A GUIDE FOR THE HEALTHCARE PROFESSIONALS

Making decisions about your breast cancer treatment:
A decision aid for women with early breast cancer
## CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>4</td>
</tr>
<tr>
<td>Contents of the PDA</td>
<td>5</td>
</tr>
<tr>
<td>Using the PDA</td>
<td>7</td>
</tr>
<tr>
<td>When to use the PDA?</td>
<td>8</td>
</tr>
<tr>
<td>Who to use the PDA</td>
<td>9</td>
</tr>
<tr>
<td>How to use the PDA</td>
<td>10</td>
</tr>
<tr>
<td>Your role</td>
<td>11</td>
</tr>
<tr>
<td>PDA evidence table</td>
<td>12</td>
</tr>
<tr>
<td>Addressing patient concerns</td>
<td>14</td>
</tr>
<tr>
<td>References</td>
<td>19</td>
</tr>
</tbody>
</table>

This booklet belongs to:
The purpose of this healthcare professionals’ guide is to help you support your patient who is making a decision about her breast cancer treatment. The target users for this guide are doctors, nurses and counsellors.

Shared decision making

In shared decision making, both healthcare professionals and patients are involved in a discussion about the decision during a consultation. Both parties have the chance to express their views and concerns and come to an agreement eventually on the decision (including not making a change).

Patient decision aids

This patient decision aid (PDA) is designed based on the concept of shared decision making. A PDA contains information about the treatment options, their advantages and disadvantages, what is important to the patient and guide them systematically through the decision making process.

In a Cochrane systematic review, PDAs have been found to improve patients’ knowledge and risk perception; help them make a decision according to their priorities; and patients who use the PDAs become more involved in decision making.¹

However, a PDA does not replace a clinical consultation. It also does not influence patients to choose one treatment option over another but allows them to make an informed decision based on their own priorities and preferences.
CONTENTS OF THE PDA

The PDA contains the following sections:

• **What are your concerns?**
  This section highlights common concerns and misconceptions about breast cancer and choice of treatment.

• **Knowing more about breast cancer**
  This section explains:
  • What is breast cancer?
  • Cause of breast cancer
  • Stage of the breast cancer
  • Natural progression of breast cancer

• **Knowing more about breast cancer treatment**
  This section contains information about of treatment options including lumpectomy, mastectomy, chemotherapy, radiotherapy, hormone therapy and alternative therapy.

• **What are your choices?**
  This section lists on the treatment options
CONTENTS OF THE PDA

• **Advantages and disadvantages of the treatment options**
  This section provides information about the advantages and disadvantages of each treatment option based on the latest research evidence.

• **Knowing the facts**
  This section contains questions which assess whether the patient has understood the information on the advantages and disadvantages of each treatment option presented in the PDA.

• **Knowing what is important to you**
  This section explores the preferences and concerns of the patient with regards to breast cancer treatment.

• **Do you need more support?**
  This section explores whether the patient needs more information about the treatment options. It also finds out if she has received support from the healthcare professionals, family members and support groups.

• **Are you ready to make a decision?**
  This last section deals with the patient’s readiness in making a decision to undergo breast cancer treatment.
The PDA can be used throughout the decision-making process, either during a clinical consultation or at home. A PDA can be used either by the patient herself, with her family or the healthcare professionals. However, a PDA does not replace a clinical consultation. Ultimately, the patient needs to discuss the decision with the healthcare professional before making the choice.

When using the PDA, it is important to consider:

- whether the patient is ready to discuss the treatment options. Some patients may feel sad after knowing the diagnosis and may not be ready to discuss the treatment for the breast cancer.
- the time and resources available. Guiding patients to make a decision requires time. The healthcare professional should allow sufficient time to use the PDA with the patient.

Below are some suggestions of how the PDA can be used. The healthcare professional is advised to use the PDA according to individual clinical practice.
WHEN TO USE THE PDA?

In the clinic at diagnosis:

- After the patient is told of the diagnosis, assess whether she is ready to discuss the treatment options.
- The doctor may consider using the PDA with the patient at this stage focusing on the treatment options.
- The patient is then given time to go through in more details after the consultation. The patient may want to discuss the PDA with the nurse or counselor after they have read the PDA.
- The patient is encouraged to continue using the PDA on her own or with her family at home.

At home

- At home, the patient can read through the PDA on her own or together with her family. This will help to reinforce the information provided during the consultation.
- She is advised to write down any questions she or her family has and discuss with the healthcare professional during the next visit to the clinic.

At the follow-up visit

- During this visit, it is important to ask the patient whether she has read the PDA at home and is ready to discuss the decision. If she is, the healthcare professional can proceed to discuss the decision with the patient (refer to How to use the PDA?)
- If the patient has not read the PDA, the healthcare professional may want to give the patient time to go through it on her own before discussing the decision.
- However, if time does not permit the patient to use the PDA, the healthcare professional may want to use the PDA selectively based on the patient’s main concern.
WHO TO USE THE PDA?

The PDA should be used by the patient together with a person who is trained to guide patients in decision making. This person can be a doctor, nurse, or a counselor.

Besides the patient, people who are involved in the decision making process, such as the husband, children, and other family members, may benefit from going through the PDA.

The PDA can be used by patients who are at different stages of decision making. For example:

- **Patients who have decided to go for surgery.** It has been found that some patients make decisions without knowing the risks and benefits of the chosen option. Therefore, these patients may still benefit from the PDA which provides information about the risks and benefits of each treatment option, including surgery.

- **Patients who refused surgery.** These patients may refuse surgery because of concerns about the complications of surgery or lack of awareness about breast cancer and its complications. They will benefit from the information on breast cancer provided in the PDA.

- **Patients who are undecided.** There are many reasons why patients delay making a decision and these include: emotionally disturbed by the diagnosis; lack of information about the treatment options; unsure of their priorities; influences from family members. The PDA provides information about the treatment options; help them to clarify their priorities; and provides an opportunity for them to discuss their concerns with the healthcare professionals.
HOW TO USE THE PDA?

The PDA guides the patient to make a decision about their breast cancer treatment by providing information about the treatment options, their advantages and disadvantages, clarifying patient’s priorities and preferences and finding out what support they need.

Therefore, the way PDA is used depends on what the patient needs at that stage. You can find out what the patient needs by

- asking ‘You have gone through the booklet. Is there anything that you would like to ask me?’
- going through each section of the PDA and ask whether they have any question
- referring to:
  - ‘Knowing what is important to you’ section to find out what their concerns are
  - ‘Do you need more support?’ section to find out what support they need
  - the ‘notes’ they have written on page 19

Once you have identified they concerns and needs, go through the relevant section of the PDA with the patient.

For example:

- If the patient wants to know the chance of cure, you can focus the consultation on discussing the section on ‘Advantages and disadvantages of each treatment option’
- If you find that the patient is concerned about the side effects of chemotherapy, you can direct your consultation by discussing information in the section on ‘Chemotherapy’ (page 10).
YOUR ROLE

- Assess the literacy of the patient.
- Assess the patient preferred role in decision making (elaborate)
- If the patient has difficulty in reading, you will need to go through the PDA with them in detail.
- If the patient can read, let the patient read the PDA on their own. Do not prompt.
- Explain in more details if the patient has any queries.
- State the facts but do not influence the patient’s decision on their treatment.
- Ensure the patient understand the advantages and disadvantages of each treatment option.
- Discuss the answers after she has completed the ‘Knowing the facts’ section (page 16).
- The patient’s needs should be addressed before they make a decision.
- Some patient may take longer to make their decision; your role is to guide and support them during the process and not to pressure them for a decision.
- Reassure them they do not need to make a decision now.

Patient Decision Aid: Evidence

The evidence of the Patient Decision Aid is based on a review of the research evidence.

When discussing the advantages and disadvantages of the treatment options with patients, it is important that you:

- Use numbers rather than percentages to explain the risks and benefits.
- Present the chance of getting as well as not getting complications from their illness.

For example:
- ‘95 out of 100 women with early breast cancer may be alive at 5 years with lumpectomy’ rather than ‘95% of the women may be alive at 5 years’.
- ‘95 out of 100 women with early breast cancer may be alive at 5 years with lumpectomy; 5 may die’.
### PDA EVIDENCE TABLE

#### Lumpectomy

| Survival          | Survival in 5 years:  
|                   | Stage 1: 95%  
|                   | Stage 2: 88%  
|                   | Stage 3: 56%  
|                   | The stage may change after histology report.  
|                   | *E.g. if more than 10 lymph nodes are involved, it will be stage 3.*  
| Local Recurrence  | Local recurrence in 8 years:  
|                   | • with radiotherapy: 10%  
|                   | • without radiotherapy: 39%  
| Systemic Recurrence | Chemotherapy:  
|                   | Absolute risk reduction with chemotherapy depends on the age and risk level.  
|                   | Age:  
|                   | • < 50 years: 4.6% - 15.1%  
|                   | • 50-69 years: 2.4% to 7.4%  
|                   | *Hormone therapy:*  
|                   | Survival benefit with tamoxifen: 9.2%  
| Complications Seromas | Out of 100 women who had lumpectomy, 6 may develop seromas; 94 may not.  
|                   | (6% risk)  
| Numbness and change in sensation in the inner aspect of the arm | The risk of developing this complication depends on the axillary surgery.  
|                   | Out of 100 women who had lumpectomy, 16-39 may get this complication; 61-84 may not.  
|                   | (16-39% risk)  
| Bleeding          | Out of 100 women who had lumpectomy, 2 may develop bleeding; 98 may not.  
|                   | (1.7% risk)  
| Lymphoedema       | Risk depends on axillary surgery  
|                   | *Sentinel Lymph Node Biopsy (SLNB):* Out of 100 women who had lumpectomy and SLNB, 5 may get lymphoedema; 95 may not.  
|                   | (5% risk)  
|                   | *Axillary Lymph Node Dissection (ALND):* Out of 100 women who had lumpectomy and ALND, 17 may get lymphoedema; 83 may not.  
|                   | (17% risk)  
| Wound infection   | Out of 100 women who had lumpectomy, 4 may get wound infection; 96 may not.  
|                   | (3.8% risk)  

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2. [2]  
3. [3]  
4. [4]  
5. [5]  
6. [6]  
7. [7]  
8. [8]  
9. [9]  
10. [10]  
12. [12]  
13. [13]  
14. [14]
<table>
<thead>
<tr>
<th>Mastectomy</th>
<th>Alt. treatment</th>
<th>Do nothing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Same as Lumpectomy</td>
<td>10 out 11 patients (n=33) who refused surgery progressed when on alternative treatment</td>
<td>Mean duration of living from onset for untreated breast cancer is 3 years</td>
</tr>
<tr>
<td>Local recurrence in 8 years (8 %)</td>
<td>Lack of evidence</td>
<td>Lack of evidence</td>
</tr>
<tr>
<td>Same as lumpectomy</td>
<td>Lack of evidence</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Out of 100 women who had mastectomy, 15-18 develop seromas; 82-85 may not. (15-18% risk)</td>
<td>Not applicable</td>
<td>Not applicable</td>
</tr>
<tr>
<td>The risk of developing this complication depends on the axillary surgery. Out of 100 women who had mastectomy, 16-39 may get this complication; 61-84 may not. (16-39% risk)</td>
<td>Not applicable</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Out of 100 women who had mastectomy, 4 may develop bleeding; 96 may not. (3.9% risk)</td>
<td>Not applicable</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Risk depends on axillary surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SLNB:</strong> Out of 100 women who had mastectomy and SLNB, 5 may get lymphoedema; 95 may not. (5% risk)</td>
<td>Not applicable</td>
<td>Not applicable</td>
</tr>
<tr>
<td><strong>ALND:</strong> Out of 100 women who had mastectomy and ALND, 16 may get lymphoedema; 84 may not. (16% risk)</td>
<td>Not applicable</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Out of 100 women who had mastectomy, 30 may get wound infection; 70 may not. (29.4% risk)</td>
<td>Not applicable</td>
<td>Not applicable</td>
</tr>
</tbody>
</table>
Women with breast cancers have many concerns. This section presents common concerns which were identified from the interviews which we have conducted with patients and healthcare professionals in Malaysia. It includes sample responses which the healthcare professional can use to address these concerns.

<table>
<thead>
<tr>
<th>Concerns</th>
<th>Patient quotes</th>
<th>Sample response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death</td>
<td>Umur tak panjanglah.</td>
<td>Early breast cancer can be treated and having breast cancer does not mean that you are going to die immediately. With surgery and further treatment, within 5 years, out of 100 women with breast cancer, 80 may live and 20 may die.</td>
</tr>
<tr>
<td>Recurrence after surgery/chemo/radiotherapy</td>
<td>I’ve heard of people having cancer again after a few years, after radio, chemo.</td>
<td>For lumpectomy, within 8 years, out of 100 women, 10 may have a relapse with radiotherapy and 39 may relapse without radiotherapy. For mastectomy, within 8 years, out of 100 women, 8 may have a relapse on the chest wall.</td>
</tr>
<tr>
<td>Surgery (e.g. pain)</td>
<td>I’m afraid of breast cancer. I’m afraid of surgery. I’m afraid of seeing the doctor’s instruments. I am afraid (of pain), even when I go for injections and taking blood.</td>
<td>Management of pain is an important aspect of your care after surgery. Your doctor and breast care nurse will be able to discuss with you further on your options of pain management. You will be fully assessed for your fitness before going for surgery.</td>
</tr>
<tr>
<td>Complications of surgery</td>
<td>Nanti kalau dah buat, tangan tak boleh rasa. Dia kata bengkak. Ada kawan yang buat operation kata bila buang tu, hilang rasa tangan.</td>
<td>Common complications after mastectomy are numbness in the inner aspect of the upper arm, seromas, bleeding, wound infection and lymphedema. They are discussed in this decision aids. Please let me know if you need any clarification.</td>
</tr>
<tr>
<td>Losing her breast</td>
<td>The doctor asked me to cut off the whole breast, I can’t accept that. Losing a breast, that feeling, I don’t know, it’s like I am not a normal woman anymore.</td>
<td>The breast is an important aspect of your body image as well as to feel whole as a woman. It is normal to grieve losing a breast; however it is important for you to know that a woman can function physically and sexually without a breast. The loss of a breast may cause some imbalance that may affect your posture. It is important that you obtain an appropriate prosthesis to use inside your bra.</td>
</tr>
</tbody>
</table>
## ADDRESSING PATIENT CONCERNS

<table>
<thead>
<tr>
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<th>Patient quotes</th>
<th>Sample response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Losing her breast</td>
<td>Terkejut. Rasa ralat. Rasa macam tak stabil.</td>
<td>Some women may consider breast reconstruction surgery where a new breast shape is created. Your surgeon can discuss this further with you.</td>
</tr>
<tr>
<td>Getting a deformed breast</td>
<td>Rasa macam cacat. Tak macam orang perempuan lain lagi.</td>
<td>Some women may consider breast reconstruction surgery where a new breast shape is created. Your surgeon can discuss this further with you.</td>
</tr>
<tr>
<td>Breast reconstruction</td>
<td>I’m so thin, where to get flesh to form the breast?</td>
<td>Some women may consider breast reconstruction surgery where a new breast shape is created. The mound can be shaped by your own tissues or use of implants. Your surgeon can discuss this further with you.</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>Chemo ini sejenis racun. Ia akan matikan sel sel dalam badan.</td>
<td>Chemotherapy is a medicine doctors use to kill cancer cells that may be lying dormant in other parts of the body that cannot be removed surgically.</td>
</tr>
<tr>
<td>Side effects of chemotherapy (e.g. weak, symptoms)</td>
<td>My friend said that chemo is very painful. I am very scared when I heard that.</td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td>I heard that after surgery, I have to go for chemo and radiotherapy. The side effects are terrible.</td>
<td>It is important for you to know that the loss of hair is temporary, and the hair will grow back within 3-6 months after chemotherapy.</td>
</tr>
<tr>
<td></td>
<td>I can’t accept the side effects (of chemo), losing hair, no appetite, sore mouth.</td>
<td>There are many ways to cope with loss of hair e.g. by using a wig or scarf. There are breast cancer support groups that may loan wigs to you. You can also get more information from your hairstylist.</td>
</tr>
<tr>
<td></td>
<td>I don’t mind surgery, but I don’t want chemo or radio.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>If I lose all my hair, how am I going to face people?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Organ dalam badan akan kena tempias kemo.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Kulit macam terbakar.</td>
<td></td>
</tr>
</tbody>
</table>
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. It is not caused by virus/bacteria and as such not contagious.

You may consider using spirituality to address your fears. Acceptance is very important for you to cope with your treatment and move on with your life after cancer.

It is normal to feel helpless after you are being diagnosed with cancer. What will make a difference is how you cope with it.

There are many women who had the same experience as you and had managed to overcome their illness. They are called survivors. You can contact them at Breast Cancer Welfare Association Malaysia:
Tel: 03 79540133
Email: info@breastcancer.org.my
Website: http://breastcancer.org.my

You will be able to return back to normal functioning after surgery. The duration that you take to recover may be influenced by the complications that you experience.

Common complications after mastectomy are numbness in the inner arm, seromas, bleeding, wound infection and lymphedema.

Shoulder dysfunction most often is the result of shoulder immobilization after surgery. It is important for you to have adequate painkillers after surgery to perform shoulder exercises.

There should not be a significant change in the muscle strength of the affected arm after lymph node dissection.
## ADDRESSING PATIENT CONCERNS

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<th>Sample response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own care after surgery and chemotherapy</td>
<td>Tak boleh buat kerja normal lah.</td>
<td>It is important for you to know that you may need support in helping you with daily household chores like cooking and caring for your children whilst recovering from surgery and during chemotherapy. However, you should be able to get back to normal living and working once your treatment has been completed.</td>
</tr>
<tr>
<td></td>
<td>Kita mungkin hilang keupayaan.</td>
<td></td>
</tr>
<tr>
<td>Care of their children and family</td>
<td>There is no one at home to care for me.</td>
<td>Getting support from family or friends is important. Make arrangements with these people to help you cope during this difficult time.</td>
</tr>
<tr>
<td></td>
<td>Bila terfikir pasal anak-anak, terus saya menangis.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Kalau saya ambil kemo dan jadi lemah sapa nak uruskan anak-anak saya. Ambil dari sekolah dan masak di rumah?</td>
<td></td>
</tr>
<tr>
<td>Husband/family disagreeing with surgery or treatment</td>
<td>Doktor kata buang semua. Bila kata buang semua keluarga kata tunggulah dulu, kita cari ikhtiar lain.</td>
<td>Consider asking your family/friend to come along so that we can discuss your treatment decisions together. Please use this decision aid to help your family and yourself to understand about breast cancer and its treatment. Together with your doctor/nurse and family members, you will make the final decision for the treatment.</td>
</tr>
<tr>
<td>Inability to return to work</td>
<td>After chemotherapy I’ll be so weak, how am I going to work?</td>
<td>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.</td>
</tr>
<tr>
<td>Financial issues</td>
<td>Risau nak bedah ni sebab tak cukup duit nak bayar.</td>
<td>The cost of surgery and adjuvant treatment varies. Your doctor will advise you accordingly. There are financial help available and we can refer you to the social worker and social welfare services.</td>
</tr>
<tr>
<td></td>
<td>I just defaulted on the payments for my insurance. Now that this happen, will they pay for my treatment?</td>
<td></td>
</tr>
</tbody>
</table>
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<tr>
<th>Concerns</th>
<th>Patient quotes</th>
<th>Sample response</th>
</tr>
</thead>
<tbody>
<tr>
<td>The unknown</td>
<td>Rasa takut, tangan menggigil.</td>
<td>Fear of cancer is a normal response. There are ways to overcome this fear. One effective way is to know the facts:</td>
</tr>
<tr>
<td></td>
<td>Pandangan saya? Penyakit merbahayalah.</td>
<td>• Most breast cancer double in size over 3-6 months.</td>
</tr>
<tr>
<td></td>
<td>Macam orang bingungla.</td>
<td>• Breast cancer often takes about 2 years to spread to other parts of the body.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Most women will live for another 2-3 years if they do not receive any treatment.</td>
</tr>
<tr>
<td>Traditional medicine can shrink the cancer</td>
<td>My sister had a small breast lump. She drank the herbal medicine and it disappeared.</td>
<td>It is important to know whether breast lumps are actually breast cancers. Most breast lumps are not cancerous and may resolve without any treatment.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>There is a lack of scientific evidence of the benefits and harms of alternative treatment.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>You may be told that alternative treatment will slow down the growth of your breast cancer.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>This may not be true because breast cancer often grows slowly even without any treatment.&quot;</td>
</tr>
<tr>
<td>The cause of breast cancer</td>
<td>What is the cause of my breast cancer? Is it the food I ate?</td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td>Lepas operation nanti bolehlah saya tahu kuman apa yang menyebabkan cancer saya ni?</td>
<td>(for other risk factor refer pg 4)</td>
</tr>
</tbody>
</table>
REFERENCES


Together, we can beat cancer!