what you have ticked off your list.



● **Shape of breast, nipple/areola, scar size, location and post-operative breast skin sensation**

Thinking about the shape of the breast and the scars helps to visualize the prospects for life after surgery.

For example, will the appearance of the breast change, and

- Will I lose my femininity?
- How will my children and grandchildren react? Will I be able to bathe with them?
- Will I be able to go to hot spring again? Will the pads I use to compensate become a nuisance?
- Will my relationship with my partner change?

You may feel worried about these things. But not all is lost. There are many things you can learn to cope with and deal with successfully. Consider the table below to see how important each thing is to you, with 0 meaning 'not important' and the higher the number, the more important it is.

Circle the number that applies to how important it is to you. You can choose from the following or examine each one individually.

	not important						important
How important is it for you to keep your breasts?	0	1	2	3	4	5	
How important is it to you that you can feel the skin of your breast?	0	1	2	3	4	5	
If you have a mastectomy, how important is it that the shape of your breast is as close as possible to its original shape?	0	1	2	3	4	5	
If you were to have a mastectomy, how important would it be for you to have breast reconstruction simultaneously?	0	1	2	3	4	5	

You may also want to examine, for example, if necessary, you can ask your doctor questions in the run-up to surgery.

How will the shape of my breasts change if I undergo surgery?

Where and how long is the scar expected to remain?

(For example, do I still want to wear fashionable open-breasted dresses after the surgery?)

(I would like to know if there is a way to make the scars as inconspicuous as possible and whether this would be suitable in my case).

● **The risk of cancer recurrence in the breast after surgery and the risk of tumor being left behind**

The risk of cancer recurrence in the breast after surgery differs only marginally depending on the surgical method.

The risk of tumor being left behind also differs. It may be difficult to think about this before surgery. However, thinking about this will help you envision how you feel after surgery.

In the table below, we can weigh the factors, with 0 meaning "not important" and a higher number meaning "important". Circle the number that best describes how important it is to you. You may choose from the following or consider them one by one.

	not important	important
How important to you is a difference of a few percent in the risk of cancer recurrence in breast due to different surgical procedures?	0	1 2 3 4 5
How important to you is to reduce the chance of tumor being left behind?	0	1 2 3 4 5
How important is it to you to eliminate the risk of reoperation due to leftover cancer?	0	1 2 3 4 5

You may also consider the following

- If I chose breast-conserving surgery and the chance of cancer recurrence in the breast was only slightly higher, would that be acceptable?

- Would I feel more comfortable having my entire breast removed?

● **Time and effort spent on surgery and recuperation**

The time and effort spent for treatment and recuperation differ depending on the method of surgery. Specifically, the length of hospitalization at the time of surgery, the time required for recovery after surgery, and whether radiotherapy is necessary after surgery differ (the length of hospitalization at the time of surgery varies depending on the facility where the patient receives treatment. Recovery time also varies from person to person. Your lifestyle (work, housework, taking care of family members such as childcare or nursing care, hobbies, etc.) may dictate the amount of time and effort you can spend on treatment and recuperation.

For example, if you wish to continue working, you will need to consider how long you can take off from work and whether you will be able to attend daily radiation therapy after breast-conserving surgery. Considering the amount of time and effort involved will help you envision your hospital stay for surgery, your hospital visits, and your outlook on daily life after surgery.

Examine how important the following points are to you. 0 means "not important" and the higher the number, the more important it is. Circle the number that applies to how important it is to you. How important is it to you that the recovery time and effort after surgery is minimal?

	not important						important
If you have breast-conserving surgery, would you be able to attend radiotherapy every weekday for approximately three to five weeks, which would be necessary afterwards?	0	1	2	3	4	5	

You may also want to consider the following

- ❑ If you have breast-conserving surgery, would you be able to attend radiotherapy every weekday for approximately three to five weeks, which would be necessary afterwards?
- ❑ If you choose breast reconstruction using an implant, would you be able to afford the hospital visits and the time required for the surgery?

● **Costs**

The costs of surgery and post-operative costs can be discussed. In addition to the cost of breast cancer surgery, there are other costs such as hospitalization, transport costs for hospital visits, pads, breast prosthesis and bras.

In addition, if you have reconstruction, you will need to gather information on which methods are covered by health insurance (public medical insurance) and which are not. If you undergo non-surgical treatment, you will have to pay for that treatment. If you have chemotherapy, you will need to buy a wig.

Examine how important the following points are to you: 0 means “not important” and the higher the number, the more important it is. Circle the number that best describes how important it is to you.

	not important						important
How important is it to you that the cost of treatment and the costs associated with treatment are as low as possible?	0	1	2	3	4	5	

Other things to consider include

- Which treatments are covered by my private medical insurance?
- Where can I buy artificial breasts and special innerwear that can also be used after surgery? How much do they cost?

● **What did other breast cancer survivors value in their choice of surgery? What did they think about, what information did they gather and with whom did they discuss it, in order to be clear about what they valued?**

I have two boys. When I was having surgery, my older son was a junior high school student and my younger son an elementary school student. I wanted to live at least until my younger son graduated from high school. I therefore made up my mind to undergo whatever treatment options were available. My family believed the same as I did.

When I told my sons about my breast cancer, they told me "We don't want anyone to know about your cancer. We don't want you to change because of cancer." So I continued to live as I had done before being diagnosed with cancer.(Ms. C)



I made a choice, with survival as my top priority. (Ms. I)



I hope to have a child in the future. I chose to undergo mastectomy because I wanted to reduce the risk of recurrence. I discussed my options with my husband and my parents and was able to make a decision after sharing my families' and my preferences. (Ms. J)



I chose my hospital based on these priorities: first, no local recurrence; second, satisfied with reconstruction; and third, shorter hospitalization and recuperation days and less time off work.

I was thinking about the worst possibilities. I didn't tell my husband any particular details and didn't discuss it with anyone. (Ms. H)



Retaining my breasts after surgery was very important to me.

I couldn't imagine losing my breasts and I wasn't confident that I would be able to overcome this mentally.

I was single at the time and wanted to get married. I was not confident that I could be proactive looking for a life partner, with or without breasts.

I also felt that I needed to get back to my pre-breast cancer self as soon as possible, so that I could return to work and get back to my daily life.

It was also important that there were no time constraints. And the fact that it was only one surgery was a major reason for my decision. I wanted to avoid having more than one surgery, because I didn't want to miss work. I also wanted to reduce the burden on my body for the surgery and reduce the cost of hospitalization. When thinking about what was important to me, listening to other people's experiences at the breast cancer self help group was very helpful. (Ms. M)



Immediately after I was informed of my breast cancer diagnosis, I thought, "I don't care what method is used as long as it saves my life." However, when I found out that there are various methods of treatment for early-stage breast cancer, I came to the conclusion: "If my breasts can be left beautifully, I want to keep them. If they are ruined, I will have a mastectomy and breast reconstruction." I was particular about the shape of my breasts. (Ms. A)



● Make sure you know how much you are ready to decide

You have the basic knowledge and have clarified what is important to you. Now let's see how ready you are to decide.

Check the boxes that apply to you.

● Do you know the benefits and risks of each option?

Yes No

● Are you clear about which benefits and risks matter most to you?

Yes No

● Do you have enough support and advice to make a choice?

Yes No

● Do you feel sure about the best choice for you?

(It is important that you feel well-informed and congruent with your values.)

Yes No

The SURE Test © O' Connor and Légaré, 2008⁸⁾

If you have a "No" to any one of the four above, you may not be fully prepared to make a decision yet. Is there anything you would like to do before you decide? Check the items on the following page to organize what you would like to do.

● Plan the next steps based on your needs.

You can also check the following items to prioritize what you would like to do next and take action.

- Nothing. I am ready to make a decision.
- I need to discuss my options with _____.
- I need to do more research on my options.
- I need to clarify which benefits (pros) and risks (cons) are most important to me.
- In addition, I need to _____.

Many people are unsure of what to do and how to proceed until they decide. Once you know what you want to do in the above, it will be easier to take the next steps.

If you still feel you don't have a good understanding of your options, you can re-read the chapter on Page 7 – “Know your options (medical knowledge of breast cancer surgery)” in this decision aid, or ask your doctor to explain it to you.

If you are still unclear about what is important to you and what you want to decide, you can re-read the chapter “Clarify what is important to you” on Page 21, or talk to other people, such as nurses, family members, or breast cancer survivors.



● How to use other breast cancer survivors' stories as information

Knowing what other breast cancer survivors valued in their choice of surgery may be helpful when clarifying what is important to you, and when having an outlook for the future. This decision aid also includes testimonials from people who have already undergone surgery. You can choose whether or not you would like to refer to the experiences of other people who have gone through more.

■ What are the benefits (advantages) of knowing other breast cancer survivors' stories?

Stories from other breast cancer survivors are “concrete and easy to understand” because they are told in the words of those who have experienced it. You will learn the following from other breast cancer survivors' experiences.

- An approximate idea of what is about to happen
- Specific experiences (when, what, how long, etc.)
- After the choice, what you think about it looking back on the journey to the choice
- What life is like as a result of choosing to do this
- (e.g., pain, size of wound, degree of distress, resume work)

■ What do you need to consider when learning about other breast cancer survivors' stories?

Each person's experience has a story. They can help you understand what is about to happen to you. However, it is important to bear in mind that “each person feels differently” after the same surgery.

- Some breast cancer survivors may have experienced pain you cannot imagine. You may have many concerns as you learn about their painful experiences. However, what one person experiences may not necessarily happen to you always.
- learning about the experiences of more than one breast cancer survivor will give you an insight into the diversity of experiences. If you can see the diversity, you may be able of imagining more than what will actually happen and not feel more anxious.
- Breast cancer treatment is ever-evolving. It is a good idea to check when you learn about your experience to find out when you were treated and when you are talking about it.

● Did other breast cancer survivors use their stories? What aspects did they find useful?

I actively met with other women with breast cancer who had joined a self-help group.

However, I was disappointed that I did not meet women who had continued working during their treatment. I needed some advice from women in the same situation as me before starting my treatment. (Ms. F)



There was no opportunity to hear or read patient experiences of surgery before I had cancer. I think that was the time when I wanted to know the most about breast cancer survivors' stories. (Ms. I)



When I had my surgery, it was around the time when breast cancer survivors' stories started appearing on the internet, like blogs. I read them, but felt the information was biased. I attended a seminar and listened to a breast cancer survivor. It was good because it encouraged me.. (Ms. C)



At the time, I was not aware that I could use other breast cancer survivors' experiences as a reference.

I wanted to make a decision based on my own feelings. I thought that with all the information on the internet, I would be even more confused. Looking back, I think I should have referred to the experiences of other breast cancer survivors a little more... (Ms. J)



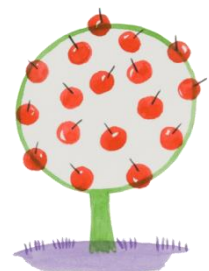
I used the experiences of other breast cancer survivors to inform my choices. I attended patient meetings and heard from breast cancer survivors. They allowed me to see and touch their breasts after surgery. I was very happy to hear from breast cancer survivors about my fears, pre- and post-operatively.

I was able to compare the feel of the reconstructed breasts with different techniques and the scars, which helped dispel my concerns and helped me make a decision about my choice. (Ms. M)



I researched on the internet and in books to find out what surgical choices other breast cancer patients had made.

Blogs and testimonials were particularly helpful in understanding how they are spending their time now after making that choice (e.g. satisfaction with the choice, regrets, etc.). However, I was confused when I saw information that I didn't want to know and didn't need. (Ms. K)



■ How to find out about other breast cancer survivors' experiences

There are several ways to find out about other breast cancer survivors' experiences. This Decision aid includes information on how to talk to them in person and how to use the internet. If you would like to find out about other breast cancer survivors' experiences, please refer to this section.

Meet and talk to a breast cancer survivors in person.

- Before undergoing surgery, you can meet directly with a breast cancer survivor and hear about their experience.
- In some patient groups, you can see and touch the breasts of people who have undergone reconstruction.
- You can also meet other people who have gone through the procedure at breast cancer self help groups (where people have undergone surgery).

Benefits

- Meeting in person makes it easier to ask questions about the experiences of others who have gone through the surgery.
- Meeting directly with the patient makes it easier to imagine what daily life will be like after the surgery.
- It is easier to obtain information on what you want to know and what you want to ask.
- You can get not only information about their experiences, but also emotional support.

Risks

- The other party is also a patient, so medical questions are not very suitable.
- Not all of the experiences of the people you meet will be available.
- If you narrow down the people you want to meet too much (for example, people in their ○○ age group, people with ○○ and ○○, people undergoing ○○ treatment, etc.),

<Tips to make good use of this information>

- Try to learn about the experiences of more than one person.
- Bear in mind that each person has a different way of feeling and thinking.
- Don't just listen to their stories, but also talk about your feelings and concerns.



Use the internet to learn about other breast cancer survivors' experiences (blogs, online communities)

- Blogs are like personal diaries. Many people write about the progress of their breast cancer treatment.
- The purpose of blogging is different for each individual. Some people want to write about their painful feelings, while others want to communicate with their friends.
- Online communities come in a variety of forms, such as Yahoo Chiebukuro, which can be viewed by anyone, and social networking services (SNS), which are members-only.
- Both blogs and online communities can be used for browsing and gaining information, or for communicating with bloggers and commenters on the internet.

Benefits

- If the information is written in concrete terms, it can be used as a reference in the future.
- If it contains specific information on how to deal with a problem, it can be useful when you are in trouble.
- You can use it at home in your spare time
- A wide range of diverse information can be obtained.
- Can be used anonymously

Risks

- Information is vast.
- It can be difficult to sort out the information you want to know from the information you don't want to know.
- Information may not be up-to-date.
- May contain incorrect medical information
- Not all of the experiences of the blogger or the person giving advice.

<Tips to make good use of this information>

- Try to get to know the experiences of more than one person.
- Be aware that each person has a different way of feeling and thinking.
- Protect your own personal information.
- When communicating with people you can't see make sure to be good mannered and engage in comfortable communication.



Other ways to find out about experiences on the internet (Health and Illness Narratives: Dipex Japan)

- Health and Illness Narratives: Dipex Japan is a database of "narratives" of people's experiences.
- The narratives are verified by members of the public, including medical professionals, before they are made public.
- As of March 2014, the narratives of 50 breast cancer patients are available to anyone on the internet free of charge.
- Website address. <http://www.dipex-j.org/>

Conclusion

● For informed and values-based choice

There is no right or wrong choice for early breast cancer surgery. If you share your values and preferences along with the professional opinion of your healthcare professionals, you can make a choice that is right for you.

Each choice has its benefits (pros) and risks (cons). To help you understand the benefits (pros) and risks (cons) of each choice from a medical perspective and to help you examine which benefits and risks you think are important from your values and to make it easier to communicate with others, such as healthcare professionals, family members and others who have been through it, this decision aid is designed to help you do this.

● Development process of the decision aid

This decision aid is based on the opinions of breast cancer survivors, doctors, nurses and nursing and medical informatics experts.

The medical information contained herein has been verified by experts specializing in breast cancer treatment.

However, it does not cover all medical literature, but it does contain basic information. It also includes testimonials from people who have undergone surgery for breast cancer (their experiences during the decision-making process before and after the surgery) at each step of the process. We have explained the purpose of the publication to those who have provided us with their stories and have obtained their consent before publishing them. Although it is not possible to cover all experiences, we have included a good balance of which surgeries were chosen.

It is not funded by any companies or other organisations related to medicine (no conflict of interest).

● Updated information in the decision aid

The content of this decision aid is reviewed and updated as needed. When using the decision aid, please check the date and time the information is updated.

The information provided here is intended to facilitate communication with your healthcare provider in making your decision and to help you organize the information you know.

(Content last updated June 16, 2014)



● Tell us your experiences of life after surgery and now.

My life after surgery is much the same as it was before I had breast cancer. I lost my breasts following mastectomy, but I had breast reconstruction.

Of course, there is no substitute for real breast, and the pain of losing my breast will always remain in my heart. I thought at the time, "It's hopeless to lose my breasts!" . But I wish I could say to myself back then that it was not like that. Now I can live a normal life with a smile on my face. (Ms. A)



I try to lead a regular life and return to my life before I had breast cancer. (Ms. L)



Many changes have taken place. Nevertheless, I have a busy but enjoyable life with my family, work, hobbies and volunteering.

I am still thinking about the future, as I consider the treatment completed when my left and right breasts are in contrast. (Ms. C)



Even after breast cancer... life after breast cancer is more exciting! (Ms. G)



It has been several years since I underwent the surgery. My life is the same as it was before the surgery.

I feel more "There is no time like the present" than I used to be than ever before (work, hobbies, exercise, etc.) . (Ms. D)



I had to have the silicon removed because of an infection after I underwent mastectomy with reconstruction. It is now a year since I completed breast reconstruction surgery. I have received only hormonal therapy.

Sometimes, I feel some tingling pain, but I can live a normal everyday life and I enjoy participating in sports. (Ms. H)



It has been seven years since my surgery. I have also completed hormone therapy.

I exercise regularly and maintain a healthy diet and lifestyle to stay healthy. I was working during my treatment and was able to work until retirement. Now I enjoy a comfortable life. (Ms. C)



This decision aid is based on four such aids developed in other countries on the choice of breast cancer surgery.

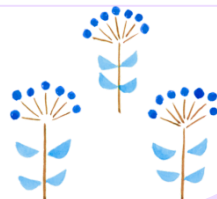
<List of decision aids developed in other countries as a reference>

1. Breast Cancer: Early-Stage Breast Cancer: Choosing Your Surgery
(Health crossroad (Health Dialog))
<https://www.healthcrossroads.com/EXAMPLE/crossroad.aspx?contentGUID=c3c65b10-bd6f-409c-afd0-4bc15fec7145> [2014-01-10]
2. Breast cancer: Should I have breast-conserving surgery or a mastectomy for early-stage cancer?
(Healthwise)
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[2014-01-10]
3. Surgery Choices for Women with DCIS or Breast Cancer
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A sheet of lined paper with a purple border and rounded corners. The page contains 20 horizontal purple lines for writing. In the bottom right corner, there is a small illustration of three stylized blue flowers with yellow stems and leaves.





A decision aid for choice regarding surgical treatment

to help patients diagnosed with breast cancer make an informed and values-based decision

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