

# PERSONAL BREAST CANCER JOURNAL

This Personal Journal is for women receiving treatment for breast cancer. It is an information organiser designed to assist you to keep track of information relating to your diagnosis and treatment path. This is for you to keep your record of diagnostic tests and results, treatments, medications and appointments.

There is a wealth of valuable information about breast cancer readily available from your breast care nurse (BCN) and other sources. We encourage you to use this Journal extensively and to take it with you to all appointments and treatment sessions.

The Journal will give you your own history of diagnosis and treatment for future reference. You will find the information you have entered a useful reference in your appointments with your doctors and other health professionals. Your doctors and support workers may also wish to add information or to refer to your writings.

We recommend that you keep a separate file for other written information you collect along your journey. Many women have also reported it useful to keep a personal diary to write about issues "of a more personal nature".

This is your record. Feel free to discard the sections of this Journal not relevant to your path and to reorganise other sections to suit your own needs.

If you require additional pages, contact your breast care nurse or support nurse and she/he will make these available to you. The Journal is also available on the web: [www.whg.org.au/breastcancer](http://www.whg.org.au/breastcancer)

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## CONTENTS

- Personal Information
  - Personal data
  - Emergency numbers
  - Relevant medical history
- Emotional well being
- Diagnosis
- Treatment
  - Surgery
  - Chemotherapy
  - Radiotherapy
  - Hormone treatments
  - Complementary therapies & alternative therapies
- Follow-up care
- Lymphoedema
- Support services & resources
- Care provider details
- Appointments
- Personal Journal Entries

# Personal Information

## PERSONAL INFORMATION

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Address: \_\_\_\_\_ Postcode: \_\_\_\_\_

Phone: \_\_\_\_\_ Mobile: \_\_\_\_\_

Medicare Number: \_\_\_\_\_ Pension Number: \_\_\_\_\_

Private Health Insurance: \_\_\_\_\_

## Next of Kin

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Address: \_\_\_\_\_ Postcode: \_\_\_\_\_

Phone: \_\_\_\_\_ Mobile: \_\_\_\_\_

### Emergency Phone Numbers

Doctor: \_\_\_\_\_ Hospital Emergency Dept: \_\_\_\_\_

Ambulance Membership number: \_\_\_\_\_

### Contact persons in an emergency

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Phone: \_\_\_\_\_ Mobile: \_\_\_\_\_

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Phone: \_\_\_\_\_ Mobile: \_\_\_\_\_

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Phone: \_\_\_\_\_ Mobile: \_\_\_\_\_

### Relevant Medical History

Date of my breast cancer diagnosis: \_\_\_\_\_

Family history of breast cancer? Yes  No  Unsure

\_\_\_\_\_

### Other major diagnosis

\_\_\_\_\_

\_\_\_\_\_

### Known allergies / adverse reactions

\_\_\_\_\_

\_\_\_\_\_

# Emotional Well Being

## **EMOTIONAL WELL BEING**

Women react in different ways when finding out they have breast cancer. Feelings of shock, anger, sadness, fear and anxiety are common. Breast cancer can also impact on the way you feel about your body, sexuality and relationships. These and other reactions may also continue or recur during and following your treatment/s. These are normal and healthy responses to your situation.

You are not alone in the way you are feeling. Talk it over with someone close to you or with the health professionals working with you. These include your general practitioner, breast care or support nurse, social worker, volunteer visitors and psychologists. A Breast Cancer Support Group may also be helpful.

If you have any concerns in talking to your family or partner about your cancer, ask for advice or assistance.

You may find it useful to keep a separate and private journal where you write how you are feeling throughout your journey.







**Diagnostic tests / procedures**

Date: \_\_\_\_\_ Test: \_\_\_\_\_

Where: *(hospital/company)* \_\_\_\_\_

Comments / results: \_\_\_\_\_

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Date: \_\_\_\_\_ Test: \_\_\_\_\_

Where: *(hospital/company)* \_\_\_\_\_

Comments / results: \_\_\_\_\_

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Date: \_\_\_\_\_ Test: \_\_\_\_\_

Where: *(hospital/company)* \_\_\_\_\_

Comments / results: \_\_\_\_\_

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**Diagnostic tests / procedures**

Date: \_\_\_\_\_ Test: \_\_\_\_\_

Where: *(hospital/company)* \_\_\_\_\_

Comments / results: \_\_\_\_\_

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Date: \_\_\_\_\_ Test: \_\_\_\_\_

Where: *(hospital/company)* \_\_\_\_\_

Comments / results: \_\_\_\_\_

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**Diagnostic tests / procedures**

Date: \_\_\_\_\_ Test: \_\_\_\_\_

Where: (*hospital/company*) \_\_\_\_\_

Comments / results: \_\_\_\_\_

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Date: \_\_\_\_\_ Test: \_\_\_\_\_

Where: (*hospital/company*) \_\_\_\_\_

Comments / results: \_\_\_\_\_

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Date: \_\_\_\_\_ Test: \_\_\_\_\_

Where: (*hospital/company*) \_\_\_\_\_

Comments / results: \_\_\_\_\_

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**Diagnostic tests / procedures**

Date: \_\_\_\_\_ Test: \_\_\_\_\_

Where: (*hospital/company*) \_\_\_\_\_

Comments / results: \_\_\_\_\_

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Date: \_\_\_\_\_ Test: \_\_\_\_\_

Where: (*hospital/company*) \_\_\_\_\_

Comments / results: \_\_\_\_\_

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# Treatment

## Treatment

Your treatment for breast cancer may consist of a single treatment or a combination of treatments. Factors influencing your treatment options will include your age, family history, past medical history and the type, size and location of your tumor. Your doctor will advise you of your treatment options.

Make sure you understand all of the information given and don't hesitate to ask questions. If you are still unsure, you may want to ask for a second opinion from another doctor.

If you are not referred to a breast care nurse or social worker, ask for a referral. These professionals can provide you with additional information and support before, during and following your treatment; and can provide practical assistance on many issues including travel, accommodation or financial aid or link you with other services.

Take your time to make decisions about your treatment. A week or two will make any difference to your treatment outcomes.

***A note on Clinical Trials:*** Clinical trials are large research projects to look at how breast cancer can be prevented and to find better treatments. This is done by comparing new breast cancer treatments with current standards treatments.

Your doctor may ask if you would like to take part in a clinical trial or, you may wish to look at what options are available by participating in one. Before you make your decision, talk with your doctor/s about the risks and benefits of you taking part in the trial.

You don't have to take part in any clinical trial if you don't want to. If you decide to participate and later change your mind, you can withdraw at any time.

Your doctors will monitor the healing of your wounds from your surgery and talk with you further about your treatment plans.

You will likely experience some restriction in your shoulder, arm and hand movements as a result of your surgery. Your breast care nurse will provide you with some exercises to assist in recovering full movement of these.

Your breast care nurse will also talk further with you about breast prosthesis, what is likely to best suit you and where you can purchase one of these. Financial assistance is available for your breast prosthesis.

If you require additional information, support or practical assistance when at home, do not hesitate to talk to your doctor, breast care nurse or social worker.

Following breast cancer surgery, some women report feeling great sadness and loss. Talk with your doctor/s and breast care nurse about how you are coping emotionally.  
- See also *'Emotional Well Being'*.

## Surgery

Date: \_\_\_\_\_ Hospital: \_\_\_\_\_ Date of Discharge: \_\_\_\_\_

Procedure/s: \_\_\_\_\_

\_\_\_\_\_

Date: \_\_\_\_\_ Hospital: \_\_\_\_\_ Date of Discharge: \_\_\_\_\_

Procedure/s: \_\_\_\_\_

\_\_\_\_\_

Date: \_\_\_\_\_ Hospital: \_\_\_\_\_ Date of Discharge: \_\_\_\_\_

Procedure/s: \_\_\_\_\_

\_\_\_\_\_

## Wound management: self monitoring

*Refer to Discharge Information Sheet on wound management*

Contact your doctor or breast care nurse:

- if your wound
  - becomes red or swollen
  - oozes fluid
  - increases in pain
  - opens or becomes bigger
  - develops an offensive odour
- if you develop a fever
- if you have any other concerns.

Notes: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Shoulder, arm & hand movement** (see also *Lymphoedema – self monitoring*)

Record any symptoms you may have with your shoulder, arm or hand movements for follow-up with your doctor, breast care nurse or physiotherapist:

Notes: \_\_\_\_\_  
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**Chemotherapy**

Chemotherapy is offered to some women with breast cancer as an additional treatment to surgery, radiotherapy or both. This is called adjuvant therapy. It aims to kill cancer cells and reduce the chance of the breast cancer coming back or recurring.

The medication is given in “cycles” over several months. Common side effects include nausea, vomiting, tiredness and loss of hair. These are temporary and are related to the type of chemotherapy medication given. Your oncologist or oncology nurse will provide more information.

**Chemotherapy**

Date: \_\_\_\_\_ Hospital: \_\_\_\_\_

Chemotherapy drugs: \_\_\_\_\_

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Side effects noted / other comments: \_\_\_\_\_

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**Chemotherapy**

Date: \_\_\_\_\_ Hospital: \_\_\_\_\_

Chemotherapy drugs: \_\_\_\_\_

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Side effects noted / other comments: \_\_\_\_\_

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**Chemotherapy**

Date: \_\_\_\_\_ Hospital: \_\_\_\_\_

Chemotherapy drugs: \_\_\_\_\_

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Side effects noted / other comments: \_\_\_\_\_

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**Chemotherapy**

Date: \_\_\_\_\_ Hospital: \_\_\_\_\_

Chemotherapy drugs: \_\_\_\_\_

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Side effects noted / other comments: \_\_\_\_\_

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**Chemotherapy**

Date: \_\_\_\_\_ Hospital: \_\_\_\_\_

Chemotherapy drugs: \_\_\_\_\_

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Side effects noted / other comments: \_\_\_\_\_

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**Chemotherapy**

Date: \_\_\_\_\_ Hospital: \_\_\_\_\_

Chemotherapy drugs: \_\_\_\_\_

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Side effects noted / other comments: \_\_\_\_\_

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**Chemotherapy**

Date: \_\_\_\_\_ Hospital: \_\_\_\_\_

Chemotherapy drugs: \_\_\_\_\_  
\_\_\_\_\_  
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Side effects noted / other comments: \_\_\_\_\_  
\_\_\_\_\_  
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\_\_\_\_\_  
\_\_\_\_\_

**Chemotherapy**

Date: ..... Hospital: .....

Chemotherapy drugs: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Side effects noted / other comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Radiotherapy

Radiotherapy is the use of X-rays to kill cancer cells. Treatment is carefully planned to reduce any effect on normal cells.

Treatment is usually given five days a week over several weeks. It is painless and only takes a few minutes for each treatment.

Side effects of radiotherapy may include general tiredness and some reddening or 'sun burning' of the skin.

Your radiation oncologist and oncology nurse will provide further information.

## Radiotherapy

Hospital / Radiotherapy Unit: \_\_\_\_\_

Areas treated: \_\_\_\_\_

Start date: \_\_\_\_\_ Finish date: \_\_\_\_\_

Comments: \_\_\_\_\_

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## Hormone treatment

Many breast cancers appear to be influenced by the female hormones, oestrogen and progesterone. Some breast cancers can be treated by adding hormones or by stopping the body's own hormones from working.

Regular checkups with your general practitioner or gynecologist are recommended for all women receiving hormone treatment for breast cancer.

## Hormone treatment

Date started: \_\_\_\_\_ Medication: \_\_\_\_\_ Date finished: \_\_\_\_\_

Date started: \_\_\_\_\_ Medication: \_\_\_\_\_ Date finished: \_\_\_\_\_

Comments: \_\_\_\_\_

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# Follow-up Care

## **FOLLOW-UP CARE**

At the completion of your treatments, your doctors will recommend a follow-up plan for regular check-ups for up to five years. Many women do not have a recurrence of breast cancer. If recurrence does occur, it is most likely to happen in the first five years following treatment. Follow-up is also important because of the risk of developing a second (new) cancer.

Depending on where you live and your own preferences, follow-up may remain with the surgeon and / or oncologist and involve your general practitioner. Alternatively, your GP may become the main person involved.

Your breast care or support nurse will make regular contact with you in the first twelve months of your follow-up care and six monthly thereafter to answer any questions you may have and to check on how you are progressing.

We strongly recommend that you continue to add your appointment information to your Journal during this time.



# Lymphoedema

## **LYMPHOEDEMA**

Most women who have breast cancer surgery may have some or all of the lymph glands under their armpit removed. Lymph glands may also be damaged by radiotherapy. Consequently, fluid may accumulate in the tissues and swelling occurs. This is known as lymphoedema. Should swelling occur, you need to contact your doctor or breast care nurse for further advice.

Signs and symptoms may include:

- a feeling of discomfort if your arm including heaviness, bursting pains, dull ache and burning sensations
- restricted joint movements (hand, wrist, elbow, shoulder)
- swelling of your fingers, hand or arm (this may be noticed by rings, watch or blouse sleeve feeling tight)

**Not all women with breast cancer get lymphoedema.**









# Support Services/Resources

## **SUPPORT SERVICES/RESOURCES**

### **Breast Cancer Support Services Phone 13 11 20** (for the cost of a local call)

This is free and confidential service provided by the Anti-Cancer Council of Victoria. Volunteer Support Persons who are supervisors of breast cancer offer practical and emotional support to other women diagnosed with breast cancer. Volunteers are accredited with the Anti-Cancer Council.

Ask your breast care nurse or social worker about this service and for any other contact information.

### **Cancer Hotline Phone 12 11 20** (for the cost of a local call)

This is a national telephone information and counselling service available to people with any type of cancer, and their family and friends. The service is staffed by specially trained people who can answer questions about any cancers and treatments, provide you with accurate written information, and put you in touch with community services and support groups.

## Support Groups

Support Groups are for people with a common problem or experience. Meetings provide the opportunity for people to talk about their experiences and to gain support and information from others. There are Breast Cancer Support Groups specifically for women with breast cancer as well as other Cancer Support Groups for people with any type of cancer and their families. Ask your breast care nurse, social worker or doctor for information on the groups in your area.

Group name: \_\_\_\_\_

Contact: \_\_\_\_\_

Meeting details: \_\_\_\_\_

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## Home Help Services

There are a number of services that may be able to provide you with practical assistance in your home with tasks such as cleaning, preparing meals etc. Ask your doctor, breast care or support nurse or social worker about the services available, your eligibility and how to apply for them. A referral by your doctor or other health professional may be required. These support services may be of benefit to yourself and your family especially during and following your treatments for breast cancer.

## BreaCan

This drop-in centre offers people affected by breast cancer with support and information that will assist them to make informed choices based on their needs. Trained volunteers, most of whom have experienced breast cancer themselves, staff the centre. The focus is on providing information, referral and peer support – not counselling or advice. The Centre is Melbourne based and plans to extend to regional Victoria in 2004. For further information phone (03) 9664 9333.

## Other support services

Service name: \_\_\_\_\_

Contact details: \_\_\_\_\_

Notes: \_\_\_\_\_

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## Other support services

Service name: \_\_\_\_\_

Contact details: \_\_\_\_\_

Notes: \_\_\_\_\_

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## Resources

Other useful information resources can be found on the internet:

- Grampians Breast Cancer Information and Services ([www.whg.org.au/breastcancer](http://www.whg.org.au/breastcancer))
- BreaCan ([www.whv.org.au/breacan.htm](http://www.whv.org.au/breacan.htm))
- Cancer Council of Victoria ([www.accv.org.au](http://www.accv.org.au))
- BreastScreen ([www.breastscreen.org.au](http://www.breastscreen.org.au))
- Breast Cancer Network Australia ([www.bcna.org.au](http://www.bcna.org.au))
- National Breast Cancer Centre ([www.nbcc.org.au](http://www.nbcc.org.au))

# Care Provider Details

## **CARE PROVIDER DETAILS**

Your Care Providers will include health professionals providing medical, allied health, information and support services to you. The Care Team will differ for each person depending on her treatment and support needs.

### **General Practitioner**

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

### **Surgeon**

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

**Medical Oncologist**

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

**Radiation Oncologist**

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

**Breast Care Nurse**

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

**Breast Care Nurse**

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

**Oncology Nurse**

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

**Address:**  
\_\_\_\_\_

**Community Nurse**

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

**Social Worker**

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

**Other care provider details**

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Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

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Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

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Name: \_\_\_\_\_ Phone: \_\_\_\_\_

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Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

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Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_









# **Personal Journal Entries**

