



## Introduction

Having tests to see if you have breast cancer, or having treatment for breast cancer, can be a stressful time.

It is important that your time in hospital is as good as possible with treatment of a high quality. But when you have had little experience of illness and hospitals, you may be unsure about what is 'good quality care'.

This booklet has been developed by a group of women, most of whom have had breast cancer to help you think about the care that you have received. They started by naming the key things that they felt would be part of good quality care. Then they listed the different ways these might be shown by those providing the care.

We know that every woman's experience will be different as will the issues that are important to you. Some of the statements in this booklet may ring true to you, others will not.

The eight areas of care identified were:

- Being Supported to Make Choices
- Best Treatment
- Complete Care
- Fairness
- Feeling Safe and Comfortable
- Good Communication
- Personalised Care
- Respect and Dignity

The following pages contain thoughts from women reflecting on the eight areas of care, and how they have been demonstrated during their care. These reflections may help you in your own personal reflections on your care.

## How can I tell the hospital about my experience?

Taking some time to provide feedback on your experience of care is important. It helps services to reflect on the care they provide and to identify areas for improvement.

There are several ways in which you can provide feedback to your hospital:

- Ask how you can contact the hospital's Patient Advocate. These are people whose job it is to speak with patients about their experience of care.
- Ask who you should write to if you wish to do this.
- Ask if there are feedback forms provided by the hospital at different stages of your treatment.
- Ask about how feedback from patients and their carers and families are used to improve the quality of care.

There is space on the back of this page on which you can provide some general feedback if you wish.

## Respect and Dignity

### Women talking about respect and dignity...

‘The fears I expressed were taken seriously and reduced by the way I was treated.’

‘I felt I was treated as a person rather than just another patient – “the left or right mastectomy”’.

### How could respect and dignity have been shown during my care?

- The doctors listened to me and encouraged me to ask questions
- My personal information and need for privacy was respected.
- I was suitably clothed and the focus was on me (with no distractions) when important things were being discussed.
- I was given an explanation and apology when kept waiting.

## Being Supported to Make Choices

### Women talking about being supported to make choices...

‘This was too big for me to decide without help. I told the surgeon I needed her to make a recommendation.’

‘My decision was different from the doctor’s recommendation, but he respected and supported my choice.’

### How could I have been supported to make choices?

- I was asked at the start and along the way how much say I would like in deciding about my treatment.
- When I asked for information to help me in making treatment choices, I was given what I needed.
- All along, I was encouraged to read and ask questions to help me make an informed choice about what treatments to have.
- I was given time to take in and deal with the cancer news and the impact on my family. This meant I could organise help for my family before I had to make decisions about my care.

## Best Treatment

### Women talking about best treatment...

‘I wanted to feel secure and confident that the doctors and other staff were a group of experts who would provide me with the best chance of a full recovery.’

‘At the end of the day, getting the best treatment I could have was most important to me.’

### How might I know I have received best treatment?

- Before surgery, I was told about the team of people looking after me and what each person would be doing for me.
- I was introduced to the person who would be my main contact during treatment.
- When I asked, I was informed of the training and experience of the staff who treated me.
- I was able to talk to and contact the breast care nurse when I needed.
- I was provided with the verbal and written information that I needed about breast cancer treatment.
- I received excellent treatment and care even though I was at a small rural hospital.

## Personalised Care

### Women talking about personalised care...

‘My oncologist remembers my stories about my family and asks about them when I return to see him.’

‘I told the anaesthetist about my previous bad experiences with painkillers and sedatives, and she reassured me about the ones to be used.’

‘As a young woman, the effect of treatment on my fertility was my greatest concern. I needed this to be factored into any decisions.’

### How could my care have been personalised?

- I was treated as a whole person. Those who cared for me asked me about my life and my needs such as my living situation, my particular concerns and any cultural and spiritual issues that were important to me.
- My treatment plan was worked out in a way that catered for my concerns and personal circumstances.
- Before offering medications, the staff checked my medical history with me.

## Good Communication

### Women talking about good communication...

‘Over time I felt myself asking more questions as I became more informed and confident – I formed a stronger bond with the doctors.’

‘Having a personal record of my diagnosis and treatment helped me to understand the different aspects of my treatment.’

### How could good communication have been shown during my care?

- The staff made an effort to explain medical terms and procedures and checked that I understood.
- I had a choice of information in different forms – paper, cassette tape, video, internet sites.
- The staff encouraged me to feel hopeful.
- I was given enough time to consider my options and make decisions that I felt comfortable with.
- The staff encouraged and supported the involvement of the people close to me.
- When I asked for information about my specific treatment, this was given to me.
- After telling me my diagnosis and treatment choices, the doctor said it was OK for me to phone after a day or two if I needed to check something.

## Complete Care

### Women talking about complete care...

‘I like the way my feelings and needs were considered.’

‘I was pleased that my doctor was open to discussions about complementary therapies.’

‘My doctor supported my use of yoga as a relaxation method.’

### How might I know I have received complete care?

- The staff often asked how I was feeling, emotionally as well as physically.
- When the staff couldn't help me with a particular concern, they offered to arrange help from someone else.
- I was encouraged to talk about everything that concerned me, not just the breast cancer.

## Fairness

### Women talking about fairness...

‘I just wanted to be given a fair go.’

‘Although I chose to be treated in Melbourne, my doctor arranged for me to have some of my treatments locally so I didn’t have to travel every week.’

### How could have fairness been shown during my care?

- When I had a particular need, the hospital was able to assist.
- I was told about the different kinds of practical support I might need and was shown how to ask for these services if I needed:
  - Financial support
  - Travel and accommodation
  - Child care.
- Interpreters were available to help me understand my diagnosis and treatment.
- My religious and cultural beliefs were respected by those who cared for me.
- My doctor was open to exploring ways for me to be treated near home so I wouldn’t have to make so many long journeys.

## Feeling Safe and Comfortable

### Women talking about feeling safe and comfortable...

‘Because I knew what to expect after surgery, I felt reassured and confident that I could handle it. It’s the unknowns that are scary!’

‘Nursing staff could tell when I needed a shoulder to cry on, which was often.’

‘One nurse was great at fixing my pillows in the middle of the night to make me comfortable.’

‘A nurse gave me a really silly ugly monkey that made me laugh every time I looked at it.’

### How could I have been made to feel safe and comfortable during my care?

- A nurse went with me to surgery – this made me feel better.
- Because both my emotional needs and my physical needs were looked after, I felt that I was receiving good quality care.
- It helped a lot when the nurses talked to me about how I was doing.
- I felt that the staff cared about the people who are important to me - my family and friends.
- The staff checked my medical history whenever it was necessary.
- The staff treated me honestly and kindly and told me clearly what was