

# Optimal care pathway for women with breast cancer





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Endorsed by



**Australian Government**  
**Cancer Australia**





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# Foreword

The pathway for cancer patients undergoing diagnosis and treatment for cancer is complex and poorly comprehended by those involved. It usually involves multiple healthcare providers and covers a range of institutions, both public and private. The optimal cancer care pathways map this journey for specific tumour types, aiming to foster an understanding of the whole pathway and its distinct components to promote quality cancer care and patient experiences. These pathways act as a reminder that the patient is the constant in this journey and that the health system has a responsibility to deliver the care experience in an appropriate and coordinated manner.

The optimal care pathways are based on a revision of the original patient management frameworks (Department of Health 2007a) which had, for the first time, attempted to map the cancer pathway in an easily understandable form.

The purpose of this work is to improve patient outcomes by facilitating consistent cancer care based on a standardised pathway of care. The pathways are applicable to care whether it is provided in a public or private service. The principles and the expected standards of good cancer care are not expected to differ, even though treatment regimens may vary from patient to patient for a whole variety of reasons.

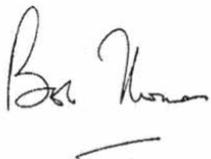
Victoria has undertaken this program of work as part of a national work plan aimed at improving cancer care. This national work plan was developed by the National Cancer Expert Reference Group (NCERG). The NCERG is a panel of experts and jurisdictional and consumer representatives that was established by the Council of Australian Governments (COAG) in 2010. In developing a national work plan for improving cancer care in Australia, the NCERG identified the value of a national approach to delivering consistent and optimal cancer care.

The NCERG has subsequently endorsed these new optimal cancer care pathways, which they agree are relevant across all jurisdictions. Each jurisdiction has been invited to adopt and co-badge these for local use.

A wide range of clinicians, peak health organisations, consumers and carers were consulted and/or participated in their development and I want to thank all concerned for their generous contributions.

I am sure that those providing cancer care will find the specific pathways useful in deciding how best to organise service delivery to achieve the best outcomes for those we care for.

Importantly, readers should note that these care pathways are not detailed clinical practice guidelines. They are not intended to constitute medical advice or replace clinical judgement.



Professor Robert Thomas OAM  
Chief Advisor Cancer, Department of Health and Human Services – Victoria

# Summary

Please note that not all women will follow every step of this pathway:

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

## Step 1 Prevention and early detection

**Risk factors:** Age, sex, family history, obesity and moderate/heavy alcohol intake are important risk factors. All women should have their individual breast cancer risk assessed.

Women at moderate or high risk should be referred to a family cancer clinic to have their risk further clarified and for possible genetic testing.

**Risk reduction:** For women at moderate or high risk of breast cancer, anti-hormonal risk-reducing

medication should be considered. Women at very high risk should consider risk-reducing surgery. The surgeon should provide clear information about the objective of the procedure.

**Screening:** Federally funded mammographic screening is available to asymptomatic women from the age of 40

through the BreastScreen Australia Program. Women aged 50-74 years should consider undergoing a two - yearly screening mammogram. Over-diagnosis needs to be considered, and women invited to screening must be informed of the potential disadvantages as well as the benefits of mammographic screening.

**Increased or high risk - refer to the breast optimal care pathway for screening recommendations.**

## Step 2 Presentation, initial investigations and referral

### Signs and symptoms:

The following should be investigated:

- a new lump or lumpiness
- a change in the size or shape of a breast
- a change to a nipple
- nipple discharge that occurs without squeezing
- a change in the skin of a breast
- axillary masses
- an unusual breast pain that does not go away.

### Assessments by a general practitioner (GP)

GP should refer all women with a suspicious lesion to a breast assessment clinic.

Examinations/investigations should include a triple test of three diagnostic components:

- medical history and clinical breast examination

- imaging – mammography and/or ultrasound
- non-excision biopsy – fine needle aspiration (FNA) cytology and/or a core biopsy.

These tests should be done within two weeks.

**Referral:** A positive result on any component of the triple test warrants referral for specialist surgical assessment and/or further investigation. Optimally, the specialist appointment should be within two weeks of a suspected diagnosis.

### Communication – lead clinician to:

- provide the woman with information that clearly describes who they are being referred to, the reason for referral and the expected timeframe for an appointment
- support the woman while waiting for the specialist appointment.

## Step 3 Diagnosis, staging and treatment planning

### Diagnostic work-up for women with breast cancer:

Family history and a medical examination, then consider following sequence of investigations:

- breast imaging tests
- ultrasound of the axilla +/- FNA nodes
- breast core biopsy if not already undertaken
- establishment of breast cancer receptor profile
- assessment for a breast cancer predisposition gene and considered for genetic counselling.

**Staging:** Appropriate for locally advanced or confirmed nodal disease and for any women with clinical symptoms or clinical suspicion of metastatic disease.

**Treatment planning:** All newly diagnosed women should be discussed by a multidisciplinary team so

that a treatment plan can be recommended.

Special considerations that need to be addressed at this stage include pregnancy, fertility and prevention of chemotherapy-induced menopause.

**Research and clinical trials:** Consider enrolment where available and appropriate.

### Communication – lead clinician to:

- discuss a timeframe for diagnosis and treatment with the woman/carer
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- provide appropriate information or refer to support services as required.

<sup>1</sup> Lead clinician – the clinician who is responsible for managing patient care.

The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

## Step 4

### Treatment:

Establish intent of treatment:

- curative
- anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- symptom palliation.

### Treatment options:

**Surgery:** Surgery for early breast cancer involves either breast-conserving surgery or mastectomy performed with or without immediate breast reconstruction surgery. Women should be fully informed of their options and offered the option of immediate or delayed reconstructive surgery if appropriate.

### Chemotherapy and other systemic therapy:

Chemotherapy or drug therapy may be appropriate as neoadjuvant or adjuvant treatment.

**Radiation therapy:** In most cases, radiation therapy is recommended for women with early breast cancer after breast-conserving surgery and in selected women after mastectomy.

For detailed information see <<http://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/clinical-practice-guidelines-management-early-breast-cancer-2nd-ed>>.

### Communication – lead clinician to:

- discuss treatment options with the woman/carer including the intent of treatment and expected outcomes
- discuss the treatment plan with the woman's GP.

## Step 5

### Care after initial treatment and recovery

Cancer survivors should be provided with the following to guide care after initial treatment.

**Treatment summary** (provide a copy to the woman/carer and her GP) outlining:

- diagnostic tests performed and results
- tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

**Follow-up care plan** (provide a copy to the woman/carer and her GP) outlining:

- medical follow-up required (tests, ongoing surveillance)
- care plans for managing the late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

### Communication – lead clinician to:

- explain the treatment summary and follow-up care plan to the woman/carer
- inform the woman/carer about secondary prevention and healthy living
- discuss the follow-up care plan with the woman's GP.

## Step 6

### Managing recurrent, residual and metastatic disease

**Detection:** Some cases of recurrent disease will be detected by routine follow-up in a woman who is asymptomatic. Some cases of metastatic disease will be detected at the same time as presentation with the initial primary breast cancer ('de novo metastatic disease').

**Treatment:** Where possible, refer the woman to the original multidisciplinary team. Treatment will depend on the location, the extent of recurrence, previous management and the woman's preferences.

**Palliative care:** Early referral can improve quality

of life and in some cases survival. Referral should be based on need, not prognosis.

For detailed information see <<http://annonc.oxfordjournals.org/content/early/2014/09/17/annonc.mdu385.full.pdf+html>>.

### Communication – lead clinician to:

- explain the treatment intent, likely outcomes and side effects to the woman/carer
- initiate a discussion regarding advance care planning if appropriate.

## Step 7

### End-of-life care

**Palliative care:** Consider referral to palliative care if not already involved. Ensure that an advance care plan is in place.

### Communication – lead clinician to:

- be open about the prognosis and discuss palliative care options with the woman/carer
- establish transition plans to ensure the woman's needs and goals are addressed in the appropriate environment.

# Summary – optimal timeframes

**Timeframes to treatment:** Timeframes should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce women’s distress. The following recommended timeframes are based on expert advice from the Breast Cancer Working Group.

Step in pathway	Care point	Timeframe
Presentation, initial investigations and referral	2.1 Signs and symptoms	A patient with signs and symptoms that may be concerning for breast cancer should be seen by their GP within two weeks. Appropriate triaging will identify patients who need to be seen earlier.
	2.2 Assessments by a GP	Tests should optimally be done within two weeks.
	2.3 Initial referral	Ideally the surgeon should see the patient with proven cancer or suspicious features within two weeks. If necessary, prior discussion should facilitate referral.
Diagnosis, staging and treatment planning	3.3 Multidisciplinary team meeting	Results of all relevant tests and imaging should be available for the multidisciplinary team discussion.
Treatment	4.2.1 Surgery	Breast surgery should occur within one month of a decision to treat with surgery (for invasive breast cancer).
	4.2.2 Chemotherapy and systemic therapy	Chemotherapy should be started ideally within four weeks of surgery. Neoadjuvant therapy should be started as soon as practicable. Endocrine therapy should start as soon as appropriate, after completion of chemotherapy and/or radiation therapy.
	4.3 Radiation therapy	For patients who don’t have chemotherapy, radiation therapy should commence within eight weeks of surgery. For patients who have chemotherapy, radiation therapy should commence three to four weeks after chemotherapy.

# Intent of the optimal cancer care pathway

The optimal cancer care pathway is intended to guide the delivery of consistent, safe, high-quality and evidencebased care for people with breast cancer.

The pathway aligns with key service improvement priorities including providing access to coordinated multidisciplinary care and supportive care and reducing unwanted variation in practice.

The optimal cancer care pathway can be used by health services and professionals as a tool to identify gaps in current cancer services and inform quality-improvement initiatives across all aspects of the care pathway. The pathway can also be used by clinicians as an information resource and tool to promote discussion and collaboration between health professionals and people affected by cancer.

The following key principles of care underpin the optimal cancer care pathway.

## Patient-centred care

Patient- or consumer-centred care is healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. Patient or consumer-centred care is increasingly being recognised as a dimension of high-quality healthcare in its own right, and there is strong evidence that a patient-centred focus can lead to improvements in healthcare quality and outcomes by increasing safety and cost-effectiveness as well as patient, family and staff satisfaction (ACSQHC 2013).

## Safe and quality care

This is provided by appropriately trained and credentialed clinicians, hospitals and clinics that have the equipment and staffing capacity to support safe and high-quality care. It incorporates collecting and evaluating treatment and outcome data to improve a woman's experience of care as well as mechanisms for ongoing service evaluation and development to ensure practice remains current and informed by evidence. Services should routinely be collecting relevant minimum datasets to support benchmarking, quality care and service improvement.

## Multidisciplinary care

This is an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each woman. There is increasing evidence that multidisciplinary care improves patient outcomes.

The benefits of adopting a multidisciplinary approach include:

- improving patient care through developing an agreed treatment plan
- providing best practice through adopting evidence-based guidelines
- improving patient satisfaction with treatment
- improving the mental wellbeing of patients
- improving access to possible clinical trials of new therapies
- increasing the timeliness of appropriate consultations and surgery and a shorter timeframe from diagnosis to treatment
- increasing the access to timely supportive and palliative care
- streamlining pathways
- reducing duplication of services (Department of Health 2007b).

## Supportive care

Supportive care is an umbrella term used to refer to services, both generalist and specialist, that may be required by those affected by cancer. Supportive care addresses a wide range of needs across the continuum of care and is increasingly seen as a core component of evidence-based clinical care. Palliative care can be part of supportive care processes. Supportive care in cancer refers to the following five domains:

- physical needs
- psychological needs
- social needs
- information needs
- spiritual needs.

All members of the multidisciplinary team have a role in providing supportive care. In addition, support from family, friends, support groups, volunteers and other community-based organisations make an important contribution to supportive care.

An important step in providing supportive care is to identify, by routine and systematic screening (using a validated screening tool) of the woman and family, views on issues they require help with for optimal health and quality-of-life outcomes. This should occur at key points along the care pathway, particularly at times of increased vulnerability including:

- initial presentation or diagnosis (first three months)
- the beginning of treatment or a new phase of treatment
- change in treatment
- change in prognosis
- end of treatment
- survivorship
- recurrence
- change in or development of new symptoms
- palliative care
- end-of-life care.

Following each assessment, potential interventions need to be discussed with the woman and carer and a mutually agreed approach to multidisciplinary care and supportive care formulated (NICE 2004).

Common indicators in women with breast cancer that may require referral for support include:

- pain or joint pain
- difficulty managing fatigue
- difficulty sleeping
- distress, depression, anxiety or fear
- menopausal symptoms
- living alone or being socially isolated
- having caring responsibilities for others
- cumulative stressful life events
- existing mental health issues
- Aboriginal or Torres Strait Islander status
- poor performance status
- being from a culturally or linguistically diverse background.

Depending on the needs of the woman, referral to an appropriate health professional(s) and/or organisation(s) should be considered including:

- community-based support services (such as Cancer Council Victoria)
- peer support groups (contact the Cancer Council on 13 11 20 or Breast Cancer Network Australia on 1800 500 258 for more information)
- a nurse practitioner and/or specialist nurse
- a psychologist or psychiatrist
- a social worker
- a dietitian
- an exercise physiologist
- a genetic counsellor
- an occupational therapist
- a physiotherapist
- specialist palliative care.

See the **appendix** for more information on supportive care and the specific needs of women with breast cancer.

## Care coordination

Care coordination is a comprehensive approach to achieving continuity of care for patients. This approach seeks to ensure that care is delivered in a logical, connected and timely manner so the medical and personal needs of the woman are met.

In the context of cancer, care coordination encompasses multiple aspects of care delivery including multidisciplinary team meetings, supportive care screening/assessment, referral practices, data collection, development of common protocols, information provision and individual clinical treatment.

Improving care coordination is the responsibility of all health professionals involved in the care of patients and should therefore be considered in their practice. Enhancing continuity of care across the health sector requires a whole-of-system response; that is, initiatives to address continuity of care occur at the health system, service, team and individual levels (Department of Health 2007c).

## Communication

It is the responsibility of the healthcare system and all people within its employ to ensure the communication needs of patients, their families and carers are met. Every person with cancer will have different communication needs, including cultural and language differences. Communication with patients should be:

- individualised
- truthful and transparent
- consistent
- in plain language (avoiding complex medical terms and jargon)
- culturally sensitive
- active, interactive and proactive
- ongoing
- delivered in an appropriate setting and context
- inclusive of patients and their families.

In communicating with patients, healthcare providers should:

- listen to patients and act on the information provided by them
- encourage expression of individual concerns, needs and emotional states
- tailor information to meet the needs of the woman, her carer and family
- use professionally trained interpreters when communicating with patients from culturally and linguistically diverse backgrounds
- ensure the woman and/or her carer and family have the opportunity to ask questions
- ensure the woman is not the conduit of information between areas of care (it is the providers' and healthcare system's responsibility to transfer information between areas of care)
- take responsibility for communication with the woman
- respond to questions in a way the woman understands
- enable all communication to be two-way.

Healthcare providers should also consider offering the woman a Question Prompt List (QPL) in advance of their consultation and recordings or written summaries of their consultations. QPL interventions are effective in improving communication, psychological and cognitive outcomes of cancer patients (Brandes et al. 2014). Providing recordings or summaries of key consultations may improve the patient's recall of information and patient satisfaction (Pitkethly et al. 2008).

## Research and clinical trials

Where practical, patients should be offered the opportunity to participate in research and/or clinical trials at any stage of the care pathway. Research and clinical trials play an important role in establishing efficacy and safety for a range of treatment interventions, as well as establishing the role of psychological, supportive care and palliative care interventions (Sjoquist & Zalcberg 2013).

While individual patients may or may not receive a personal benefit from the intervention, there is evidence that outcomes for participants in research and clinical trials are generally improved, perhaps due to the rigour of the process required by the trial. Leading cancer agencies often recommend participation in research and clinical trials as an important part of patient care. Even in the absence of measurable benefit to patients, participation in research and clinical trials will contribute to the care of cancer patients in the future (Peppercorn et al. 2004).

# Optimal cancer care pathway

The optimal cancer care pathway outlines seven critical steps in the patient journey. While the seven steps appear in a linear model, in practice, patient care does not always occur in this way but depends on the particular situation (such as the type of cancer, when and how the cancer is diagnosed, prognosis, management, the women's decisions and her physiological response to treatment).

Breast cancer is the most common cancer in Australian women, accounting for more than 27 per cent of newly diagnosed cancers, and the second most common cause of death from cancer. Breast cancer is uncommon in males, with less than one in 100 cases of breast cancer occurring in men (AIHW 2014). **Please note this document refers to women throughout. This is for practical reasons. The recommendations are intended to apply to all patients.**

Early breast cancer is breast cancer that is contained in the breast and may or may not have spread to lymph nodes in the armpit. Advanced breast cancer usually refers to metastatic breast cancer that has spread to other parts of the body. Locally advanced breast cancer is breast cancer with extensive axillary nodal involvement and that may have spread to areas near the breast, such as the chest wall.

## Step 1: Prevention and early detection

This step outlines recommendations for the prevention and early detection of breast cancer.

### 1.1 Risk factors

Age and sex are important risk factors for developing breast cancer; 70 per cent of cases occur in women over 50 years of age (NBOCC 2009).

Other risk factors include:

- family history of breast cancer and/or other cancers such as ovarian cancer
- not engaging in adequate physical activity (two or more hours of brisk walking or equivalent per week) (NBOCC 2009)
- obesity and weight gain in adulthood
- post-menopausal obesity
- moderate to heavy alcohol intake (more than two standard drinks per day)
- a previous diagnosis of breast cancer
- women diagnosed with DCIS (ductal carcinoma in situ)
- women diagnosed with LCIS (lobular carcinoma in situ)
- never having breastfed
- nulliparity
- past history of specific types of benign breast disease, atypical ductal hyperplasia (ADH) and atypical lobular hyperplasia (ALH) (Hartmann et al. 2014)
- higher mammographic breast density corrected for age and body mass index (BMI) (AIHW 2012)
- older age at menopause or younger age at menarche
- exposure to diethylstilboestrol (DES) in utero (NBOCC 2009)
- late age at first birth
- use of combined hormone replacement therapy and use of the oral contraceptive pill within the last 10 years
- chest radiation therapy before age 40.

By understanding a woman's personal breast cancer risk level, health professionals are able to offer the most appropriate evidence-based prevention and early detection strategies. Thus all women should have their individual breast cancer risk assessed. This will usually initially occur in primary care. Cancer risk assessment should be repeated when major risk factors change (for example, new family cancer history, breast biopsy showing atypical hyperplasia or LCIS).

There are a number of validated computerised breast cancer risk assessment tools that estimate an individual woman's breast cancer risk based on her personal risk factors:

- the IBIS tool available at <[www.ems-trials.org/riskevaluator/](http://www.ems-trials.org/riskevaluator/)>
- the Cancer Australia tool available at <<http://canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer/your-risk/calculate>>
- the Cancer Australia Familial Risk Assessment tool available at <<http://canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer/your-risk/calculate>>.

In Australia, lifetime population risk of breast cancer is 12 per cent. Cancer Australia defines levels of breast cancer risk as follows:

- average risk: < 1.5 × population risk
- moderate risk: 1.5–3 × population risk
- high risk: > 3 × population risk (NBOCC 2009).

Women at moderate or high risk due to their family cancer history should be referred to a family cancer clinic to have their risk further clarified and for possible genetic testing. Practitioners should refer to the published *eviQ Cancer genetics – breast and ovarian cancer referral guidelines* (eviQ 2015).

Women found to be at high lifetime risk of breast cancer (> 3 × average) should be advised to consider regular clinical examination, annual mammogram from about five years before their youngest relative developed breast cancer and annual MRI from this age until 50, preferably as part of an organised surveillance and risk-reducing program.

## 1.2 Risk reduction

All women should be encouraged to optimise their modifiable breast cancer risk factors. Adopting this range of healthy lifestyle choices improves general health, including the risks of several cancers.

Evidence is accumulating that physical exercise reduces breast cancer risk. Even approximately 1.5 hours of exercise per week is associated with a 20 per cent risk reduction (Bernstein et al. 2005). The protective effect of exercise is independent of other factors, such as weight.

Maintaining a healthy body weight, particularly after menopause, is important in reducing the risk of breast cancer. Excess fat in postmenopausal women can result in increased oestrogen levels that increase the risk for breast cancer. Eating a healthy diet, particularly avoiding a high-calorie diet, may be protective against breast cancer.

The use of alcohol is clearly linked with a heightened risk of breast cancer. Avoiding or limiting alcohol intake should be encouraged. Daily consumption of one alcoholic drink is associated with a small increase in risk. Women who drink two to five alcoholic drinks daily have a 1.5 times increased risk compared with non-drinkers.

For women at moderate or high risk of breast cancer, risk-reducing medication should be considered. In addition, women at high risk should consider risk-reducing surgery.

### 1.2.1 Risk-reducing medication for women at moderate or high risk

For women assessed as having an increased risk of breast cancer, anti-hormonal risk-reducing medication such as tamoxifen or an aromatase inhibitor is an option to lower the risk of developing breast cancer. Decisions about whether to use risk-reducing medication should be based on a clear understanding of the absolute benefits and risks for each individual woman.

### 1.2.2 Risk-reducing surgery for women at high risk

Risk-reducing surgery may be considered by women at high risk of developing breast cancer (NCI 2015), including those with a mutation in a major breast cancer predisposition gene, such as BRCA1 or BRCA2 (Cancer Council Australia 2015).

Bilateral risk-reducing mastectomy reduces the relative risk of breast cancer by at least 95 per cent (NCI 2015). Even with total mastectomy, not all breast tissue can be removed. The remaining breast tissue may be at risk of becoming cancerous in the future.

Bilateral risk-reducing salpingo-oophorectomy in premenopausal women under the age of 40 reduces the risk of breast cancer by approximately 50 per cent (NCI 2015). Women with a mutation in BRCA1 or BRCA2 are also at substantially increased risk of ovarian and fallopian tube cancers. Bilateral risk-reducing salpingo-oophorectomy reduces the risk of these cancers by 90 per cent.

For women who are considering risk-reducing surgery, the surgeon should provide:

- a clear description of the risk-reducing surgery technique, including options for reconstructive surgery, and clear information about the objective of the procedure
- information about managing menopausal symptoms and other long-term side effects including use of hormone replacement therapy (HRT)
- a discussion about the factors influencing psychosocial wellbeing post risk-reducing surgery.

### 1.3 Screening

Early detection through screening mammography has several benefits including improved mortality rates, increased treatment options and improved quality of life (Cancer Australia 2009). For women with small tumours at diagnosis (< 10 mm), there is a more than 95 per cent relative five-year survival rate (Cancer Australia 2012).

Federally funded mammographic screening is available to asymptomatic women from the age of 40 through the BreastScreen Australia program. It is recommended that women aged 50–74 consider undergoing a two-yearly screening mammogram. Annual screening may be offered to women at increased risk. For selected women at very high risk, breast MRI screening may be appropriate in addition to mammography. A doctor's referral is not required for screening through BreastScreen Australia but GPs' encouragement is a key factor in women's participation in screening.

Women who have symptoms or signs of breast cancer require prompt investigation of their symptoms, including diagnostic imaging. Screening mammography is not advised for these women as it may lead to false reassurance and delayed diagnosis.

Not all breast cancers are detectable on screening mammograms, and new cancers may arise in the interval between mammograms. Women should be aware of the look and feel of their breasts and report concerns to their GP.

Screening permits early cancer detection of breast cancer, which improves mortality rates. But screening can also lead to anxiety and additional investigations for non-malignant processes. At present it is impossible to predict which cancers detected by screening may progress during a woman's life. For this reason, over-diagnosis needs to be considered, and women invited to screening must be informed of the potential disadvantages as well as the benefits of mammographic screening (Lee & Peters 2013).

#### Further information

See Cancer Australia's position statement on over-diagnosis at <<http://canceraustralia.gov.au/publications-and-resources/position-statements/overdiagnosis-mammographic-screening>>.

## Step 2: Presentation, initial investigations and referral

This step outlines the process for establishing a diagnosis and appropriate referral. The types of investigation undertaken by the general or primary practitioner depend on many factors, including access to diagnostic tests, medical specialists and women's preferences.

A significant proportion of breast cancers are found in apparently asymptomatic women through routine breast screening.

### 2.1 Signs and symptoms

The following signs and symptoms found by the woman herself or her GP should be investigated:

- a new lump or lumpiness, especially involving only one breast
- a change in the size or shape of a breast
- a change to a nipple, such as crusting, ulceration, redness or inversion
- nipple discharge that occurs without squeezing
- a change in the skin of a breast such as redness or dimpling
- axillary masses
- an unusual breast pain that does not go away (Cancer Australia 2015).

#### Timeframe for general practitioner consultation

Timeframes for completing investigations should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce women's distress.

The following recommended timeframes are based on expert advice from the Breast Cancer Working Group:<sup>1</sup>

A patient with signs that may be concerning for breast cancer should be seen by their GP within two weeks. Appropriate triaging will identify women who need to be seen earlier.

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<sup>1</sup> The multidisciplinary experts group that participated in a clinical workshop to develop content for the breast cancer optimal care pathway are listed in the acknowledgements list.

## **2.2 Assessments by a general practitioner in symptomatic women and mammographic screening in asymptomatic women**

### **2.2.1 Assessments by a general practitioner**

The types of investigation undertaken by a general or primary practitioner depend on many factors including access to diagnostic tests and medical specialists and the woman's preferences. GPs should refer all women with a suspicious lesion to a breast assessment clinic (with noted exceptions, where appropriate).

Examinations/investigations should include a triple test of three diagnostic components:

- medical history and clinical breast examination
- imaging – mammography and/or ultrasound
- non-excision biopsy – FNA cytology and/or a core biopsy.

Based on the best available evidence, the triple test provides the most effective means of diagnosing breast cancer in women with breast symptoms.

A positive result on any component of the triple test warrants referral for specialist surgical assessment and/or further investigation irrespective of any other normal test results. This implies that not all three components of the triple test need to be performed to reach the conclusion that appropriate referral is needed. The triple test is positive if any component is indeterminate, suspicious or malignant (NBCC 2006; Zorbas et al. 2006).

### **2.2.2 Mammographic screening in asymptomatic women**

A significant proportion of breast cancers are diagnosed through mammographic screening in women who are asymptomatic.

BreastScreen Australia services operate within the framework of a comprehensive set of national accreditation standards that specify requirements for the safety/quality of diagnostic tests, timeliness of services and multidisciplinary care.

BreastScreen Australia services take responsibility for screening and investigation of screen-detected lesions, including needle biopsies. After multidisciplinary assessment and review of results, recommendations are made for the next steps in management. The woman and her GP are advised of these recommendations in writing. Surgery and ongoing care is typically not part of the BreastScreen program and has to be coordinated by the GP through appropriate surgical referral.

#### **Timeframe for completing investigations**

Timeframes for completing investigations should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce women's distress.

The following recommended timeframes are based on expert advice from the Breast Cancer Working Group: Optimally these tests should be done within two weeks.

## 2.3 Initial referral

If the diagnosis of breast malignancy is confirmed or the results are inconsistent or indeterminate, referral to a breast surgeon is warranted. Referral should include all clinical information, medical and psychosocial background and all images and diagnostic reports (old and new)

### Timeframe for referral to a specialist

Timeframes for referral should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce women's distress.

The following recommended timeframes are based on expert advice from the Breast Cancer Working Group:

Ideally the surgeon should see the patient with proven cancer or suspicious features within two weeks. If necessary, prior discussion should facilitate referral.

The supportive and liaison role of the woman's GP and practice team in this process is critical.

## 2.4 Support and communication

### 2.4.1 Supportive care

An individualised clinical assessment is required to meet the identified needs of a woman, her carer and family; referral should be as required.

In addition to common issues identified in the **appendix**, specific needs that may arise at this time include:

- appropriate information about the likely tests and processes
- appropriate information for people from culturally and linguistically diverse backgrounds.

### 2.4.2 Communication with the patient, carer and family

Effective communication is essential at every step of the care pathway. Effective communication with the woman and carers is particularly important given the prevalence of low health literacy in Australia (estimated at 60 per cent of Australian adults) (ACSQHC 2013).

The general or primary practitioner should:

- provide the woman with information that clearly describes who they are being referred to, the reason for referral and the expected timeframe for an appointment
- support the woman while waiting for the specialist appointment including for the emotional distress of dealing with a potential cancer diagnosis.

## Step 3: Diagnosis, staging and treatment planning

Step 3 outlines the process for confirming the diagnosis and stage of cancer, as well as planning subsequent treatment. The guiding principle is that interaction between appropriate multidisciplinary team members should determine the treatment plan.

### 3.1 Staging investigations (diagnostic work-up for women with breast cancer)

The diagnostic work-up for women with breast cancer consists of a thorough history including family history, and a medical examination, after which the following sequence of investigations may be considered:

- appropriate breast imaging tests including bilateral mammography and ultrasound
- ultrasound of the axilla (including FNA of nodes if the axillary ultrasound is abnormal)
- breast core biopsy if not already undertaken (a tissue diagnosis is essential prior to multidisciplinary discussion)
- establishment of breast cancer receptor profile (ER, PR, HER2).

Patients should be assessed for the possibility of a breast cancer predisposition gene and considered for genetic counselling if appropriate.

### 3.2 Staging investigations for distant disease

Staging is appropriate in women with confirmed nodal disease and for any women with clinical symptoms or clinical suspicion of metastatic disease. Routine computed tomography (CT) and bone scan are not recommended for most women with early breast cancer.

For a woman presenting with de novo metastatic disease, see step 6.

### **3.3 Treatment planning**

#### **3.3.1 The optimal timing for multidisciplinary team planning**

Prior to commencing treatment all women with newly diagnosed breast cancer should be discussed in a multidisciplinary team meeting so that a treatment plan can be recommended, including consideration for neoadjuvant therapy. The level of discussion may vary depending on both the clinical and psychosocial factors.

Results of all relevant tests, including all imaging investigations and pathology results, should be available for the multidisciplinary team discussion. Information about the woman's concerns, preferences and social circumstances should also be available. If a woman chooses to have a second opinion, this should be facilitated.

There may also need to be a review of existing treatment plans for women who have been discussed previously.

#### **3.3.2 Responsibilities of the multidisciplinary team**

These are to:

- nominate a team member to be the lead clinician (the lead clinician may change over time depending on the stage of the care pathway and where care is being provided)
- nominate a team member to coordinate patient care
- develop and document an agreed treatment plan at the multidisciplinary team meeting
- circulate the agreed treatment plan to relevant team members, including the woman's GP.

#### **3.3.3 Responsibilities of individual team members**

The medical practitioner who made the referral is responsible for the woman until care is passed to another practitioner.

The general or primary medical practitioner may play a number of roles in all stages of the cancer pathway including diagnosis, referral, treatment, coordination and continuity of care, as well as providing information and support to the woman and her family.

The care coordinator (usually a breast care nurse) is responsible for ensuring there is continuity throughout the care process and coordination of all necessary care for a particular phase. The person taking this responsibility may change over the course of the pathway.

The lead clinician is a clinician responsible for overseeing the activity of the team and for implementing treatment within the multidisciplinary setting.

### 3.3.4 Members of the multidisciplinary team for breast cancer

The multidisciplinary team should comprise the core disciplines integral to providing good care. Team membership will vary according to cancer type but should reflect both clinical and psychosocial aspects of care. Additional expertise or specialist services may be required for some women (Department of Health 2007b).

Team members may include a:

- breast surgeon\*
- care coordinator (usually a breast care nurse)\*
- medical oncologist\*
- nurse(s) (with appropriate expertise such as a breast care nurse)\*
- pathologist\*
- radiation oncologist\*
- radiologist\*
- clinical trials coordinator
- dietitian
- exercise physiologist
- fertility specialist
- GP
- geneticist and/or genetic counsellor
- occupational therapist
- palliative care specialist
- pharmacist
- physiotherapist
- plastic surgeon
- psychologist
- psychiatrist
- social worker.

\* Core members of the multidisciplinary team are expected to attend most multidisciplinary team meetings either in person or remotely.

### 3.4 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

- The Australia and New Zealand Breast Cancer Trials Group (ANZBCTG) coordinates multicentre national and international clinical trials. For more information visit <<https://www.anzbctg.org/content/6/about-australia-new-zealand-breast-cancer-trial-group>>.
- Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit <[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)>.

### **3.5 Special considerations**

Special considerations that need to be addressed at this stage include issues around pregnancy, fertility and prevention of chemotherapy-induced menopause.

### **3.6 Prehabilitation, support and communication**

#### **3.6.1 Prehabilitation**

Cancer prehabilitation uses a multidisciplinary approach combining exercise, nutrition and psychological strategies to prepare patients for the challenges of cancer treatment such as surgery, chemotherapy and radiation therapy.

Evidence indicates that prehabilitating newly diagnosed patients with cancer prior to starting treatment can be beneficial. This may include conducting a physical and psychological assessment to establish a baseline function level, identifying impairments and providing targeted interventions to improve the patient's health, thereby reducing the incidence and severity of current and future impairments related to cancer and its treatment (Silver & Baima 2013). The supportive and liaison role of the breast care nurse in this process is critical.

Studies have demonstrated that the breast care nurse role enhances early recognition of unmet needs, reduces psychological distress, improves continuity of care and increases understanding of diagnosis and treatment (NBCC 2001). All women should be assessed by a breast care nurse at the time of diagnosis.

Medications should be reviewed at this point to ensure optimisation and to improve adherence to medicines used for comorbid conditions.

### 3.6.2 Supportive care

Screening with a validated screening tool (such as the National Comprehensive Cancer Network distress thermometer), assessment and referral to appropriate health professionals or organisations is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues outlined in the **appendix**, specific needs that may arise at this time include the following.

- The option of fertility preservation and preservation of ovarian function needs to be discussed prior to starting treatment. Referral to a fertility service for counselling and evaluation of options may be appropriate. For detailed information on fertility preservation refer to Breast Cancer Network Australia's 'Fertility-related choices' available at <[https://www.bcna.org.au/sites/default/files/fertility\\_decision\\_aid\\_20120117.pdf](https://www.bcna.org.au/sites/default/files/fertility_decision_aid_20120117.pdf)>.
- Upper limb and breast lymphoedema following lymphadenectomy is a potential treatment side effect in women with breast cancers (NBCC & NCCI 2003), which has a significant effect on survivor quality of life. Referral (preferably preoperatively) to a health professional with accredited lymphoedema management qualifications, offering the full scope of complex lymphoedema therapy, may be needed.
- Guidance for financial and employment issues (such as loss of income and having to deal with travel and accommodation requirements for rural patients and caring arrangements for other family members) may be required.
- Weight changes, which can be a significant issue for women, may require referral to a dietitian before, during and after treatment.
- Help with the emotional distress of dealing with a cancer diagnosis is often required.
- Family distress if familial cancer identified is a common issue.
- Appropriate information for people from culturally and linguistically diverse backgrounds should be provided.

### 3.6.3 Communication with the patient

The lead clinician should:

- offer advice to the women and her carers on the benefits of and how to access support from breast cancer peer support groups, groups for carers and special interest groups
- establish if the woman has a regular or preferred GP
- discuss a timeframe for diagnosis and treatment with the woman and carer
- discuss the benefits of multidisciplinary care and make the woman aware that her health information will be available to the team for the discussion at the multidisciplinary team meeting
- provide referral to a fertility specialist prior to beginning treatment (for women who wish to consider childbearing after treatment)
- offer individualised breast cancer information that meets the needs of the woman and carer (this may involve advice from health professionals as well as written and visual resources)
- offer advice on how to access information and support from websites, community and national cancer services and support groups
- use a professionally trained interpreter to communicate with people from culturally or linguistically diverse backgrounds
- review comorbidities prior to surgery to reduce the likelihood of post-operative complications.

### **3.6.4 Communication with the general practitioner**

The lead clinician should:

- ensure regular and timely (within a week) communication with the woman's GP regarding the treatment plan and recommendations from multidisciplinary team meetings
- notify the GP if the woman does not attend appointments
- gather information from the GP including their perspective on the woman (psychological issues, social issues and comorbidities) and locally available support services
- contribute to the development of a chronic disease and mental healthcare plan as required
- discuss shared care arrangements between the multidisciplinary team and the GP
- invite the GP to participate in multidisciplinary team meetings (consider using video- or teleconferencing).

## Step 4: Treatment

Step 4 outlines the treatment options for breast cancer. For detailed information on treatment options refer to Cancer Australia's Clinical practice guidelines for the management of early breast cancer (2nd edn) at <http://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/clinical-practice-guidelines-management-early-breast-cancer-2nd-ed>.

Recommendations for managing early breast cancer in women with an identified BRCA1 or BRCA2 gene mutation or who are at high risk of a gene mutation can be found at <http://canceraustralia.gov.au/about-us/news/new-clinical-practice-guideline-recommendations-management-early-breast-cancer-women-identified> and aromatase inhibitors adjuvant endocrine therapy post-menopausal receptor-positive early breast cancer at <http://canceraustralia.gov.au/publications-resources/cancer-australia-publications/aromatase-inhibitors-adjuvant-endocrine-therapy>.

### 4.1 Treatment intent

The intent of treatment can be defined as one of the following:

- curative
- anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- symptom palliation.

The morbidity and risks of treatment need to be balanced against the potential benefits.

The lead clinician should discuss treatment intent and prognosis (if desired by the woman) with the woman and carer prior to beginning treatment.

If appropriate, advance care planning should be initiated with women at this stage. There can be multiple benefits to this such as ensuring the woman's preferences are known and respected after the loss of decision-making capacity (AHMAC 2011).

### 4.2 Treatment options

The aim of treatment for breast cancer and the types of treatment recommended depend on the type, stage and location of the cancer and the woman's age, health and preferences (Cancer Australia 2015).

The advantages and disadvantages of each treatment and associated potential side effects should be discussed with the woman.

#### Treatment for early and locally advanced disease

Early and locally advanced breast cancer is treated with curative intent.

##### 4.2.1 Surgery

Surgery for early breast cancer involves either breast-conserving surgery or mastectomy. Breast-conserving surgery followed by radiation therapy is as effective as mastectomy for most women with early breast cancer (Cancer Australia 2015).

Women with a clinically and radiologically negative axilla should be offered sentinel node biopsy. Axillary treatment with surgery and/or radiation therapy should be considered for women with nodal disease.

Oncoplastic breast surgery should be considered where appropriate.

### Breast reconstruction surgery

Mastectomy can be performed with or without immediate breast reconstruction surgery. Women should be fully informed of their options and offered the option of immediate or delayed reconstructive surgery if appropriate.

#### The training and experience required of the surgeons are as follows:

- breast surgeon (FRACS or equivalent, including membership of BreastSurgANZ) with adequate training and experience in breast cancer surgery and institutional cross-credentialing and agreed scope of practice within this area (ACSQHC 2004)
- plastic surgeon with an interest and expertise in breast reconstructive surgery.

### Timeframe for commencing treatment

Timeframes for starting treatment should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce women's distress.

The following recommended timeframes are based on expert advice from the Breast Cancer Working Group:

- Breast surgery should occur ideally within one month of a decision to treat with surgery (for invasive breast cancer).

#### Hospital or treatment unit characteristics for providing safe and quality care include:

- appropriate nursing and theatre resources to manage complex surgery
- 24-hour medical staff availability
- 24-hour operating room access
- specialist pathology expertise
- in-house access to specialist radiology and nuclear medicine expertise.

### 4.2.2 Chemotherapy and other systemic therapy

Neoadjuvant therapy, usually chemotherapy, may be appropriate for locally advanced breast cancers as well as some larger operable breast cancers to down-stage tumours, either to make them operable or to allow breast-conserving therapy.

For early breast cancers following surgery, a further discussion at the multidisciplinary team meeting will determine the appropriateness and type of systemic therapy. All women with invasive cancer should be considered for systemic therapy.

Targeted/biological therapies and/or anti-hormonal therapies can reduce the risk of recurrence in women with some subtypes of early breast cancer. Trastuzumab in combination with chemotherapy has been shown to significantly improve survival outcomes for women with early stage HER2-positive breast cancer (Perez et al. 2014). All women with hormone receptor-positive breast cancer should be considered for anti-hormonal therapy. Endocrine therapy should be administered for five years and longer in higher risk cases.

### Timeframe for commencing treatment

Timeframes for starting treatment should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce women's distress.

The following recommended timeframes are based on expert advice from the Breast Cancer Working Group:

- Chemotherapy should be started ideally within four weeks of surgery.
- Neoadjuvant chemotherapy should start within four weeks of a decision to treat with neoadjuvant chemotherapy.
- Endocrine therapy should start as soon as appropriate, after completion of chemotherapy and/or radiation therapy (and in some cases will be started prior to chemotherapy).

### Training, experience and treatment centre characteristics

The following training and experience is required of the appropriate specialist(s):

- Medical oncologists (RACP or equivalent) must have adequate training and experience with institutional credentialling and agreed scope of practice within this area (ACSQHC 2004).
- Nurses must have adequate training in chemotherapy administration and handling and disposal of cytotoxic waste.
- Chemotherapy should be prepared by a pharmacist with adequate training in chemotherapy medication, including dosing calculations according to protocols, formulations and/or preparation.
- In a setting where no medical oncologist is locally available, some components of less complex therapies may be delivered by a medical practitioner and/or nurse with training and experience with credentialling and agreed scope of practice within this area under the guidance of a medical oncologist. This should be in accordance with a detailed treatment plan or agreed protocol, and with communication as agreed with the medical oncologist or as clinically required.

### Hospital or treatment unit characteristics for providing safe and quality care include:

- a clearly defined path to emergency care and advice after hours
- access to basic haematology and biochemistry testing
- cytotoxic drugs prepared in a pharmacy with appropriate facilities
- occupational health and safety guidelines regarding handling of cytotoxic drugs, including safe prescribing, preparation, dispensing, supplying, administering, storing, manufacturing, compounding and monitoring the effects of medicines (ACSQHC 2011)
- guidelines and protocols are available to deliver treatment safely (including dealing with extravasation of drugs).

#### 4.2.3 Radiation therapy

In most cases, radiation therapy is recommended for women with early breast cancer after breast-conserving surgery. Radiation therapy should be considered in selected women after mastectomy. Hypofractionated radiation therapy (a three- to four-week course) should be considered for women where appropriate.

### Timeframe for commencing treatment

Timeframes for starting treatment should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce women's distress.

The following recommended timeframes are based on expert advice from the Breast Cancer Working Group:

- For women who do not have adjuvant chemotherapy, radiation therapy should commence within eight weeks of surgery.
- For women who have adjuvant chemotherapy, radiation therapy should commence three to four weeks after chemotherapy.

### Training, experience and treatment centre characteristics

Training and experience of the radiation oncologist:

- radiation oncologist (FRANZCR or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice within this area (ACSQHC 2004).

### Hospital or treatment unit characteristics for providing safe and quality care include:

- appropriately credentialled radiation therapists and physicists
- radiation therapy nurses
- access to CT/MRI scanning for simulation and planning
- mechanisms for coordinating chemotherapy and radiation therapy, especially where facility is not collocated
- access to allied health services.

## 4.3 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

For more information visit <<https://www.anzbctg.org/content/6/about-australia-new-zealand-breast-cancer-trial-group>> and <[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)>.

#### 4.4 Complementary or alternative therapies

The lead clinician should discuss the woman's use (or intended use) of complementary or alternative therapies not prescribed by the multidisciplinary team to discuss safety and efficacy and identify any potential toxicity or drug interactions.

The lead clinician should seek a comprehensive list of all complementary and alternative medicines being taken and explore the woman's reason for using these therapies and the evidence base.

Most alternative therapies and some complementary therapies have not been assessed for efficacy or safety. Some have been studied and found to be harmful or ineffective.

Some complementary therapies may assist in some cases and the treating team should be open to discussing the potential benefits for the individual.

If the woman expresses an interest in using complementary therapies, the lead clinician should consider referring them to health professionals within the multidisciplinary team who have knowledge of complementary and alternative therapies (such as a clinical pharmacist, dietitian or psychologist) to help her reach an informed decision.

The lead clinician should assure women who use complementary or alternative therapies that they can still access multidisciplinary team reviews (NBCC & NCCI 2003) and encourage full disclosure about therapies being used (Cancer Australia 2010).

##### Further information

- See Cancer Australia's position statement on complementary and alternative therapies at <<http://canceraustralia.gov.au/publications-and-resources/position-statements/complementary-and-alternative-therapies>>.
- See the Clinical Oncology Society of Australia's position statement at <[www.cosa.org.au/publications/position-statements.aspx](http://www.cosa.org.au/publications/position-statements.aspx)>.

## 4.5 Support and communication

### 4.5.1 Supportive care

Screening with a validated screening tool and assessment and referral to appropriate health professionals and/or organisations is required to meet the needs of individual women, their families and carers.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include the following.

#### Physical needs

- Weight changes can be a significant issue for women and may require referral to a dietitian before, during and after treatment.
- Menopause symptoms may require referral to a menopause clinic.
- General healthcare issues (for example, smoking cessation and sleep disturbance) can be referred to a GP.
- Encouraging exercise can be referred to an accredited exercise practitioner.
- Early management for acute pain postoperatively to avoid chronic pain may be needed.
- Reduced sexual interest and sexual dysfunction may require referral to a clinician skilled in this area.
- Treatment for physical symptoms such as pain, arthralgia and fatigue may be needed.
- Decline in mobility and/or functional status as a result of treatment may necessitate a referral to physiotherapy or occupational therapy.
- Upper limb and breast lymphoedema following lymphadenectomy is a potential treatment side effect in women with breast cancers (NBCC & NCCI 2003) that has a significant effect on survivor quality of life. Referral (preferably preoperatively) to a health professional with accredited lymphoedema management qualifications, offering the full scope of complex lymphoedema therapy, may be needed.
- Bowel dysfunction, gastrointestinal or abdominal symptoms as a result of treatment may require support from a dietitian.
- Although treatments have improved, neuropathy, cardiac dysfunction and nausea and vomiting are still serious side effects of cancer chemotherapy. Managing them is important for improving quality of life.
- Women may need support to cope with hair loss (refer to the Look Good, Feel Better program and/or consider scalp cooling).
- Assistance with managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications may require referral to a pharmacist.

### Psychological needs

- Anxiety/depression, interpersonal problems, stress and adjustment difficulties may require referral to a counsellor or mental health professional.
- Alteration of cognitive functioning in women treated with chemotherapy and radiation therapy requires strategies such as maintaining written notes or a diary and repetition of information (NBCC & NCCI 2003).

### Fertility preservation and preservation of ovarian function

- Loss of fertility, sexual dysfunction or other symptoms associated with treatment or surgically or chemically induced menopause require sensitive discussion and possible referral to a clinician skilled in this area (NBCC & NCCI 2003).

### Social/practical needs

- Potential isolation from normal support networks, particularly for rural women who are staying away from home for treatment, may necessitate extra support.
- Financial issues related to loss of income and additional expenses as a result of illness and/or treatment may need attention.
- Legal issues (including accessing superannuation, advance care planning, appointing a power of attorney and completing a will) may require advice from relevant professionals.

### Information needs

- Appropriate information for people from culturally and linguistically diverse backgrounds should be provided.

#### 4.5.2 Communication with the woman, carer and family

The lead clinician should:

- offer advice to women and carers on the benefits of and how to access support from breast cancer peer support groups, groups for carers and special interest groups
- discuss the treatment plan with the woman and her carer, including the intent of treatment and expected outcomes (a written plan should be provided)
- provide the woman and carer with information on possible side effects of treatment, self-management strategies and emergency contacts.

#### 4.5.3 Communication with the general practitioner

The lead clinician should:

- discuss with the woman's GP their role in symptom management, psychosocial care and referral to local services
- ensure regular and timely two-way communication regarding
  - the treatment plan, including intent and potential side effects
  - supportive and palliative care requirements
  - the woman's prognosis and their understanding of this
  - enrolment in research and/or clinical trials
  - changes in treatment or medications
  - recommendations from the multidisciplinary team.

## Step 5: Care after initial treatment and recovery

The transition from active treatment to post-treatment care is critical to long-term health. After completion of initial treatment, women should be provided with a treatment summary and follow-up care plan including a comprehensive list of issues identified by all members of the multidisciplinary team. Transition from acute to primary or community care will vary depending on the type and stage of cancer and needs to be planned. In some cases, women will require ongoing, hospital-based care.

### 5.1 Survivorship

In the past two decades, the number of people surviving cancer has increased. International research shows there is an important need to focus on helping cancer survivors cope with life beyond their acute treatment. Cancer survivors experience particular issues, often different from women having active treatment for cancer.

Many cancer survivors experience persisting side effects at the end of treatment. Emotional and psychological issues include distress, anxiety, depression, cognitive changes and fear of cancer recurrence. Late effects may occur months or years later and are dependent on the type of cancer treatment. Survivors may experience altered relationships and may encounter practical issues, including difficulties with return to work or study, and financial hardship.

Survivors generally need to see a doctor for regular followup, often for five or more years after cancer treatment finishes. The Institute of Medicine, in its report *From cancer patient to cancer survivor: Lost in transition*, describes four essential components of survivorship care (Hewitt et al. 2006):

- the prevention of recurrent and new cancers, as well as late effects
- surveillance for cancer recurrence or second cancers; and screening and assessment for medical and psychosocial late effects
- interventions to deal with the consequences of cancer and cancer treatments (including management of symptoms, distress and practical issues)
- coordination of care between all providers to ensure the woman's needs are met.

All women should be educated in managing their own health needs (NCSI 2015).

## 5.2 Post-treatment care planning

### 5.2.1 Treatment summary

Upon completion of initial treatment, the woman, the woman's carer (as appropriate) and GP should receive a treatment summary outlining:

- the diagnostic tests performed and results
- tumour characteristics
- the type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

### 5.2.2 Follow-up care

Care in the post-treatment phase is driven by predicted risks (such as the risk of recurrence, developing late effects and psychological issues) as well as individual clinical and supportive care needs. It is important that post-treatment care is evidence-based and consistent with guidelines.

Responsibility for follow-up care should be agreed between the lead clinician, the woman's GP, relevant members of the multidisciplinary team and the woman, with an agreed plan documented that outlines:

- what medical follow-up is required (surveillance for cancer spread, recurrence or secondary cancers, screening and assessment for medical and psychosocial effects)
- care plans from other health professionals to manage the consequences of cancer and treatment
- a process for rapid re-entry to specialist medical services for suspected recurrence.

In particular circumstances, follow-up care can safely and effectively be provided:

- in the primary care setting
- by other suitably trained staff (for example, nurse-led follow-up)
- in a non-face-to-face setting (for example, by telehealth).

The options for follow-up should be discussed at the completion of the primary treatment.

- A woman's follow-up schedule will be planned based on her individual circumstances. Investigations should be determined on a case-by-case basis.
- Most follow-up will involve a history, including updating personal history and enquiry about persistent symptoms that might require investigation to exclude metastatic disease. Family cancer history should be updated.
- If the woman has previously had genetic testing that revealed an unclassified variant in a cancer predisposition gene, the clinician should liaise regularly with the relevant family cancer centre until the variant is classified as benign or pathogenic.
- Physical examination, and particularly breast examination and limb circumference measure, should be conducted. Annual mammography (unless the woman underwent a bilateral mastectomy) should be undertaken. In some cases it may be appropriate to also undertake breast ultrasound or MRI.
- Appropriate follow-up does not involve chest x-rays, bone scans, CT scans, positron emission tomography (PET) scans or blood tests unless the cancer has spread or there are symptoms suggesting metastases.
- Toxicity related to treatment should be monitored and managed, including bone health and cardiovascular health. There is a significant role for physiotherapy in the prevention of osteoporosis.
- Premenopausal women who develop amenorrhoea are at risk of rapid bone loss. There is evidence that oral bisphosphonates are effective in reducing bone loss.
- Continue to prompt general good health.

**Adherence to ongoing recommended treatment such as endocrine therapy should be reviewed and side effects managed proactively in order to optimise adherence.**

Access to a range of health professions may be required including physiotherapy, occupational therapy, nursing, social work, dietetics, genetic counselling and psychology.

### 5.3 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

For more information visit <<https://www.anzbtg.org/content/6/about-australia-new-zealand-breast-cancer-trial-group>> and <[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)>.

### 5.4 Support and communication

#### 5.4.1 Supportive care

Screening using a validated screening tool and assessment and referral to appropriate health professionals and community-based support services is required to meet the needs of individual women, their families and carers.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include the following.

#### Physical needs

- Weight changes can be a significant issue for women and may require referral to a dietitian before, during and after treatment.
- Menopause symptoms may require referral to a menopause clinic.
- General healthcare issues (for example, smoking cessation and sleep disturbance) can be referred to a GP.
- Reduced sexual interest and sexual dysfunction may require referral to a clinician skilled in this area.
- Treatment for physical symptoms such as pain, arthralgia and fatigue may be needed.
- Decline in mobility and/or functional status as a result of treatment may necessitate a referral to physiotherapy or occupational therapy.
- Upper limb and breast lymphoedema following lymphadenectomy is a potential treatment side effect in women with breast cancers (NBCC & NCCI 2003) that has a significant effect on survivor quality of life. Referral (preferably preoperatively) to a health professional with accredited lymphoedema management qualifications, offering the full scope of complex lymphoedema therapy, may be needed.
- Bowel dysfunction, gastrointestinal or abdominal symptoms as a result of treatment may require support from a dietitian.
- Although treatments have improved, neuropathy, cardiac dysfunction and nausea and vomiting are still serious side effects of cancer chemotherapy. Managing them is important for improving quality of life.
- Women may need support to cope with hair loss (refer to the Look Good, Feel Better program and/or consider scalp cooling).
- Assistance with managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications may require referral to a pharmacist.

### Psychological needs

- Family distress, if familial cancer identified, may require support.
- Emotional distress arising from fear of disease recurrence, changes in body image, returning to work, anxiety/depression, interpersonal problems and sexuality concerns may need attention.
- Anxiety/depression, interpersonal problems, stress and adjustment difficulties may require referral to a counsellor or mental health professional.
- Alteration of cognitive functioning in women treated with chemotherapy and radiation therapy requires strategies such as maintaining written notes or a diary and repetition of information (NBCC & NCCI 2003).

### Social/practical needs

- Difficulties with return to work or study may require extra support.
- Financial issues related to loss of income and additional expenses as a result of illness and/or treatment may need attention.
- Legal issues (including accessing superannuation, advance care planning, appointing a power of attorney and completing a will) may require advice from relevant professionals.

### Information needs

- Appropriate information for people from culturally and linguistically diverse backgrounds should be provided.

#### 5.4.2 Rehabilitation and recovery

Rehabilitation may be required at any point of the care pathway from preparing for treatment through to disease-free survival and palliative care.

Issues that may need to be addressed include managing cancer-related fatigue, cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae.

#### 5.4.3 Communication with the woman, carer and family

The lead clinician should:

- discuss the management of any of the issues identified in 5.4.1
- offer advice to women and carers on the benefits of and how to access support from breast cancer peer support groups, groups for carers and special interest groups
- explain the treatment summary and follow-up care plan
- provide information about the signs and symptoms of recurrent disease
- provide information about secondary prevention and healthy living.

#### 5.4.4 Communication with the general practitioner

The lead clinician should ensure regular, timely, two-way communication with the woman's GP regarding:

- the follow-up care plan
- potential late effects
- supportive care requirements
- the woman's progress
- recommendations from the multidisciplinary team
- any shared care arrangements
- a process for rapid re-entry to medical services for women with suspected recurrence.

## Step 6: Managing locoregional recurrence or metastatic disease

Step 6 is concerned with managing locoregional recurrence and metastatic disease.

Some women will present with symptoms of recurrent disease in the locoregional area or at distant sites, or both. Some cases of recurrent disease will be detected by routine follow-up in a woman who is asymptomatic. All cases should undergo investigation (staging scans) to establish the extent of disease and be rebiopsied if possible; biopsies should have receptor status re-evaluated.

For detailed information on treatment options for advanced breast cancer refer to the ESO-ESMO 2nd international consensus guidelines for advanced breast cancer (ABC2) (Cardoso et al. 2014) at <http://annonc.oxfordjournals.org/content/early/2014/09/17/annonc.mdu385.full.pdf+html>.

### 6.1 Managing locoregional recurrence

Some women will present with symptoms of recurrent disease in the locoregional area.

#### 6.1.1 Multidisciplinary team

There should be timely referral to the original multidisciplinary team (where possible).

Care coordination is the responsibility of all health professionals involved in the woman's care and should be considered in their practice. This is particularly important for women with metastatic disease or those with multiple comorbidities or supportive care needs.

#### 6.1.2 Treatment

Treatment will depend on the location and extent of the recurrence and on previous management and the woman's preferences. The woman should be reassessed at a multidisciplinary team meeting and treatment may include all modalities of care. All modalities may be considered and the woman should be investigated for distant spread.

In most cases, a combination of anticancer and supportive therapies will provide the most effective overall management of recurrent disease.

Regular assessment of response to therapy should be undertaken and the therapy changed if disease progresses, or as appropriate.

#### 6.1.3 Palliative care

Early referral to palliative care for symptom management can improve the quality of life for women with breast cancer.

## 6.2 Managing metastatic disease

Some women will present with symptoms of metastatic disease. Some cases of metastatic disease will be detected at the same time as presentation with the initial primary breast cancer ('de novo metastatic disease').

There should be a rebiopsy of accessible sites and re-evaluation of biomarkers.

There should be a complete assessment of the sites of disease including CTs of the abdomen and pelvis and the of the chest, bone scans and blood tumour markers.

### 6.2.1 Multidisciplinary team

There should be timely referral to the original multidisciplinary team (where possible).

### 6.2.2 Treatment

Treatment will depend on the location and extent of the cancer and previous treatments, and may include all modalities of therapies including antiresorptive therapy if bone metastases are present.

Regular assessment of the woman's response to therapy should be undertaken and the therapy changed if disease progresses or as appropriate.

In women with hormone receptor-positive breast cancer without rapidly progressing visceral disease, endocrine therapy may be the most appropriate treatment initially with use of chemotherapy when endocrine responsiveness is lost.

Many endocrine therapies are effective in producing antitumour responses in metastatic breast cancer. These can often be used in sequence to gain successive responses to treatment. They include:

- ovarian ablation/suppression in pre-menopausal women
- selective oestrogen receptor modulators such as tamoxifen
- aromatase inhibitors, which block oestrogen production.

### 6.2.3 Palliative care

Early referral to palliative care can improve the quality of life for people with cancer and in some cases may be associated with survival benefits (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014).

The lead clinician should ensure timely and appropriate referral to palliative care services. Referral to palliative care services should be based on need, not prognosis.

Patients should be encouraged to develop an advance care plan, where appropriate (AHMAC 2011).

Ensure carers and families receive the information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

### Further information

Refer women and their carers to Palliative Care Australia via <[www.palliativecare.org.au](http://www.palliativecare.org.au)>.

## 6.3 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

For more information visit <<https://www.anzbctg.org/content/6/about-australia-new-zealand-breast-cancer-trial-group>> and <[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)>.

## 6.4 Support and communication

### 6.4.1 Supportive care

Screening, assessment and referral to appropriate health professionals is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include the following.

#### Physical needs

- Weight changes can be a significant issue for women and may require referral to a dietitian before, during and after treatment.
- General healthcare issues (for example, smoking cessation and sleep disturbance) can be referred to a GP.
- Reduced sexual interest and sexual dysfunction may require referral to a clinician skilled in this area.
- Treatment for physical symptoms such as pain, arthralgia and fatigue may be needed.
- Decline in mobility and/or functional status as a result of treatment may necessitate a referral to physiotherapy or occupational therapy.
- Upper limb and breast lymphoedema following lymphadenectomy is a potential treatment side effect in women with breast cancers (NBCC & NCCI 2003) that has a significant effect on survivor quality of life. Referral (preferably preoperatively) to a health professional with accredited lymphoedema management qualifications, offering the full scope of complex lymphoedema therapy, may be needed.
- Bowel dysfunction, gastrointestinal or abdominal symptoms as a result of treatment may require support from a dietitian.
- Assistance with managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications may require referral to a pharmacist.

#### Psychological needs

- Emotional distress arising from fear of disease recurrence, changes in body image, returning to work, anxiety/depression, interpersonal problems and sexuality concerns may need attention.
- Anxiety/depression, interpersonal problems, stress and adjustment difficulties may require referral to a counsellor or mental health professional.
- Alteration of cognitive functioning in women treated with chemotherapy and radiation therapy requires strategies such as maintaining written notes or a diary and repetition of information (NBCC & NCCI 2003).

### **Social/practical needs**

- Potential isolation from normal support networks, particularly for rural women who are staying away from home for treatment, may need attention.
- Financial issues related to loss of income and additional expenses as a result of illness and/or treatment may need support.
- Legal issues (including accessing superannuation, advance care planning, appointing a power of attorney and completing a will) may require advice from relevant professionals.

### **Information needs**

- Appropriate information for people from culturally and linguistically diverse backgrounds should be provided.

### **6.4.2 Rehabilitation**

Rehabilitation may be required at any point of the care pathway from preparing for treatment through to disease-free survival and palliative care.

Issues that may need to be addressed include managing cancer-related fatigue, cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae.

### **6.4.3 Communication with the woman, carer and family**

The lead clinician should ensure there is adequate discussion with the woman and her carer about the diagnosis and recommended treatment, including the intent of treatment and possible outcomes, likely adverse effects and supportive care options available.

Initiate a discussion regarding advance care planning with the woman and carer if appropriate.

## Step 7: End-of-life care

End-of-life care is appropriate when the woman's symptoms are increasing and functional status is declining. Step 7 is concerned with maintaining the woman's quality of life and addressing her health and supportive care needs as she approaches the end of life, as well as the needs of her family and carer. Consideration of appropriate venues of care is essential. The principles of a palliative approach to care need to be shared by the team when making decisions with the woman and her family.

### 7.1 Multidisciplinary palliative care

If not already involved, referral to palliative care should be considered at this stage (including nursing, pastoral care, palliative medicine specialist backup, inpatient palliative bed access (as required), social work and bereavement counselling) with GP engagement.

If not already in place, the woman and carer should be encouraged to develop an advance care plan (AHMAC 2011).

The multidisciplinary palliative care team may consider seeking additional expertise from a:

- pain specialist
- pastoral carer or spiritual advisor
- bereavement counsellor
- therapist (for example, music or art).

The team might also recommend accessing:

- home- and community-based care
- specialist community palliative care workers
- community nursing.

Consideration of an appropriate place of care and preferred place of death is essential.

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

#### Further information

Refer the woman and her carer to Palliative Care Australia via <[www.palliativecare.org.au](http://www.palliativecare.org.au)>.

### 7.2 Research and clinical trials

Participation in research and clinical trials should be encouraged where available and appropriate.

For more information visit <<https://www.anzbctg.org/content/6/about-australia-new-zealand-breast-cancer-trial-group>> and <[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)>.

## 7.3 Support and communication

### 7.3.1 Supportive care

Screening, assessment and referral to appropriate health professionals is required to meet the identified needs of the woman, her carer and family.

In addition to the common issues identified in the **appendix**, specific issues that may arise at this time include:

- emotional and psychological distress from anticipatory grief, existential distress, fear of death/dying, anxiety/depression, interpersonal problems and anticipatory bereavement support for the woman as well as her carer and family
- practical, financial and emotional impacts on carers and family members resulting from the increased care needs of the woman
- legal issues relevant to people with advanced disease such as accessing superannuation early, advance care planning, powers of attorney and completing a will
- information for women and families about arranging a funeral
- specific spiritual needs that may benefit from the involvement of pastoral care
- bereavement support for family and friends
- specific support for families where a parent is dying and will leave behind bereaved children or adolescents, creating special family needs
- physical symptoms including pain and fatigue
- change in physical appearance
- increasing dependence on others
- decline in mobility and/or functional status impacting on her discharge destination.

### 7.3.2 Communication with the woman, carer and family

The lead clinician should:

- be open to and encourage discussion about the expected disease course, with due consideration to personal and cultural beliefs and expectations
- discuss palliative care options including inpatient and community-based services as well as dying at home and subsequent arrangements
- provide the woman and carer with the contact details of a palliative care service.

### 7.3.3 Communication with the general practitioner

The lead clinician should discuss end-of-life care planning and transitioning planning to ensure the woman's needs and goals are addressed in the appropriate environment. The woman's GP should be kept fully informed and involved in major developments in the woman's illness trajectory.

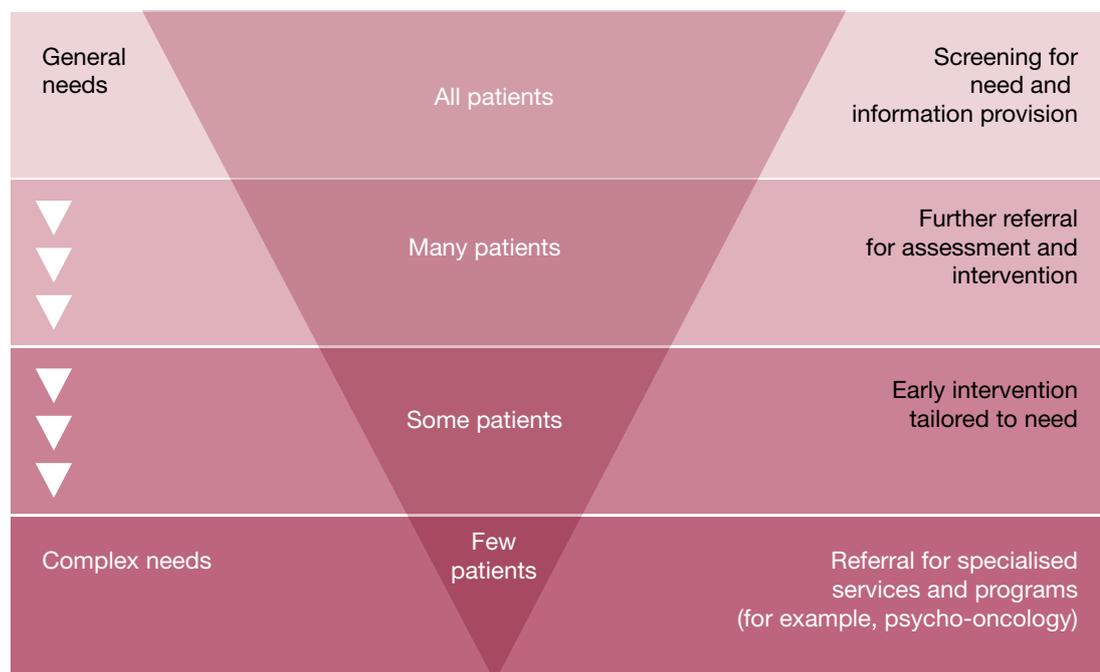
# Appendix: Supportive care

Supportive care in cancer refers to the following five domains:

- physical domain, which includes a wide range of physical symptoms that may be acute, relatively short-lived or ongoing, requiring continuing interventions or rehabilitation (NBCC & NCCI 2003)
- psychological domain, which includes a range of issues related to the person's mental health and personal relationships (NBCC & NCCI 2003)
- social domain, which includes a range of social and practical issues that will impact on the individual and their family such as the need for emotional support, maintaining social networks and financial concerns (NICE 2004)
- information domain, which includes access to information about cancer and its treatment, support services and the health system overall (NBCC & NCCI 2003)
- spiritual domain, which focuses on the person's changing sense of self and challenges to their underlying beliefs and existential concerns (NICE 2004).

Fitch's (2000) model of supportive care (Figure 1) recognises the variety and level of intervention required at each critical point as well as the need to be specific to the individual. The model targets the type and level of intervention required to meet women's supportive care needs.

**Figure 1: The tiered approach**



While all women require general information, only a few will require specialised intervention. Common indicators in women with breast cancer who may require referral to appropriate health professionals and/or organisations include the following:

### **Physical needs**

- Weight changes can be a significant issue for women and may require referral to a dietitian before, during and after treatment.
- Menopause symptoms may require referral to a menopause clinic.
- General healthcare issues (for example, smoking cessation and sleep disturbance) can be referred to a GP.
- Reduced sexual interest and sexual dysfunction may require referral to a clinician skilled in this area.
- Treatment for physical symptoms such as pain, arthralgia and fatigue may be needed.
- Decline in mobility and/or functional status as a result of treatment may necessitate a referral to physiotherapy or occupational therapy.
- Bowel dysfunction, gastrointestinal or abdominal symptoms as a result of treatment may require support from a dietitian.
- Upper limb and breast lymphoedema following lymphadenectomy is a potential treatment side effect in women with breast cancers (NBCC & NCCI 2003) that has a significant effect on survivor quality of life. Referral (preferably preoperatively) to a health professional with accredited lymphoedema management qualifications, offering the full scope of complex lymphoedema therapy, may be needed.
- Although treatments have improved, neuropathy, cardiac dysfunction and nausea and vomiting are still serious side effects of cancer chemotherapy. Managing them is important for improving quality of life.
- Women may need support to cope with hair loss (refer to the Look Good, Feel Better program and/or consider scalp cooling).
- Assistance with managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications may require referral to a pharmacist.

## Psychological needs

- For some populations (culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islanders, and lesbian, transgender and intersex communities) a breast cancer diagnosis can come with additional psycho-social complexities. Discrimination uncertainty may also make these groups less inclined to seek regular medical and gynaecological care. Access to expert health professionals who possess knowledge specific to the psychosocial needs of these groups may be required.
- Alteration of cognitive functioning in women treated with chemotherapy and radiation therapy requires strategies such as maintaining written notes or a diary and repetition of information (NBCC & NCCI 2003).
- Those with a pre-existing mental health disorder have a higher risk of psychological disturbance.
- Women who have had extensive surgery or who receive a multimodality treatment strategy for breast cancer are at high risk of depression and heightened anxiety. Regular screening for depression and anxiety specifically for these women is required. Strategies such as information provision, relaxation techniques, meditation (Kearney & Richardson 2006) and a referral to a psychologist or psychiatrist as required may be helpful.
- Fear of cancer recurrence is reported to be extremely common in the post-treatment phase. Some women may have disabling symptoms and may benefit from referral to psychology services.
- Distress and depression can be just as common in carers and family members including children.
- Consider a referral to a psychologist, psychiatrist or social worker if the woman is:
  - displaying emotional cues such as tearfulness, distress, avoidance and withdrawal
  - preoccupied with or dwelling on thoughts about cancer and death
  - displaying fears about the treatment process and/or the changed goals of their treatment
  - worried about loss associated with their daily function, dependence on others and loss of dignity
  - becoming isolated from family and friends and withdrawing from company and activities that they previously enjoyed
  - feeling hopeless and helpless about the impact that breast cancer is having on their life and the disruption to their life plans
  - struggling with communicating to family and loved ones about the implications of their cancer diagnosis and treatment
  - experiencing changes in sexual intimacy, libido and function
  - struggling with the diagnosis of metastatic or advanced disease
  - having difficulties with quitting drug and alcohol use
  - having difficulties transitioning to palliative care.

### **Body image**

- Support and counselling from a psychologist, psychiatrist, occupational therapist or social worker may be required.
- Disfigurement and scarring from appearance-altering treatment (and possible need for a prosthetic), which may require referral to a specialist psychologist, psychiatrist or social worker.

### **Fertility preservation and preservation of ovarian function**

- Loss of fertility, sexual dysfunction or other symptoms associated with treatment or surgically or chemically induced menopause require sensitive discussion and possible referral to a clinician skilled in this area (NBCC & NCCI 2003).
- The option of fertility preservation and preservation of ovarian function needs to be discussed prior to treatment starting. Referral to a fertility service for counselling and evaluation of options may be appropriate. For detailed information on fertility preservation refer to Breast Cancer Network Australia's Fertility-related choices available at <[https://www.bcna.org.au/sites/default/files/fertility\\_decision\\_aid\\_20120117.pdf](https://www.bcna.org.au/sites/default/files/fertility_decision_aid_20120117.pdf)>.

### **Social/practical needs**

- Significant restrictions to social activities may require referral to a social worker, occupational therapist, psychologist or psychiatrist.
- Potential isolation from normal support networks, particularly for rural women who are staying away from home for treatment, may be needed.
- Financial issues related to loss of income and additional expenses as a result of illness and/or treatment may require additional support.
- Legal issues (including accessing superannuation, advance care planning, appointing a power of attorney and completing a will) may require referral to relevant professionals.

### **Spiritual needs**

- Women with cancer and their families should have access to spiritual support appropriate to their needs throughout the cancer journey.
- Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual caregivers who can act as a resource for women, carers and staff. They should also have up-to-date awareness of local community resources for spiritual care.

## Populations with special needs

### Elderly women with cancer

Planning and delivering appropriate cancer care for elderly women presents a number of challenges. Improved communication between the fields of oncology and geriatrics is required to facilitate the delivery of best practice care, which takes into account physiological age, complex comorbidities, risk of adverse events and drug interactions, as well as implications of cognitive impairment on suitability of treatment and consent (Steer et al. 2009).

A national interdisciplinary workshop convened by the Clinical Oncology Society of Australia recommended that women over the age of 70 undergo some form of geriatric assessment, in line with international guidelines (COSA 2013). Assessment can be used to determine life expectancy and treatment tolerance as well as identifying conditions that might interfere with treatment including:

- function
- comorbidity
- presence of geriatric syndromes
- nutrition
- polypharmacy
- cognition
- emotional status
- social supports.

Guided intervention using aged care services is appropriate.

### Younger women

While there is no accepted definition of 'young' regarding breast cancer, younger women have been defined in previous guidelines as women aged 40 or younger at breast cancer diagnosis (NBCC 2004). Approximately 700 women under the age of 40 are diagnosed with breast cancer in Australia each year (AIHW 2014). Studies suggest that younger women with breast cancer have worse disease-free and overall survival outcomes (NBOCC 2007). Younger women with breast cancer are also likely to face different issues in treatment and follow-up. Concerns may include:

- fertility and pregnancy following treatments
- sexual difficulties at higher rates than older women with breast cancer (NBOCC 2007)
- greater impact on body image (NBOCC 2007)
- needs of dependent children, including child care issues
- increased concerns about the impact of diagnosis and treatment on relationships compared with older women (NBOCC 2007)
- concerns about their employment and financial status
- early menopause.

### **Pregnancy-associated breast cancer**

Pregnancy-associated breast cancer, defined as breast cancer diagnosed during pregnancy or in the year after a pregnancy, accounts for seven per cent of breast cancers in young women (Ives 2009), which is around 100 women annually in Australia. These women typically have higher disease-stage and more aggressive tumour features at diagnosis. However, when matched by age and disease stage with other breast cancer cases, there appears to be no survival difference, except in women diagnosed in the postpartum period, who have higher mortality and increased distant recurrence even after accounting for these factors.

A multidisciplinary team approach is essential in managing this group. Initial investigation of any breast symptom in a pregnant or lactating woman should be the same as any other woman, to avoid diagnostic delays. The treating team should include health professionals involved in the treatment of breast cancer, the care of pregnancy and psychosocial support. The recommended obstetric and cancer management of a woman presenting with gestational breast cancer will be dependent on the fetal gestation and disease status at diagnosis.

### **Men with breast cancer**

Breast cancer in men is uncommon, with about 145 men diagnosed annually in Australia (AIHW 2014). Given the low number of diagnoses and the identification of breast cancer in the general community as a 'female disease', many men who are diagnosed with breast cancer can feel isolated and unsupported. This has the potential to cause significant psychological distress and may lead to anxiety and depression. Those working in the area should be alert to the increased risk for psychological complications, impact on body image and isolation. Peer support may be useful to normalise the feeling and side effects of treatment. All resources should be cognisant of not excluding men as this has the potential to further ostracise an already isolated group.

## **Aboriginal and Torres Strait Islander communities**

The burden of cancer is higher in the Australian Indigenous population (AIHW 2014). Survival also significantly decreases as remoteness increases, unlike the survival rates of non-Indigenous Australians. Aboriginal and Torres Strait Islander people in Australia have high rates of certain lifestyle risk factors including tobacco smoking, higher alcohol consumption, poor diet and low levels of physical activity (Cancer Australia 2013). The high prevalence of these risk factors is believed to be a significant contributing factor to the patterns of cancer incidence and mortality rates in this population group (Robotin et al. 2008).

In caring for Aboriginal and Torres Strait Islander people diagnosed with cancer, the current gap in survivorship is a significant issue. The following approaches are recommended to improve survivorship outcomes (Cancer Australia 2013):

- Raise awareness of risk factors and deliver key cancer messages.
- Develop evidence-based information and resources for community and health professionals.
- Provide training for Aboriginal and Torres Strait Islander health workers and develop training resources.
- Increase understanding of the barriers to care and support.
- Encourage and fund research.
- Improve knowledge within the community to act on cancer risk and symptoms.
- Improve the capacity of Aboriginal and Torres Strait Islander health workers to provide cancer care and support to their communities.
- Improve system responsiveness to cultural needs.
- Improve our understanding of care gaps through data monitoring and targeted priority research.

## **Culturally and linguistically diverse communities**

For women from culturally and linguistically diverse backgrounds in Australia, a cancer diagnosis can come with additional complexities, particularly when English proficiency is poor. In many languages there is not a direct translation of the word 'cancer', which can make communicating vital information difficult. Perceptions of cancer and related issues can differ greatly in those from culturally diverse backgrounds and can impact on the understanding and decision making that follows a cancer diagnosis. In addition to different cultural beliefs, when English language skills are limited there is potential for miscommunication of important information and advice, which can lead to increased stress and anxiety for women. A professionally trained interpreter (not a family member or friend) should be made available when communicating with people with limited English proficiency. Navigation of the Australian healthcare system can pose problems for those born overseas and particular attention should be paid to supporting these women (Department of Health 2009).

# Resource list

## For patients, families and carers

### Australian Cancer Survivorship Centre

Has general and tumour-specific information, primarily focused on the post-treatment survivorship phase

- Telephone: (03) 9656 5207
- <[www.petermac.org/cancersurvivorship](http://www.petermac.org/cancersurvivorship)>

### beyondblue

Information on depression, anxiety and related disorders, available treatment and support services

- Telephone: 1300 22 4636
- <[www.beyondblue.org.au](http://www.beyondblue.org.au)>

### Breast Cancer Network Australia

Specific information on breast cancer

- Telephone: 1800 500 258
- <[www.bcna.org.au](http://www.bcna.org.au)>

### Cancer Australia

Information on cancer prevention, screening, diagnosis, treatment and supportive care for Australians affected by cancer, and their families and carers

- Telephone: 1800 624 973
- <[www.canceraustralia.gov.au](http://www.canceraustralia.gov.au)>

### Cancer Council (operated by Cancer Council Victoria)

A confidential telephone support service for people affected by cancer providing information on treatment, cancer support groups and other community resources

- Telephone: 13 11 20 (Monday to Friday, 8.30 am – 5.30 pm)
- <[www.cancervic.org.au](http://www.cancervic.org.au)>

### CanTeen

Australian organisation for young people living with cancer that offers support, information and resources

- Telephone: 1800 226 833
- <[www.canteen.org.au](http://www.canteen.org.au)>

### Care Search: Palliative Care Knowledge Network

Information for patients and carers on living with illness and practical advice on how to care and finding services

- Telephone: (08) 7221 8233
- <[www.caresearch.com.au](http://www.caresearch.com.au)>

### Look Good, Feel Better

A non-medical, free community service program dedicated to teaching women how to manage the appearance-related side effects caused by cancer treatment

- Telephone: 1800 650 960 (Monday to Thursday 9.00am to 5.00pm)
- <[www.lgfb.org.au](http://www.lgfb.org.au)>

## For health professionals

### Australian Cancer Trials

Information on the latest clinical trials in cancer care, including trials that are recruiting new participants

- <[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)>

### Cancer Australia

Information for health professionals including guidelines, cancer guides, reports, fact sheets, DVDs, posters and pamphlets

- <[www.canceraustralia.gov.au](http://www.canceraustralia.gov.au)>

### Cancer Council Australia

Information on prevention, research, treatment and support provided by Australia's peak independent cancer authority

- <[www.cancer.org.au](http://www.cancer.org.au)>

**eviQ**

Clinical information resource providing health professionals with current evidence-based, peer-maintained, best practice cancer treatment protocols and information relevant to the Australian clinical environment

- <[www.eviq.org.au](http://www.eviq.org.au)>

**National Health and Medical Research Council**

Information on clinical practice guidelines, cancer prevention and treatment

- <[www.nhmrc.gov.au](http://www.nhmrc.gov.au)>

# Glossary

**Advance care planning** – a process of discussing future medical treatment and care based on an individual's preferences, goals, beliefs and values, which can guide future decisions should the person become unable to communicate.

**Alternative therapies** – treatments that are used in place of conventional medical treatment, often in the hope they will provide a cure.

**Care coordinator** – the health professional nominated by the multidisciplinary team to coordinate patient care. The care coordinator may change over time depending on the patient's stage in the care pathway and where care is primarily located.

**Complementary therapies** – supportive treatment used in conjunction with conventional medical treatment. These treatments may improve wellbeing and quality of life and help women deal with the side effects of cancer.

**End-of-life care** – a distinct phase of palliative care that is appropriate when a woman's symptoms are increasing and functional status is declining despite anti-cancer therapy.

**General/primary medical practitioner** – the practitioner to whom the woman first presents with symptoms; this may be the general practitioner, an emergency department clinician or a medical professional providing cancer screening services.

**Lead clinician** – the clinician who is responsible for managing patient care. The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

**Multidisciplinary care** – an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and develop an individual treatment plan collaboratively for each woman (Department of Health 2007b).

**Multidisciplinary team** – comprises the core disciplines integral to providing good care. The team is flexible in approach, reflects the woman's clinical and psychosocial needs and has processes to facilitate good communication.

**Optimal cancer care pathway** – the key principles and practices required at each stage of the care pathway to guide the delivery of consistent, safe, high-quality and evidence-based care.

**Palliative care** – any form of medical care or treatment that concentrates on reducing the severity of disease symptoms.

**Patient management frameworks** – tumour stream models adopted in Victoria in 2003 to reduce variation in cancer care. The optimal cancer care pathways are updated versions of these models.

**Prehabilitation** – one or more interventions performed in a newly diagnosed cancer patient that are designed to improve physical and mental health outcomes as the woman undergoes treatment and beyond.

**Primary specialist** – the person who makes the referral to the multidisciplinary team (such as specialist physician, surgeon, oncologist, palliative care specialist). This person will also make referrals for treatment and will be responsible for overseeing follow-up care.

**Rehabilitation** – comprises multidisciplinary efforts to allow the woman to achieve optimal physical, social, physiological and vocational functioning within the limits imposed by the disease and its treatment.

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## Governance – project steering committee representation

Ballarat Health Services

Cancer Australia

Cancer Council Victoria Strategy and Support  
Consumer representatives

Department of Health & Human Services, Cancer Strategy and Development

Grampians Integrated Cancer Service  
Monash University

North Eastern Melbourne Integrated Cancer Service

Peter MacCallum Cancer Centre

Royal Hobart Hospital

Western Health

## Medical colleges and peak organisations invited to provide feedback

Allied Health Professions Australia

Australian Association of Nuclear Medicine Specialists

Australian and New Zealand Society of Palliative Care

Australian Chapter of Palliative Medicine, Royal Australasian College of Physicians

Australian College of Nursing

Australian Institute of Radiography

Australian Medical Association

Australian Psychological Society

Breast Cancer Network Australia (BCNA)

Interventional Radiology Society of Australasia

Medical Oncology Group of Australia

National Breast Cancer Foundation

Oncology Social Work Australia (OSWA)

Royal Australasian College of Physicians

Royal Australasian College of Surgeons (RACS)

Royal Australian and New Zealand College of Psychiatrists

Royal Australian and New Zealand College  
of Radiologists (RANZCR)  
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**Other stakeholders consulted to provide  
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