MAKING DECISIONS ABOUT YOUR BREAST CANCER TREATMENT:

A decision aid for women with early breast cancer
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This booklet belongs to:


Your doctor/nurse is:


What are your concerns?

It is normal to feel shocked, angry, anxious, fearful or sad when first diagnosed with breast cancer. You should give yourself some time to think through and accept the diagnosis of breast cancer before making a decision about the treatment.

Women with early breast cancer often have many questions:

1. Why did I get breast cancer?
2. What exactly is breast cancer?
3. Am I going to die?
4. How long am I going to live?
5. Do I have to go for surgery?
6. Are there other ways of treating breast cancer besides surgery?
7. Do I need to go for chemotherapy?
8. Can I try traditional and complementary therapy?
9. How is my family (including my husband) going to take this?
10. Will my children get breast cancer too?

This booklet will answer these questions and guide you to make an informed choice about the treatment. You are advised to speak to your doctor or nurse about your concerns and feelings.

This booklet should be used together with your doctor or nurse.
What is breast cancer?

Breast cancer is the most common cancer among women in Malaysia and around the world. One in twenty women will develop breast cancer in their lifetime.

Women often discover that they have breast cancer when:

- they go for screening (mammogram)
- they find a lump in their breast
- there is discharge from the nipple

*B Blood test is not helpful to detect breast cancer*

Cancer occurs when cells in our body turn abnormal and start to grow out of control. In breast cancer, these abnormal cells grow in the breast to become a lump. Breast cancer is usually painless and, if not treated, may spread to other parts of the body such as lymph nodes, lungs, liver, bones and brain.

What causes breast cancer?

A person’s genetic make-up, lifestyle and other environmental factors may put a woman at risk of getting breast cancer. However, in most cases, no specific cause can be found.

The risk factors include:

- family history of breast or ovarian cancer (mother, sister or daughter)
- past history of breast lumps (certain types), breast or ovarian cancer
- breast cancer genes (BRCA 1 or 2)
- past exposure to high-dose radiation like radiotherapy
Knowing more about breast cancer

Your doctor would recommend the treatment of your breast cancer based on:

- the stage of the cancer
- the grade of the cancer
- whether or not the cancer is sensitive to oestrogen, a female hormone

What are the stages of breast cancer?

The stage of breast cancer depends on the size of the tumour and how far it has spread. The earlier the stage of breast cancer, the better the chance of cure.

There are four stages of breast cancer:

- **Stage 1** – The breast cancer is less than 2cm in size. The lymph nodes under the arm are not affected and the cancer has not spread
- **Stage 2** – The breast cancer is between 2 and 5cm in size. The lymph nodes may be affected but the cancer has not spread.
- **Stage 3** – The size of the breast cancer is more than 5cm or it has spread to the skin or chest wall
- **Stage 4** – The breast cancer has spread to other parts of the body such as lungs, liver, bones and brain

You have stage ________________ breast cancer.

You may need additional investigations such as mammograms and CT scan to find out the stage of your breast cancer.
Knowing more about breast cancer

What happens to people with breast cancer?

It is important for you to know the following facts:

1. Most breast cancer double in size over 3-6 months.
2. Breast cancer often takes about 2 years to spread to other parts of the body.
3. Most women will live for another 2-3 years if they do not receive any treatment.
4. You may be told that alternative treatment will slow down the growth of your breast cancer. This may not be true because breast cancer often grows slowly even without any treatment.
Knowing more about breast cancer treatments

What are the treatment options for early breast cancer?

- Most doctors would recommend surgery because it is the most effective way to treat early breast cancer.
- Chemotherapy, radiotherapy or hormone therapy may be necessary after the surgery. They can improve the chance of cure and prevent the cancer from coming back.
- Some women prefer to seek alternative treatment such as food supplement, herbal medicine or spiritual healing. There is no good scientific evidence to suggest that they can slow down or cure cancer.

In the next section, we will explain each of the treatment options to you.
Knowing more about breast cancer treatments

Surgery

There are two types of surgery for early breast cancer:

- Lumpectomy
- Mastectomy

For both lumpectomy and mastectomy, an operation to the armpit is done during the surgery to assess whether the cancer has spread to the lymph nodes. Your doctor will discuss this further with you.

Lumpectomy

Some women prefer lumpectomy because it helps to conserve their breast.

- In lumpectomy, only part of the breast is removed. The surgeon will remove the cancer lump and up to 1 cm of the surrounding breast tissue.

- Cancer cells may move to the lymph nodes in the armpit. If so, they will be removed during the surgery.

- After surgery, a drain is used to remove any fluid or blood that collects under the wound. This drain consists of a soft plastic tube connected to a plastic bottle. It will be removed once there is no more fluid or blood.

- Most women can go home within a day or two.

- Occasionally, another surgery may be needed if cancer cells are too close to the edge of the tissue removed during lumpectomy. This happens in 5 out of 100 people.
Knowing more about breast cancer treatments

Mastectomy

- In mastectomy, the whole breast, including the nipple, is removed leaving a flat chest wall with a scar.

- Most women spend 2-3 nights in hospital. Like lumpectomy, a drain which consists of a soft plastic tube connected to a plastic bottle will be used to remove any fluid or blood collecting under the wound.

- Some women may consider breast reconstruction surgery where a new breast shape is created. Your surgeon can discuss this further with you.

Complications of surgery

- Complications can happen after mastectomy. This include:
  - **Seromas**: Fluid may gather in the wound a few weeks after the surgery. The fluid can be removed easily with a needle and syringe.
  - **Bleeding**: Sometimes blood gathers in the wound causing a swelling.
  - **Wound infection**: Infection may occur at the wound after surgery. This can be treated with antibiotics.
  - **Lymphoedema**: This is a long-term problem where your arm may become swollen and painful after surgery. This is because surgery may damage the lymphatic drainage under your armpit and causes the lymphatic fluid to accumulate in your arm.
Chemotherapy

- Chemotherapy is a medicine doctors use to kill cancer cells in the breast and those that might have spread to other parts of the body.
- It is usually given after surgery but before radiotherapy.
- After surgery, a doctor with special training in chemotherapy and radiotherapy (called an oncologist) will advise you whether you need chemotherapy.
- Chemotherapy is given as outpatient once every three weeks over a period of 4-6 months. It is given through a line that delivers the medicine into the blood.
- Common side effects of chemotherapy include: mouth ulcers, nausea and vomiting, hair loss, tiredness and changes in the menses.
- Each person responds differently to the chemotherapy but most people would need to take leave from work during chemotherapy.
- These symptoms are temporary and can be reduced by medicine.
- Infections and anaemia are more likely to happen after chemotherapy. A blood test is taken before each treatment to check whether you are fit to undergo the next cycle of chemotherapy.
- Chemotherapy may cause early menopause and infertility in some women. This is only temporary and the body will recover fully.

Please talk to your doctor or breast care nurse if you have any concerns about chemotherapy.
Knowing more about breast cancer treatments

Radiotherapy

- In radiotherapy, small doses of radiation are given to kill the cancer cells around the breast.
- Radiotherapy usually starts 6 weeks after surgery when the wound has healed.
- If you have been advised to undergo chemotherapy and radiotherapy, the chemotherapy will often be given first.
- Common side effects of radiotherapy include:
  - the skin may become red, itchy, sore or tender.
  - tiredness
  - hair loss in the treated area but not the hair on the head.
  - scarring of the lung
  - numbness, weakness and pain of the shoulder, arm and hand
  - lymphoedema
  - the breast may shrink over time
Knowing more about breast cancer treatments

Hormone therapy

• Some breast cancers are ‘hormone-sensitive’. Female hormones that are found naturally in women may stimulate cancer growth. Therefore, hormone therapy works by preventing the female hormones from stimulating cancer cells to grow.

• After surgery, the cancer is tested for sensitivity to the female hormone estrogen. This helps the doctor to decide whether you will benefit from hormone therapy.

• Sometimes hormone therapy replaces surgery for women who are too ill to undergo surgery

• Side effects include: hot flushes, night sweats, mood swing, weight gain and painful joints

Alternative treatment

Some women prefer alternative treatment such as food supplement, herbal medicine or spiritual healing. So far, there is no good scientific evidence to support using alternative treatment to cure breast cancer.

Modern medicine is based on scientific evidence while alternative treatment is often based on individual practitioners’ experience.

You may want to ask the following questions before considering alternative treatment:

• ‘Is the alternative practitioner qualified in treating breast cancer?’
• ‘Is there any scientific information based on human beings (not animals)?’
• ‘If there are claims that a person is cured, ask whether is it a breast cancer or a benign breast lump?’
• ‘What is the chance of alternative treatment curing breast cancer compared to surgery?’

It is important to know that most breast cancers grow slowly and do not spread immediately. If the breast cancer does not grow or spread within a few months, it does not mean that the alternative treatment is effective.
What are your choices?

Women with early breast cancer may choose:
- Surgery
- Alternative treatment
- No treatment

If you are considering surgery, your doctor may recommend:
- Lumpectomy or
- Mastectomy

Your doctor may advise you to undergo chemotherapy or radiotherapy after the surgery. If you are not ready to make these decisions now, you can do it after the surgery.
## Advantages and disadvantages

<table>
<thead>
<tr>
<th></th>
<th>Lumpectomy</th>
<th>Mastectomy</th>
<th>Alternative treatment</th>
<th>No treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How long will I live?</strong> (Cancer is considered cured if it does not come back in 5 years)</td>
<td>In 5 years, out of 100 women with breast cancer, 80 may live and 20 may die (with radiotherapy)</td>
<td>Same as lumpectomy</td>
<td>No good information is available. Ask the practitioner</td>
<td>Most women will die within 5 years</td>
</tr>
<tr>
<td><strong>Will the cancer come back?</strong></td>
<td>In 8 years, out of 100 women, 10 may have a relapse and 90 may not (with radiotherapy): 39 may have a relapse and 61 may not (without radiotherapy)</td>
<td>In 8 years, out of 100 women, 8 may have a relapse on the chest wall and 92 may not</td>
<td>No good information is available. Ask the practitioner</td>
<td>Most women will die within 5 years</td>
</tr>
<tr>
<td><strong>Will I need another operation?</strong></td>
<td>May be If there are cancer cells remaining. This happens in 5 out of 100 women</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td><strong>Will I get lymphoedema?</strong></td>
<td>Out of 100 women, 5 may get lymphoedema and 95 may not (with sentinel lymph node biopsy*); 17 may get lymphoedema and 83 may not (with axillary lymph node dissection*)</td>
<td>Same as lumpectomy</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

*please check with your doctor/nurse.*
## A decision aid for women with early breast cancer

### Of each treatment option

<table>
<thead>
<tr>
<th>Will I lose my breast?</th>
<th>Lumpectomy</th>
<th>Mastectomy</th>
<th>Alternative treatment</th>
<th>No treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>However, if the tumour margins are involved or if there is a recurrence in the future, a mastectomy will be recommended</td>
<td></td>
<td>However, you may consider breast reconstruction</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Is chemotherapy recommended?</th>
<th>Yes</th>
<th>Yes</th>
<th>No</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>(depending on oncologist...</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<table>
<thead>
<tr>
<th>Is radiotherapy recommended?</th>
<th>Yes</th>
<th>No</th>
<th>No</th>
<th>No</th>
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</thead>
<tbody>
<tr>
<td>(Unless the axillary lymph nodes are involved or the tumour is very large or involving the margins)</td>
<td></td>
<td></td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>How much does it cost?</th>
<th></th>
<th></th>
<th></th>
<th>No cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>(To be completed by your doctor/nurse)</td>
<td></td>
<td></td>
<td>(To be completed by the practitioner)</td>
<td>However, you may need treatment as the cancer grows and this will incur cost.</td>
</tr>
</tbody>
</table>
Knowing the facts

Please answer the following questions to find out whether you have understood the information we have given you so far. Your doctor or nurse will go through the answers with you later. You can also find the answers at the bottom of page 18.

You can tick more than one option.

A. Which of the options has the best chance of curing your cancer in 5 years?
   - No treatment
   - Lumpectomy
   - Mastectomy
   - Alternative treatment

B. Which of the options has the best chance of preventing relapse in 5 years?
   - No treatment
   - Lumpectomy with radiotherapy
   - Mastectomy
   - Alternative treatment

C. Which of the options may require chemotherapy?
   - No treatment
   - Lumpectomy
   - Mastectomy
   - Alternative treatment

D. Which of the options may require radiotherapy?
   - No treatment
   - Lumpectomy
   - Mastectomy
   - Alternative treatment

E. Which of the options has good scientific evidence for breast cancer treatment?
   - No treatment
   - Lumpectomy
   - Mastectomy
   - Alternative treatment
Knowing what is important to you

You may be receiving advice on breast cancer treatment from different people and sources. It is important that you spend time thinking about what is important to you before making a decision.

Please tick the boxes that apply to you. You can tick more than one.

**Surgery**
- I prefer surgery because
  - it offers the best chance of cure
  - I don’t want the breast cancer to come back
  - it has the most scientific evidence

**No surgery**
- I prefer not to have surgery because
  - I don’t want to lose my breast
  - I don’t want to have the side effects of surgery
  - I prefer treatment that is natural (e.g. herbs)

I am concerned:
- ☐ about going for chemotherapy after surgery
- ☐ about going for radiotherapy after surgery
- ☐ that the treatment is expensive
- ☐ that my husband or partner may not agree with my choice of treatment
- ☐ that my family may not agree with my choice of treatment
- ☐ whether I can recover quickly to return to my daily routine
- ☐ who is going to take care of my family when I am on treatment
- ☐ whether I am strong enough spiritually to undergo the treatment

*Please write down any other concerns on page 19.*
Do you need more support?

Please tick the appropriate boxes.

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
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- Do you know enough about each breast cancer treatment option to make a choice?
- Are you clear about what is most important to you to make a choice?
- Do you have enough support and advice from your doctor or nurse to make a choice?
- Do you have enough support from your family to make a choice?
- Do you need more time to think about the decision?

Answers to ‘Knowing the fact’ on page 16:
A. Mastectomy or Lumpectomy; B. Lumpectomy with radiotherapy; C. Lumpectomy or mastectomy; D. Lumpectomy or mastectomy; E. Lumpectomy or mastectomy.
Are you ready to make a decision about your breast cancer treatment?

☐ No, I am not ready
☐ Yes, I am ready

If you are ready to make a decision, which choice do you prefer?

☐ No treatment
☐ Lumpectomy
☐ Mastectomy
☐ Alternative treatment

If you are not ready to make a decision, you can come back later and discuss your decision with your doctor or nurse.

Use the space below to write down your concerns and questions for your doctor/nurse.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

This decision aid is not intended to replace the advice of your doctor.
Together, we can beat cancer!

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