

# **BREAST CANCER**

## **Life after diagnosis - What you need to know, ask and expect**

*Please note that the following information might not represent the most current facts. The Commission strongly suggest you seek assistance and current information from the Cancer Council Helpline on 13 11 20 or by visiting their website <http://www.cancer.org.au/Home.htm>*

### **What is breast cancer?**

Breast cancer is a malignant tumour, which starts within the breast tissue. If breast cancer spreads it usually first appears in the lymph nodes in the armpit. Beyond this it tends to go to the bones, liver and lungs and becomes known as metastatic breast cancer.

### **How prevalent is it?**

Breast cancer is the biggest cancer killer of Australian women. About 10,000 diagnoses are made each year and 2,632 died from it in 1996, including 20 men. The good news is that breast cancer can be detected early when the tumour is quite small through increased awareness, self examination and regular mammograms (the BreastScreen Australia Program offers free mammograms to women 50-69 years). Early breast cancer has a very good prognosis - over 90% will survive.

### **How did I get it?**

Damaged genes cause breast cancer. In about 5% of women those genes are inherited. In 95% of women the cause of the damage is unknown. All of the known risk factors are weak predictors (quite unlike the relationship between smoking and lung cancer) and are the subject of on-going research.

### **Why do I feel so powerless?**

Breast cancer seems to arrive unannounced, taking an otherwise well woman completely by surprise. Where there is no apparent reason for contracting a disease, its existence in your body is harder to accept and the consequences are harder to manage. Women speak of: feeling shocked on diagnosis; being thrown into an unknown world where the language is difficult to understand; and feeling part of a treatment production line.

### **What are the options for treatment?**

The types of treatment available should be fully discussed with your breast cancer specialist. Biopsy, breast conserving surgery, mastectomy, reconstruction, sampling or clearance of lymph nodes in the armpit, radiotherapy, chemotherapy and hormonal treatment are the main options available. The choice of treatment will depend on the type of cancer and what you and your doctors decide is in your best interests and is acceptable to you.

### **How should I be treated?**

The breast cancer patient has a right to expect optimal care and be treated with respect by health providers as well as family, friends and the community. Some women may want to leave decisions entirely in the hands of their medical advisers but many will not. It is important that you have access to information so that you can properly consider all treatment options. Ask questions and find out as much as you can about the condition and health services from the health provider.

### **Don't rush decisions**

Some people have expressed regret about the treatment received, particularly when decisions were taken without adequate information. This can add to their feeling of powerlessness. One of the most difficult and distressing times is between the moment of

diagnosis and surgery. There is no need to rush into decisions as an extra week or two after diagnosis will not make any difference to the outcome of most breast cancer patients.

### **Coping with emotional stress**

Feelings of anger, guilt, denial and loss of confidence in your body are common for many women. But over time, they should diminish. Some people find they gain a new perspective towards their priorities and the balance in their life.

### **Choosing your specialists**

Ask your General Practitioner to refer you to specialists who concentrate on breast cancer, particularly in the case of surgeons. It is important to feel comfortable and confident with your specialists. Remember, a second opinion is your right and most professionals will be happy to recommend another doctor. Make sure you have answers to your questions and consider taking a partner or friend as support. As it may be difficult to retain information when you are in shock, taking notes or using a tape recorder could be helpful. You will find that you have several different medical advisers. Expect your specialists to work as a team. Some treatment centres provide a multi-disciplinary care team to deal with all aspects of your condition. Many women feel comfortable and confident being cared for by this team approach.

### **Knowing what sort of breast cancer you have and its implications**

Your pathology report is the most important document for your doctors and for you in the management of your cancer. Its classification of your tumour will indicate the types of treatment, which are suitable. Ask your doctor:

- for a copy of the report as soon as possible after diagnosis and keep it with you for reference at all stages;
- to go through the report very clearly and write down the explanation.

### **Communicating with health professionals and service providers**

You should be given information about your condition, treatment options, risks, benefits and side effects of procedures, in language you can understand. Ask as many questions as you need to so that you can make an informed decision. The use of pictures, models or written summaries may be useful. A community language interpreter should be provided if you need one (and is reasonably available).

### **Ongoing support in the community**

Your recovery and general peace of mind can be helped by making contact with others in the same situation. The Breast Cancer Support Service, which you may first meet while in hospital, is an organisation designed to provide practical and social support. Talking to friends who have had similar experiences also helps. Some hospitals, particularly large public ones, have in-house counsellors, physiotherapists, social workers, support groups and regular information sessions. Media hype and people in the community who insist they know "the cure", pressing their remedies, can be very distressing. Remember, this may be a particularly vulnerable time for you.

### **Are alternative therapies helpful?**

Discuss this with your medical adviser as some alternative therapies may counteract breast cancer treatments (for example chemo, radio or hormonal therapy). There is much anecdotal, rather than trialled, evidence to suggest that some alternative therapies are beneficial. It is generally agreed that for real gain, they should be used in conjunction with regular medical management. Natural therapies are now being more closely examined by researchers.

### **Information & Support**

The Cancer Council Helpline can provide information over the phone on 13 11 20. The website of the Cancer Council (<http://www.cancer.org.au>) includes some useful information sheets, which are attached for your information.

## **The Health Care Complaints Commission**

The Commission acts in the public interest by assessing, resolving and investigating complaints about health care with a view to maintaining and improving the quality of health care services in NSW.

### **What can be complained about**

A complaint may be made about any aspect of health care services, for example the care and treatment provided by health practitioners or hospitals and inappropriate communication or behaviour.

### **How to make a complaint**

It is a good idea for complaints or concerns to be discussed first with the hospital or health service provider. If the health service provider does not respond to the complaint or the person making the complaint is not satisfied with their actions, then contact the Commission.

You can obtain information from a Telephone Inquiry Officer at the Commission. If you want to lodge a complaint then it must be in writing and set out clearly and in simple language, the nature of the complaint, what actually happened, where and when the event occurred and who was involved.

### **HCCC Contact details**

Telephone:	(02) 9219 7444
Toll free in NSW:	(1800) 043 159
TTY service for the hearing impaired:	(02) 9219 7555
<b>Fax:</b>	(02) 9281 4585
<b>Website:</b>	<a href="http://www.hccc.nsw.gov.au">http://www.hccc.nsw.gov.au</a>
<b>E-mail:</b>	<a href="mailto:hccc@hccc.nsw.gov.au">hccc@hccc.nsw.gov.au</a>
<b>HCCC Address:</b>	Level 13, 323 Castlereagh Street
SYDNEY NSW 2010 Australia	
HCCC Postal Address:	Locked Mail Bag 18
Strawberry Hills NSW 2012	

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