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Psychosocial clinical practice guidelines
information, support and counselling
for women with breast cancer
Psychosocial clinical practice guidelines: information, support and counselling for women with breast cancer

Prepared by the NHMRC National Breast Cancer Centre
Psychosocial Working Group

Issued by the National Health and Medical Research Council in accordance with the National Health and Medical Research Act, 1992 (Cth).

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The strategic intent of the NHMRC is to work with others for the health of all Australians, by promoting informed debate on ethics and policy, providing knowledge based advice, fostering a high quality and internationally recognised research base, and applying research rigour to health issues.

This document was prepared by the National Breast Cancer Centre Psychosocial Working Group. NHMRC documents are prepared by panels of experts drawn from appropriate Australian academic, professional, community and government organisations.

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# Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>List of tables</td>
<td>v</td>
</tr>
<tr>
<td>Foreword</td>
<td>vii</td>
</tr>
<tr>
<td>Executive Summary</td>
<td>ix</td>
</tr>
<tr>
<td><strong>PART I</strong> INTRODUCTION AND BACKGROUND</td>
<td>1</td>
</tr>
<tr>
<td>1.1 The impact of breast cancer and the benefits of psychosocial intervention for women with breast cancer</td>
<td>1</td>
</tr>
<tr>
<td>1.2 The development of these guidelines</td>
<td>2</td>
</tr>
<tr>
<td>1.3 Summary of evidence</td>
<td>5</td>
</tr>
<tr>
<td><strong>PART II</strong> PROVIDING INFORMATION</td>
<td>7</td>
</tr>
<tr>
<td>2.1 General interactional skills</td>
<td>7</td>
</tr>
<tr>
<td>2.2 Telling a woman that she has breast cancer, a recurrence or metastases</td>
<td>9</td>
</tr>
<tr>
<td>2.3 Discussing prognosis</td>
<td>12</td>
</tr>
<tr>
<td>2.4 Discussing treatment options: providing information and choice</td>
<td>17</td>
</tr>
<tr>
<td>2.5 Preparing women for potentially threatening procedures and treatment</td>
<td>23</td>
</tr>
<tr>
<td><strong>PART III</strong> PROVIDING SUPPORT AND COUNSELLING</td>
<td>25</td>
</tr>
<tr>
<td>3.1 Providing emotional and social support</td>
<td>25</td>
</tr>
<tr>
<td>3.2 Providing psychological care</td>
<td>28</td>
</tr>
<tr>
<td>3.3 Practical needs and financial issues</td>
<td>45</td>
</tr>
<tr>
<td>3.4 Dealing with cultural issues</td>
<td>47</td>
</tr>
<tr>
<td>3.5 Ensuring continuity of care</td>
<td>52</td>
</tr>
<tr>
<td>3.6 Support in palliative care</td>
<td>55</td>
</tr>
</tbody>
</table>
## LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1</td>
<td>General interactional skills</td>
<td>8</td>
</tr>
<tr>
<td>2.2</td>
<td>Recommended steps for telling a woman she has breast cancer, a recurrence or metastases</td>
<td>11</td>
</tr>
<tr>
<td>2.3</td>
<td>Recommended steps for discussing prognosis with women with breast cancer</td>
<td>16</td>
</tr>
<tr>
<td>2.4</td>
<td>Recommended steps for effectively discussing treatment options with women with breast cancer</td>
<td>22</td>
</tr>
<tr>
<td>2.5</td>
<td>Recommended steps involved in adequately preparing a woman for a potentially threatening medical procedure</td>
<td>24</td>
</tr>
<tr>
<td>3.1A</td>
<td>Recommended steps involved in ensuring that all women have adequate emotional and social support</td>
<td>26</td>
</tr>
<tr>
<td>3.1B</td>
<td>Support interventions that can improve the emotional wellbeing of women with breast cancer</td>
<td>27</td>
</tr>
<tr>
<td>3.2A</td>
<td>Types of therapy and their impact on cancer patients</td>
<td>29</td>
</tr>
<tr>
<td>3.2B</td>
<td>Impact of different intervention techniques on specific psychological problems</td>
<td>36</td>
</tr>
<tr>
<td>3.2C</td>
<td>Factors associated with an increased risk of psychosocial problems</td>
<td>40</td>
</tr>
<tr>
<td>3.2D</td>
<td>Recommended steps for screening women with breast cancer for significant clinical problems</td>
<td>41</td>
</tr>
<tr>
<td>3.2E</td>
<td>Example clinician questions to screen for psychological difficulties</td>
<td>42</td>
</tr>
<tr>
<td>3.3</td>
<td>Recommended steps involved in dealing with practical issues</td>
<td>47</td>
</tr>
<tr>
<td>3.4</td>
<td>Recommended steps involved in dealing with cultural issues</td>
<td>52</td>
</tr>
<tr>
<td>3.5</td>
<td>Recommended steps for establishing continuity of care</td>
<td>55</td>
</tr>
<tr>
<td>3.6</td>
<td>Recommended steps involved in providing support in palliative care</td>
<td>59</td>
</tr>
</tbody>
</table>
IMPORTANT NOTICE

This document is a guide to appropriate practice, to be followed subject to the clinician’s judgment in each case.

The guidelines are designed to provide information to assist decision-making and are based on the evidence available at time of publication. They are not meant to be prescriptive.
FOREWORD

In October, 1995, the National Health and Medical Research Council released Clinical Practice Guidelines for the Management of Early Breast Cancer. These evidence-based guidelines were developed to ensure effective clinical practice and improve the health outcomes for women with early breast cancer. Although these guidelines alluded to psychosocial outcomes, there were few specific recommendations about effective clinical practice in this area.

Women with breast cancer suffer significant emotional morbidity. In addition to the distress, fear and grief consequent upon diagnosis, up to 45 per cent of women suffer anxiety or depressive disorders. These disorders have a major impact on the woman’s functioning, and that of her family, as well as posing a major occupational and economic burden.

Women continue to request more information in order to better understand breast cancer, its impact on them and their family, and the treatment options available. Women are only able to participate as they wish in clinical decisions if they have access to such information. For women from rural areas, and those from particular cultural groups, access to such information and services represents a major unmet need. Clinical experience also suggests that treating doctors and other members of the treatment team desire guidance on the emotional needs of women, and the means of effectively providing information and support for them.

The NHMRC National Breast Cancer Centre Psychosocial Working Group first convened in 1995 to consider the extent and type of psychosocial needs of women with breast cancer, and the most effective ways of providing appropriate interventions. This multidisciplinary group developed detailed and specific clinical practice guidelines based on the best available evidence about the psychosocial aspects of breast cancer management.

These evidence-based guidelines have been designed for use by health professionals who come in contact with women during breast cancer diagnosis, treatment, or palliation. The document is multidisciplinary in its focus and the recommendations applicable to diverse treatment settings.

These guidelines provide clear recommendations, predominantly based on level I and level II evidence. I am confident that their successful implementation in routine clinical practice will help to reduce the suffering of women and their families coping with breast cancer.

Dr Jane Turner
Chair, National Breast Cancer Centre Psychosocial Working Group
EXECUTIVE SUMMARY

Approximately 10,000 Australian women are diagnosed with breast cancer each year. As a result, many face practical, emotional and psychological demands in addition to their physical treatment. The evidence shows that these psychosocial needs are significant and frequently go undetected and unmet. Up to 45 per cent of women with early breast cancer experience an anxiety or mood disorder. Additionally, many women report inadequate information to guide their decision-making and are disadvantaged because of a lack of knowledge about practical support, even when such services are available. The impact on their family is also high.

The psychosocial clinical practice guidelines were developed by the National Breast Cancer Centres multi-disciplinary working party to assist members of the treatment team to provide evidence-based supportive care to meet these psychosocial needs. The guidelines were based on seven comprehensive and systematic reviews of the research and an extensive consultative process to ensure their clinical relevance.

Many of the recommendations are based on level I (meta-analyses) and level II (randomised controlled trial) evidence, particularly those relating to information provision, psychological interventions and emotional and social support (see 1.3, Summary of Evidence). For example, there is level I evidence that psychological preparation for surgery improves both physical and psychological outcomes after surgery. There is also level I evidence that appropriate psychological intervention does reduce the high levels of psychological morbidity experienced by women with breast cancer.

The guidelines also provide a valuable resource for facilitating the practical care of women with breast cancer including information about financial assistance and services for women with specific needs.

Implementation of these guidelines have the potential to improve healthcare outcomes, including a reduction in psychological morbidity and emotional distress, improved wellbeing and satisfaction with care. Many of the guideline recommendations require no infrastructure or additional resources and are able to be widely implemented. As such they represent an important resource to improve breast cancer care in treatment settings throughout Australia.
PART I

INTRODUCTION AND BACKGROUND

1.1 The impact of breast cancer

Approximately 10,000 Australian women are diagnosed with breast cancer each year and one in 11 will be diagnosed with the disease by the age of 74.1 The diagnosis of breast cancer may be made following a woman presenting for routine screening or after symptoms are investigated. These 10,000 women who seek treatment after their diagnosis come from diverse cultural and religious backgrounds, may live in urban, rural or remote settings and may occupy roles within traditional or non-traditional family units.

Despite the diversity of this population, each woman will experience a range of practical, psychological and emotional challenges as a result of her diagnosis and treatment. These may include: coping with the shock of diagnosis; treatment side effects, such as nausea, vomiting, fatigue and physical changes in body appearance and functioning. The life of each woman may be further disrupted by changes in role and family functioning, occupational or employment and financial status. Many women will also have to come to terms with progressive illness and approaching death.

The psychological impact of breast cancer and its demands are significant. The few available estimates of the prevalence of long-term psychological distress in cancer patients range from 20 per cent to 66 per cent.2,3 While most women with breast cancer experience symptoms of anxiety, 12 per cent to 30 per cent have been found to experience clinically significant anxiety problems (level IVa).4-6 Research about Australian women with early breast cancer indicated similar levels of morbidity, with anxiety disorders detected in 23 per cent of those interviewed (level IVa).4,7,8

Australian Bureau of Statistics report that 17 per cent of Australian women in the general community will experience an anxiety or depressive disorder in a 12-month period,9 while a US study estimated that 5.8 per cent of the general population will develop clinical depression at some point in their lives.10 There is some evidence that depression is at least twice as common in women undergoing surgery for cancer as in women without cancer.11,12 For example, Fallowfield found that 29 per cent of women suffered depression following a mastectomy and 21 per cent of women suffered depression 12 months later; whereas, for breast-conserving therapy, 22 per cent of women suffered depression post-operatively and 21 per cent suffered depression after 12 months.11 Dean reported that 20 per cent of women undergoing adjuvant therapy for breast cancer experienced minor depression.13 Among cancer patients with progressive disease and in palliative care, some studies report that up to 40 per cent of patients are clinically depressed.14

The experience of breast cancer may continue to have an emotional impact on some women long after their diagnosis. Residual concerns about recurrence and fear of checkups may last for many years after the original diagnosis. The diagnosis
of a recurrence is a very stressful time, and up to 50 per cent of women experience psychiatric disorders at this time.\textsuperscript{15,16}

The benefits of support for women with breast cancer

Much can be done to improve a woman’s adjustment to the diagnosis and treatment of breast cancer. Each woman will have her own ways of coping which may have helped in the past, and which may include religious faith or specific problem solving techniques. All members of the treatment team may also play a role in strengthening the woman’s own resources by providing additional emotional, informational and practical assistance, and appropriately fostering a sense of hope or optimism.

Cumulative evidence now demonstrates that psychological therapies improve emotional adjustment and social functioning, and reduce both treatment and disease-related distress in cancer patients. In a meta-analysis of 45 randomised controlled trials in cancer patients, those receiving psychological therapies had, on average, a significant improvement of 12 per cent in emotional adjustment, 10 per cent in social functioning, 14 per cent in treatment and disease-related symptoms, and 14 per cent in overall improvement in their quality of life when compared to those not receiving psychological therapies (level I).\textsuperscript{17} A meta-analysis of 116 intervention studies showed that cancer patients receiving psycho-educational or psychosocial interventions had much lower rates of anxiety, depression, mood disturbances, nausea, vomiting and pain, and significantly greater knowledge about disease and treatment, than no intervention controls (level I).\textsuperscript{18}

Evidence from meta-analyses of randomised controlled trials indicates the efficacy of both supportive and cognitive-behavioural therapies in the treatment of depressive disorders in women with breast cancer (level I),\textsuperscript{18,19} and the efficacy of both individual and group therapies (level I).\textsuperscript{19}

1.2 Development of these guidelines

Need for evidence-based psychosocial clinical practice guidelines

A large body of evidence indicates that psychosocial interventions can benefit the emotional adjustment and social functioning of cancer patients. However, there are few guidelines available on providing direct psychosocial interventions and the provision of supportive care for women with breast cancer.

The Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer, and their implementation and evaluation strategy (see Appendix B), have been developed following the steps and parameters recommended by the NHMRC\textsuperscript{20} in response to this need.
Objective and scope of the guidelines

The objective of the psychosocial clinical practice guidelines is to assist health professionals in achieving the goal of providing an evidence base for all aspects of the clinical care of women with breast cancer, by documenting recommendations derived from the best available evidence on the psychosocial aspects of care.

The provision of optimal care is reliant upon effective physical and psychological care. Evidence-based recommendations on the treatment of breast cancer are provided in the:

- Clinical Practice Guidelines for the Management of Early Breast Cancer
- Clinical Practice Guidelines for the Management of Advanced Breast Cancer

The psychosocial clinical practice guidelines augment the treatment guidelines by providing evidence-based recommendations on:

- the provision of information;
- the integration of quality of life issues into the care of women with breast cancer;
- minimising the social and psychological impact of breast cancer on a woman and her family; and
- strategies for the identification and management of women experiencing significant emotional disturbance.

These guidelines identify fundamental themes in the provision of psychological care and all evidence-based recommendations detailed herein merit attention and action. It is acknowledged however, that local circumstances and the availability of resources may influence the implementation of some recommendations. Indeed, some recommendations may be difficult to implement due to local resource constraints, such as the current availability of psychiatrists, clinical psychologists or specialist breast nurses. Therefore, the guidelines are not rigid procedural paths, they are intended to allow flexibility in their implementation, dependent upon available resources and individual treatment centre characteristics.

A further objective of the guidelines is to provide practitioners with evidence-based criteria against which their service and interventions can be monitored. The use of guidelines-based audit criteria will assist the identification of local strengths and weaknesses in the provision of psychological care, and provide a measure by which changes in service delivery may be evaluated over time.

Target audience

These guidelines were developed for use by all members of the diagnostic and treatment team, which may include surgeons, radiation oncologists, medical oncologists, general practitioners, nurses, social workers, psychologists, psychiatrists, physiotherapists and occupational therapists.
It is recognised that while some aspects of psychosocial care are common to all the health professionals involved in a woman's treatment and care, different members of the treatment team will be responsible for specific aspects of the psychosocial care of women with breast cancer.

Development of these guidelines
A series of consensus meetings were held with members from the relevant professions and consumers, and comprehensive literature reviews were undertaken, to identify the evidence base for key decision points. The seven comprehensive literature reviews, which form the basis of this document, cover the scientific literature prior to 1997. In keeping with NHMRC recommendations the literature reviews identify and synthesise the best available scientific evidence on the key practice-related issues. On the basis of areas of need identified by these reviews, specific studies were also commissioned by the National Breast Cancer Centre Psychosocial working group.

The evidence rating system used in the reviews of the scientific literature is based on recommendations for intervention studies by the NHMRC’s Standing Committee on Quality of Care and Health Outcomes (QCHOC), which was adapted from the rating system developed by the US Preventive Services Task Force. The National Breast Cancer Centre Psychosocial working group have expanded the QCHOC’s evidence rating system in order to highlight the distinction between level IV evidence gained from well-conducted descriptive research (level IVa), and evidence drawn from clinical expertise (level IVb). The evidence-rating system used in these guidelines is as follows:

**Level I**
evidence is obtained from a systematic review of all relevant randomised controlled trials, usually found in meta-analyses

**Level II**
evidence is obtained from at least one properly designed randomised controlled trial

**Level III**
evidence is obtained from well-designed controlled trials without randomisation; or from well-designed cohort or case-control analytic studies, preferably from more than one centre of research; or from multiple time series, with or without the intervention

**Level IVa**
evidence is obtained from descriptive studies of provider practices, patient behaviours, knowledge, or attitudes or a systematic review of the descriptive studies

**Level IVb**
represents the opinions of respected authorities based on clinical experience or reports of expert committees.

For intervention studies, Level I represents the gold standard of evidence. Recommendations based on lower levels of evidence have been included in this document because of the insight offered by well-conducted research or clinical consensus on pertinent issues which have not been subject to investigation using randomised control trial methodology.
Annotated references of key research articles are contained in the Psychosocial Guideline’s Supporting Research Supplement, and full copies of all reviews are available from the National Breast Cancer Centre (NBCC).

Appendix B further details the process for the development and evaluation of these guidelines.

### 1.3 Summary of evidence

The following table highlights those summary statements which are supported by level I and level II evidence in these guidelines. The appropriate sections in the text expand the context of this evidence, including discussion of significant, clinically relevant recommendations based on evidence from other than level I or level II study designs.

<table>
<thead>
<tr>
<th>Summary Statements with Level I and II Evidence</th>
<th>Level</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>General interactional skills - Chapter 2.1</strong></td>
<td></td>
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<tr>
<td>Women’s understanding, recall and/or satisfaction with care increases when techniques such as the following are used:</td>
<td></td>
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<tr>
<td>• taping of the consultation</td>
<td>II</td>
<td>36, 37</td>
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<tr>
<td>• general information tapes</td>
<td>II</td>
<td>35</td>
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<tr>
<td>• a summary letter as a “follow-up” to the consultation</td>
<td>II</td>
<td>3</td>
</tr>
<tr>
<td>• the presence of a specialist breast nurse</td>
<td>II</td>
<td>39</td>
</tr>
<tr>
<td><strong>Discussing prognosis - Chapter 2.3</strong></td>
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<tr>
<td>Factors such as the amount of information, mode of expression (descriptive vs probabilistic), framing (negative or positive) and a doctor’s communication style influences a woman’s decision about treatment</td>
<td>II</td>
<td>57</td>
</tr>
<tr>
<td>II</td>
<td>48, 49</td>
<td></td>
</tr>
<tr>
<td><strong>Providing information and choice - Chapter 2.4</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appropriate detailed information promotes understanding and increases the psychological wellbeing of women with breast cancer</td>
<td>I</td>
<td>18</td>
</tr>
<tr>
<td>Discussions with a specialist breast nurse reduce psychological morbidity and increase understanding of breast cancer, recall of information and perceptions of support for women with breast cancer</td>
<td>II</td>
<td>39, 71-73</td>
</tr>
<tr>
<td>Women’s recall of information increases when they are provided with individualised information</td>
<td>II</td>
<td>37, 38, 77, 78, 80, 81</td>
</tr>
</tbody>
</table>
Preparing women for potentially threatening procedures and treatment - Chapter 2.5

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Providing women with information about the procedure they are about to undergo reduces emotional distress and improves psychological and physical recovery.

Providing women with procedural information from a clinician, allied health professional or specialist breast nurse, a booklet and/or videotape decreases anxiety, and psychological distress.

Providing women with psychosocial support before undergoing surgery reduces psychological distress.

Providing emotional and social support - Chapter 3.1

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Appropriate counselling improves the wellbeing of women with breast cancer.

The opportunity to discuss feelings with a member of the treatment team or counsellor decreases psychosocial distress.

Specialist breast nurses enhance early recognition of social support needs and decrease psychological distress.

Providing psychological care - Chapter 3.2

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<td>19</td>
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A variety of psychological interventions, including involvement in group support, reduce psychological distress. However, greater beneficial effects are observed when therapies are longer and conducted by more highly trained therapists.

Depression in women with breast cancer can be managed by incorporating a combination of supportive psychotherapy, cognitive and behavioural techniques, and pharmacotherapy.

In cases of anxiety, cognitive and behavioural techniques (e.g., muscle relaxation and imagery) are effective treatment options. However, when anxiety or panic impedes or complicates treatment, prompt assessment from a psychiatrist or clinical psychologist may be required.

Ensuring continuity of care - Chapter 3.5

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<td>II</td>
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Specialist breast nurses improve understanding and provide continuity of care throughout the treatment process.

Patient-held records improve continuity of care.

6 Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer.
PART II

PROVIDING INFORMATION

2.1 General interactional skills

The way a clinician and the treatment team relates to, and communicates with, a woman with breast cancer can have significant benefits for the woman and her family. These benefits potentially include improvements in psychological adjustment, decision-making, treatment compliance and satisfaction with care.

Women with cancer repeatedly report a desire to be well-informed. Research also indicates that up to 66 per cent prefer key information to come from a hospital doctor (level IVa). Effective communication, however, involves more than the provision of information; it requires a process of individually-tailored explanation, problem-solving and acknowledgment of the woman’s feelings.

There are a number of communication skills that are relevant to any clinical situation and should be considered in any consultation with women with breast cancer. These general interactional skills include the following, and are summarised in Table 2.1 (page 8):

Skills to convey support
- expressing empathy and listening actively improves psychological adjustment (level III); (level IVa). Expressing empathy means acknowledging the woman’s feelings, e.g. ‘this must be very hard for you to hear’. Listening actively includes verbally acknowledging what she has said and/or asking questions to clarify what she means.

Delivering medical information in plain English
- giving clear, specific information (level III);
- explaining medical terms and avoiding medical jargon (level III);
- actively encouraging questions (level II);
- actively checking understanding, e.g. ‘just so I can be sure I’ve explained everything clearly, could you summarise what you think your options are?’ (level III);
- repeating and summarising important pieces of information (level III).

Using strategies shown to increase satisfaction, recall and understanding
- written information (level III);
- general information tapes (level II);
- taping of the consultation (level II);
- a summary letter as a “follow-up” to the consultation (level II);
- presence of a specialist breast nurse (level II).
Communicating in a quiet and private environment

Information about breast cancer and treatment information often has considerable emotional impact on women. If women are confronted with treatment-related information in a distracting environment (e.g., an open ward) or by professionals who they perceive to be rushed and unsupportive (e.g., during a ward round), much information can be forgotten, satisfaction compromised and poor adjustment may result.

Table 2.1: General interactional skills

The following skills should be considered in any consultation with women with breast cancer:

Supportive communication
- Asking the woman if she would like someone to be with her during the consultation
- Show regard and concern for the woman by using appropriate verbal and non-verbal behaviour, including sitting attentively and facilitating the woman’s responses
- Use verbal and non-verbal behaviours which are appropriate to a woman’s age and cultural background
- Express empathy and listen actively
- Allow and encourage the woman to express her feelings (e.g., crying, talking about concerns, fears, anger, anxieties, etc.)
- Handle embarrassing or disturbing topics directly and sensitively.

Delivering medical information in plain English
- Assess a woman’s understanding before providing additional information
- Explain difficult terms and avoid medical jargon
- Use explicit categorisation (provide information clearly grouped in specific topics).

Strategies to aid recall and understanding
- Actively encourage questions and seek understanding
- Make use of simple diagrams and pictures where appropriate
- Repeat and summarise important information
- Reinforce important information by using one or more of the following aids:
  - Writing down relevant information
  - Taping the consultation as needed and if wanted
  - Sending the woman a summary letter as follow-up.

Ongoing support
- Assess the woman’s level of family or social support
- Provide the names and contact details of relevant persons or organisations to obtain more information
- Refer to a specialist breast nurse or other relevant professional for support as required.
2.2 **Telling a woman that she has breast cancer, a recurrence or metastases**

A diagnosis of breast cancer may be made following routine screening or in response to a detected symptom. By its very nature, the diagnosis can be tremendously difficult for everyone involved. From the doctor's perspective, it can be one of the most personally difficult roles s/he must perform.

The way in which diagnostic news is delivered affects not only the woman’s understanding of the illness, but can also impact on her longer term psychological adjustment (level III); (level IVa). For example, reaction to the diagnosis of a life-threatening illness has recently been accepted in criteria for post traumatic stress disorder (level III).30

Most existing guidelines, and the relatively small amount of research in this area, have focused on giving the initial diagnosis, but this is just the first step in communicating the news about breast cancer. Further news, such as recurrence or metastases, may prove more difficult to communicate than the initial diagnosis. Evidence indicates that the psychological impact of news of a recurrence may be more devastating than the initial diagnosis (level III).31

**Physical and social setting**

Women may receive the news of diagnosis of breast cancer in one of a number of settings, including hospital clinics, wards or breast screen facilities. The NHMRC Clinical Practice Guidelines for the Management of Early Breast Cancer21 suggest that a diagnosis of cancer should be given in a place which is quiet and private and that a support person invited to be present whenever key information or results are to be presented to the woman. A specialist breast nurse or in the case of BreastScreen, a counsellor may be helpful at this time. Special measures may be necessary to ensure privacy if a woman is presented with test results in a hospital ward setting. Women may need time to discuss issues arising from this news, and would benefit from having this time without interruptions.

**Type of information**

Research suggests that most women prefer to be told all of the information about their disease, even if it is bad news. The most appropriate approach is to tailor the information to the individual woman’s needs (level IVa).32

Most women appear to be satisfied with the way that they are told their diagnosis, but would like more information, particularly about their test results and their prognosis (level IVa).41 There is also a duty of care for clinicians to disclose any information which may impact on the woman’s treatment outcomes and/or quality of life.

Many women will be concerned about the possibility of death and dying at the time of a diagnosis of breast cancer. However, it may not be until the woman is diagnosed with a recurrence or distant metastasis that clinically, she needs to face the issue of death from breast cancer. The clinician has an important role in supporting the woman to address these issues in a manner appropriate for her. It is
important to acknowledge fears the woman may express, and provide her with the relevant information. In the case of early stage breast cancer, for example, the five-year survival rate is currently better than 70 per cent (Level IVa).42

Increasing understanding

A woman’s ability to recall medical information is an important factor in her ability to take a role in making treatment decisions. Effective methods of communication ensure the woman is best able to absorb, understand and recall information.

Discussing difficult issues

Every woman’s response to the news of a diagnosis, recurrence or metastasis will be influenced by her personality, past experience, social situation, responsibilities and disease burden. She may employ one of many coping strategies, and coping strategies used may vary over time (level IVa).43 It is important for the clinician to encourage all women to talk about any concerns about the illness and its impact that are important to them, and offer appropriate support.

Women’s preferences

In an Australian survey (level IVa),44 the majority of women wanted members of the treatment team to do the following:

• encourage her to bring a relative or friend;
• keep checking how she is feeling and give emotional support;
• give an opportunity to ask questions and listen to her fears and concerns;
• ask if she would like a second opinion;
• write down and summarise what she has been told;
• explain any medical terms and check understanding;
• give her published information on her situation;
• keep checking whether she wants to be told the prognosis;
• emphasise the good aspects of the prognosis;
• talk about complementary therapies (eg relaxation); and
• provide information about support services.

Other strategies for providing good support include:

• repeating information, especially information given initially about prognosis and treatment;
• taking into consideration any other health concerns that are not related to breast cancer; and
• maintaining supportive, non-verbal communication, such as good eye contact.

Further, it is particularly important that a woman’s general practitioner be kept informed, however, this may be difficult in rural and remote areas. Recommended steps for discussing diagnoses with women are detailed in Table 2.2.
Table 2.2:  Recommended steps for telling a woman she has breast cancer, a recurrence or metastases.

These steps are recommended in conjunction with the general interactional skills in Table 2.1.

1. **Prior to discussing diagnosis, recurrence or metastases**
   - Ensure the news is given in person, in a quiet, private place and allow enough uninterrupted time
   - Encourage a second person to be present if appropriate
   - Arrange to provide other methods to convey the information (eg written materials, video tapes, tapes of consultations, etc.).

2. **When providing the information**
   - Assess the woman’s understanding of her condition and the woman’s personal preference for information
   - Briefly explain the process by which the diagnosis was reached
   - Provide information simply and honestly, using lay terms without using euphemisms
   - Avoid the notion that ‘nothing can be done’
   - Clearly indicate that the woman will have the final decision regarding her care.

3. **Emotional and supportive role**
   - Encourage the woman to express her feelings (eg crying freely, talking about concerns, fears, anger, anxieties, etc.) and respond to her feelings with empathy
   - Address disturbing or embarrassing topics directly, and with sensitivity
   - Assess the type and level of assistance that may be required, such as financial, transport or childcare assistance
   - Provide information about support services.

4. **Concluding the discussion**
   - Summarise main points of the consultation and assess the woman’s understanding
   - Ask if there is anything further the woman would like to discuss
   - Offer assistance to tell others difficult news
   - Indicate your availability for contact to address any questions or concerns and arrange a further appointment to review the situation within a stated time period (eg within 24 hours to two weeks).

5. **After discussing a diagnosis, recurrence or metastases**
   - Document information given to the woman and family members
   - Let others, particularly the woman’s general practitioner, know the extent of information given and your perception of the woman’s understanding.

Adapted from How to Break Bad News, by the NSW Cancer Council and NHMRC Clinical Guidelines for the Management of Early Breast Cancer.

Psychosocial clinical practice guidelines providing information, support and counselling for women with breast cancer 11
2.3 Discussing prognosis

The NHMRC recommends that patients should be encouraged to make their own decisions about medical treatment options or procedures, and that in order to do this, patients should be given ‘adequate information about all pertinent matters, including even low probability or risk in a form which promotes understanding’.

Although there is no evidence that women wish information to be withheld, research is unclear as to which information they find most useful, such as giving specific information (eg median survival) or general comments (eg ‘I think your chances are good’); type of statistics (eg average time gained, risk reduction or survival curves); and whether to discuss exceptional cases. Recommended steps for discussing prognosis are presented in Table 2.3 (page 16).

As few studies focus specifically on prognosis, much of the data quoted below comes from an Australian survey of 100 women with early stage breast cancer (level IVa).

Influence on psychological adjustment

There are no data about how communication of risk impacts on subsequent psychological adjustment. Most studies refer broadly to the diagnostic interview or to discussion of treatment options (level III). Although these studies cover risk, they do not tease out the differential impact of components of the interview.

Influence of risk communication on treatment decisions

A number of studies have reported that variations in the communication of risk of recurrence and relative risk reduction can influence the choice made regarding different treatment options (level IVa). While clinicians may not intend to influence the woman in either direction, a balanced presentation of the facts will assist her decision-making process.

Current practice and patient preferences for content

While Australian patients are now routinely told their diagnosis (level IVa), there have been few studies documenting how many women seek or receive prognostic information. In an Australian study, only 27 per cent of patients with breast cancer or melanoma interviewed 6-12 months after their diagnosis said they had been told their prognosis, whereas 57 per cent wanted prognostic information (level IVa).

Women with breast cancer were surveyed about their preferences to be told specific types of prognostic information (level IVa). In this sample there was considerable variation in preference for different types of information. The proportion of women indicating a preference for specific types of prognostic information are listed below:

- the probability of cure (94 per cent of women);
- the chances that the recommended treatment would work (91 per cent);
• staging details (92 per cent);
• 10-year survival figures with adjuvant therapy (60 per cent);
• 10-year survival figures without adjuvant therapy (45 per cent);
• the risk of the cancer shortening their lives compared to other life events (45 per cent);
• the longest survival of women in their situation (53 per cent);
• the average survival of women in their situation (44 per cent); and
• the shortest survival of women in their situation (44 per cent).

The findings suggest that women desire to know both the positive and negative aspects when discussing survival. One approach is to give all women all the relevant information. Another is to tell women what type of prognostic information is available, then ask how much of this information they want to hear (level IVa).

Prognosis is best discussed in relation to the outcomes of different treatment options and by emphasising the hope-giving aspects of each option. Certain communication skills may enhance women’s perceptions of hopefulness. For example, one study concluded that patients want physicians to adopt an ‘attitude of confident openness and to act as supportive and encouraging coaches rather than acting as detached clinicians or consoling caretakers’ (Sardell & Trierweiler 1993:363).

Ratings of hopefulness and favourability were related to the overall emotional adjustment to the illness (level IVa).

Women’s preferences for support during, and following, provision of prognosis

The way information is given may be as or more important to women than the content of that information. One study found that women whose surgeons used counselling techniques during the cancer diagnostic interview showed improved psychological adjustment to their cancer (level III). The same study showed that women perceived the clinician’s caring attitude to be more important than information-giving.

Timing of prognostic information

There are very few data about the optimal time to talk about prognosis. However, 91 per cent of women in an Australian survey indicated a preference for prognosis to be discussed at the first visit with their cancer specialist, before treatment has commenced. Nevertheless, 64 per cent of respondents wanted their doctor to check with them first before telling them their prognosis (level IVa).

This suggests that women prefer to be given information in a staged manner, which gives them the opportunity to confirm their diagnosis and prognosis, formulate questions, and have these questions addressed prior to commencing treatment. Stepwise disclosure, in which clinicians offer specific prognostic information at
treatment decision points, can be provided to women who wish to receive it following careful explanation (level II).

To help a woman make fully informed treatment choices, information about prognosis should be offered during the discussion of the outcomes of her different treatment options. Additionally, given that information preferences change over time (level III), it is important to keep checking how much information the woman wants.

**Framing**

The treatment decision made may depend on how clinical information is presented or ‘framed’ by healthcare professionals; for example, positive framing outlines the chances of survival, while negative framing outlines the chances of dying.

A number of studies presenting hypothetical medical situations have shown that individuals (both those with an illness and healthy volunteers), were more willing to select risky medical options when probabilistic information was worded positively (chances of survival), rather than negatively (chances of dying) (level II), while descriptive reports of consultation behaviour in another study suggest that negative framing is the style of communication most frequently employed by oncologists (level III). An Australian survey found that 43 per cent of women preferred positively framed statements, 33 per cent preferred negatively framed statements (level IVa), while descriptive reports of consultation behaviour in another study suggest that negative framing is the style of communication most frequently employed by oncologists (level III). Several breast cancer-specific studies have also emphasised the importance of an effective communication style in addition to the framing of information (level III).

**Numerical versus verbal estimates of risk**

Women vary in their preference for the presentation of numerical or non-numerical estimates of risk (level II). Yet the way in which patients translate non-numerical probability terms (eg certain, almost certain, very likely, probable, frequent), into numerical estimates also varies. Thus, the use of these terms can lead to misunderstanding among clinicians, and between clinicians and lay people (level III). An Australian study confirmed this, finding no consistency in the interpretation of the verbal description ‘good’ in relation to chances of survival. The same study demonstrated that there was no agreement concerning the non-numerical interpretation of the risk statistic ‘30 per cent’, with 48 per cent of women perceiving this statistic indicative of a low risk, 34 per cent a medium and 15 per cent a high risk (level IVa).

Consequently, when discussing the outcome of treatments or prognosis, a clinician needs to check a woman’s understanding of numerical and non-numerical estimates of risk in order to establish that she has correctly interpreted this complex information. The clinician may need to correct a woman’s estimation of the expected benefits of treatment. This adjustment of expectations can be distressing.
for patients and their families. Therefore, the women needs to be offered the time and resources in order to consider the benefits and limitations of treatment options.

**Amount of information/explanation**

Providing verbal explanations of graphs and figures has been found to influence treatment decisions (level II). Treatments offering long-term benefits were more likely to be chosen when a longer discussion had taken place. It was not giving additional facts that affected a person’s preferences, but rather the increased explanation about these facts.

Another study also examined the impact of survival information on treatment decisions by older patients. Patients over 65 years were more likely to choose the treatment option giving better short-term survival rather than the option with poorer short-term outcome and improved long-term survival. Patients with higher levels of education were, however, more likely to prefer the option with better long-term survival, even if there was a risk of poorer short-term survival (level II).

**Mode of presentation**

No studies were identified which compared different modes of presentation, such as visual versus verbal information, or the use of different statistics, such as five year versus 10-year survival rates. Findings from the Australian study (level IVa) provide some useful information:

- Most women (81 per cent) could interpret survival graphs; however, very few understood statistical terms, with only 26 per cent selecting the correct definition of ‘median survival’ from four options—the majority thought it meant ‘average’.
- Less than half of the women (47 per cent) could do the mathematical calculations necessary to interpret relative risk reduction. Women’s understanding would increase if clinicians did several example calculations to explain this concept.
- 32 per cent of women did not understand risk at all, and thought that their doctor could predict whether or not they would relapse.
Table 2.3: Recommended steps for discussing prognosis with women with breast cancer.

These steps are recommended in conjunction with the general interactional skills in Table 2.1.

Offering prognostic information
Consider offering information prior to commencing treatment
- Ask first if the woman wants to be given information on prognosis (eg ‘I can tell you what happens to most women in your situation. Would you like me to do that?’) and what she currently understands and expects.

Aspects of prognosis to discuss
Adhere to the woman’s stated preference for information about prognosis if desired, provide the:
- staging details and their implications for prognosis
- chances of being cured or that cancer will never return
- likely benefits and risks of adjuvant therapy
- chance of the cancer shortening the woman’s life compared to other life events (eg heart disease)
- average and longest survival times, emphasising a range rather than a single time point.

How to discuss prognosis
- Preface any prognosis estimate with its limitations
  - Explain that you can’t predict how the woman as an individual will respond to the illness and its treatment
  - Provide an initial estimate of prognosis based on available information; explain how this may be revised by additional information (suggest a time frame for when additional prognostic information is likely to be available)
- Use mixed framing (give chances of cure first, and then chances of relapse)
- Present information in a variety of ways (words, statistics, graphs)
  - Combine verbal estimates (eg small) with a numerical estimate as well
  - Provide verbal explanations of survival graphs
- When explaining relative risk reduction, provide several examples of the calculations
  - Only use statistical terminology (ie median, hazard risk ratio) if a woman is familiar with these concepts.

Concluding the discussion
- Summarise main points of the consultation and reassess the woman’s understanding
- Emphasise hope-giving aspects of the information, such as extraordinary survivors
- Indicate your availability for contact to address any questions or concerns and arrange a further appointment to review situation within a stated time period.

Adapted from Lobb et al. Communication of prognosis in early breast cancer. NHMRC National Breast Cancer Centre.
2.4 Discussing treatment options: providing information and choice

Access to accurate and reliable information about treatment options is of major importance for women with breast cancer (level IVa). Detailed evidence based information and treatment recommendations are documented in the:

- Clinical practice guidelines for the management of early breast cancer; and
- Clinical practice guidelines for the management of advanced breast cancer.

In addition, the way in which the information is communicated to the woman needs to be carefully considered. The following issues are relevant when providing treatment information and choice to women with breast cancer, and are summarised in Table 2.4 (page 22) later in this section.

Requirement for informed consent

Informed consent involves several steps:

- information must be given in a manner that ensures ease of comprehension;
- the woman should be able to assess the overall effects of the medical condition and treatments before making a treatment decision; and
- clinicians are obliged legally and ethically to warn a person of any risk inherent in a proposed treatment, and
- women need to be supported in making their own medical care decisions, if that is their wish.

Amount of information

Research has shown that adequate information is related to increased psychological well-being (level I), and that receiving information about chances of cure and spread of disease is important to women with breast cancer (level III). Other findings include:

- women desired additional information about their cancer and its treatment (level IVa);
- women who believed they had been poorly informed were twice as likely to be depressed and/or anxious 12 months after diagnosis as those who thought they had been adequately informed (level III); and
- a review of satisfaction with the amount of information received by women with breast cancer found that of eight studies, six indicated high levels of dissatisfaction (level IVa).

Content of information

Few studies have concentrated on the type of information required. Available studies show patients want information about their cancer, treatment options, the likelihood that treatment will be a success, possible side-effects and practical issues...
In order to make an informed choice about surgery, women will require information about immediate and long term treatments, for example the possible need for radiotherapy or chemotherapy. The National Breast Cancer Centre (NBCC) has developed information for women and their families about breast cancer and treatment options. These consumer guidelines are based on the relevant NHMRC clinical practice guidelines and are available from the NBCC.

**Format of information**

Current research does not offer clear guidance about the most appropriate information format. One review indicated that women have no clear preference for verbal or printed information, believing each complements the other (level IVa). A study of women receiving chemotherapy for breast cancer found that they preferred receiving verbal information from the oncologist in the consulting room (31 per cent) or written materials, including newspapers (18 per cent), magazine articles (71 per cent) and popular books (12 per cent) (level IVa).

There is evidence that the opportunity for further discussions with a specialist breast nurse who is present during consultation can assist understanding and reduce psychological morbidity (level II). Several methods have been trialed to give women specific information about their own diagnosis and management:

- tape recordings of the consultation have been shown to improve understanding, as have personalised follow up letters (level II). However, one study showed that a general information cassette may impair recall of specific information provided in a consultation (level II);
- the use of decision aids have shown benefits for both clinicians and patients in assisting with understanding and decision-making (level IVa);
- a personalised health record has not been trialed with women with breast cancer, but has been shown to be effective in improving understanding in relation to other health issues (level II) and;
- the use of CD-ROM and internet programs is being explored. These programs are flexible and enable women to select the information they are most interested in, and can provide video clips and testimonials. As yet, there have been few evaluations of the effectiveness of such products. In one randomised controlled trial, they did not affect women’s involvement in treatment decisions, although women tended to learn more about breast cancer from multimedia packages than from reading a brochure (level II).

Psycho-educational programs have both psychological/supportive and skills/knowledge building components. Several studies have found that psycho-educational programs decrease anxiety (level II) and depression (level II), and increase knowledge (level II) and (level III). Psycho-educational programs may be provided on an individual or group basis over a number of weeks, and may include information about breast cancer, treatment, coping strategies and complementary therapies.
With regard to the content of information and its presentation, it appears that a broad-based approach using a variety of media may best satisfy a woman’s information needs.

**Timing**

Although there have been suggestions that the time of diagnosis is an inappropriate time to provide other information due to the inhibiting effect of anxiety and distress, research indicates that women feel capable of taking and using information at this time to form treatment-related decisions (level IVa). The NHMRC offers a number of options for the timing of information delivery, including:

- the staged provision of information;
- employing a nurse or counsellor with experience in caring for women with breast cancer to reinforce information provided by other health professionals;
- attention to message framing; and
- coaching women to ask questions relevant to their particular circumstance.

**Clinician’s interpersonal style**

The way clinicians present information significantly affects women’s recall of information (level IVa). Women retain more information when it is tailored to their needs, rather than being given in a standard format (level III). In a trial of educational methods to improve patient involvement in decision-making, it was found that clinicians who actively sought patient involvement were more likely to have patients who participate in the decision-making process (level II). Women prefer communication styles which provide information in a ‘sensitive and reassuring’ way and to be treated as individuals (level IVa).

**Involvement in decision-making**

Available research suggests that there are wide variations in women’s preferences for involvement in decision-making (level III) (level IVa). For instance, a large scale study of women with breast cancer in Canada found that 22 per cent wanted to select their own treatment, 44 per cent wanted to do so in collaboration with their physicians, and 34 per cent wanted to delegate this responsibility to their doctors (level III). A review of studies examining women’s preference for involvement in treatment decisions found that most women reported a desire to make a collaborative decision; a significant proportion preferred to defer to their doctor, while a small proportion of women wanted to make their own decision following the consultation (level IVa). An Australian study has also found that women’s preference for involvement in decision-making may change over time (level III), so the clinician should consider reviewing a woman’s preference for involvement in decision-making throughout the treatment process and at each phase of care.
Providing a woman with a copy of the NBCC consumer guidelines\textsuperscript{69} will assist her consideration of her treatment options. The consumer guidelines provide examples of questions which women may find useful in clarifying the sort of information they need. Willingness of clinicians to answer such questions conveys an interest in promoting the woman’s understanding of her situation and her treatment options.

Improved understanding of factors that influence a woman’s treatment decisions can facilitate the consent process, and lead to a higher rate of informed decision-making. It appears that choice of treatment is influenced by a number of factors, including:

- demographic variables, such as age, financial status and whether the woman resides in a rural or urban location (level III);\textsuperscript{66} (level IVa)\textsuperscript{70,87};
- external factors, such as media, family and friends (level IVa);\textsuperscript{88}
- psychological factors, such as body image concerns (level III)\textsuperscript{89} (level IVa)\textsuperscript{90,91}; and
- the physician’s preferences for treatment (level IVa).\textsuperscript{85}

Clinicians should ask women about the factors that are important to them in making treatment decisions and discuss alternatives for expanding treatment options. For example, a woman with breast cancer from rural and remote areas may be concerned about choosing breast-conserving therapy because it means she must travel for treatments such as radiotherapy. This may raise significant difficulties for her and her family and clinicians should ensure that the woman has access to information about travel and accommodation assistance (Refer to sections 3.3 and Appendix F). This information is available from each state and territory cancer organisation (Refer to Appendix E).

**Providing choice**

The NHMRC\textsuperscript{69} has identified a number of barriers to the provision of choice to women, including:

- lack of continuity of care, particularly in public hospitals;
- lack of time between diagnosis and treatment;
- lack of consistent information;
- discussion about treatment options in the presence of medical students;
- lack of consultation time; and
- inappropriate discussions about treatment options while women are undressed or lying down.
Clinical trials
Clinical trials are generally conducted in Australia through national and international collaboration, such as the Australian New Zealand Breast Cancer Trials Group (ANZBCTG). Research suggests that women participating in randomised clinical trials do not experience any more psychological, sexual or social problems from those women treated outside clinical trials (level III). Doctors should consider informing eligible women about appropriate clinical trials, and according to the NHMRC:

- reassure women that specialists participating in clinical trials are in touch with the best and most up-to-date treatments available, and are seeking to improve them;
- take time to provide as much information as the woman needs and desires, in a manner which promotes understanding and enables informed decision-making;
- explain that the control group in a randomised clinical trial receives the best available standard therapy which would be offered outside the trial;
- not ask the woman to participate while she is in a vulnerable position, such as undressed or lying down;
- not coerce;
- allow time for the woman to decide; and
- inform the woman that she can withdraw from the trial at any time without explanation or compromising her medical care.

Helping a woman make a decision about participation in a clinical trial
When women are asked to participate in a clinical trial, they are faced with a variety of decisions about the conduct and ethical considerations of the trial, including:

- the effect of participation or non-participation on treatment;
- the roles of the doctor as clinician and as researcher;
- the process of informed consent; and
- the timing of the request for participation and the benefits and costs of participation (level IVa).

In order to assist women to become better informed and have a better understanding of clinical trials, the NBCC is working with the NHMRC Clinical Trials Centre to develop a web page and register for consumers on the Internet, and has facilitated ways of improving consumer participation in the development of clinical trials.
Table 2.4: Recommended steps for effectively discussing treatment options with women with breast cancer.

These steps are recommended in conjunction with the general interactional skills in Table 2.1.

Information about treatment
- Explain to the woman using language that she understands what treatment options are available and ask how much detail she would like about each option
- Tailor the information to the woman’s needs and preferences for information content and detail, which may include a discussion of the expected outcomes of each treatment option and the major side-effects of each treatment
- Use a variety of media to provide information about treatment options (eg written information, video tapes, tapes of consultations, etc.)
- Ask the woman to talk about the concerns she has regarding different options.

Decision-making about treatment
- Ask the woman how much she would like to be involved in decision-making and adhere to this decision
- If the woman is by herself ask whether she would like to discuss treatment options with family or friends and tell the woman that there is an opportunity for them to be involved in treatment decisions
- Assure the woman that there is enough time to consider the treatment options and offer to arrange for her to come back with a decision
- Be aware that the woman’s preferences may change over time—decision-making should not be seen as a once-only event.

Emotional and supportive role
- Encourage the woman to express her feelings (eg crying freely, talking about concerns, fears, anger, anxieties, etc.) and respond to her feelings with empathy
- Address disturbing or embarrassing topics directly, and with sensitivity
- Provide information about support services.

Concluding the discussion
- Summarise main points of the consultation and assess the woman’s understanding
- Ask if there is anything further the woman would like to discuss
- Offer assistance to tell others difficult news
- Indicate your availability to address any questions or concerns and arrange a further appointment to review the situation within a stated time period (eg within 24 hours to two weeks).

After discussing a diagnosis, recurrence or metastases
- Document information given to the woman and family members
- Let others, particularly the woman’s general practitioner, know the extent of information given and your perception of the woman’s understanding.

Adapted from Cockburn J. Effectively discussing treatment options with women with breast cancer. NHMRC National Breast Cancer Centre.
2.5 Preparing women for potentially threatening procedures and treatment

This section describes the issues in providing information to women prior to potentially stressful medical procedures and interventions, such as breast surgery and open biopsy. The comments are also applicable to chemotherapy and radiotherapy.

Women who face the prospect of having mastectomy or breast-conserving surgery frequently experience high levels of anxiety and psychological distress (level II). While few studies have examined the best approaches for preparing women for these procedures, research with other patient groups provides evidence of appropriate strategies.

Providing women with information about the procedure they are about to undergo significantly reduces their emotional distress and improves their psychological and physical recovery (level I). The majority of research also indicates that adequate preparation for threatening medical procedures can reduce the level of anxiety and lead to faster recovery, with fewer problems such as anticipatory side-effects (level I).

Procedural information includes practical details about what will happen before, during and after a procedure. A variety of formats for providing information about procedures have been shown to decrease anxiety and psychological distress, including discussions with a clinician or allied health professional (level II), support from a specialist breast nurse (level II), a booklet (level II) or videotape information (level II).

Sensory information describes what the person is likely to experience before, during and after the procedure, including their feelings in response to the preoperative medication, the amount and type of pain, and so on. It has produced significant reductions in anxiety in patients undergoing medical procedures (level I). The best results appear to be achieved by the provision of both sensory and procedural information (level I). Psychosocial support has also been shown to be useful at this time (level I).

Psychosocial support strategies that could be commenced prior to treatment procedures include providing women with an outlet to discuss concerns and fears; coping and relaxation strategies; and offering education about exercises, information and available resources that may be helpful. Ideally, this role would be performed by a specialist breast nurse, but could also be offered by other members of the treatment team, as appropriate.
Table 2.5: Recommended steps involved in adequately preparing a woman for a potentially threatening medical procedure.

These steps are recommended in conjunction with the general interactional skills in Table 2.1 (page 8).

**Before the procedure**
- Explain why the procedure is needed and the expected outcome
- Ask how much detail she would like to know about the procedure before explaining it
- The information may include
  - where the procedure might take place, and who will perform it
  - any tests needed before the procedure
  - what the woman will need to do before the procedure
  - what the woman is likely to experience during and after the procedure
- Encourage her to talk about her concerns such as pain, fear, death, embarrassment
- Ask her what she thinks she can do to cope
- Enquire about, and reinforce, previous coping strategies (eg relaxation and imagery).

**During the procedure**
- Provide information about what will be done and how it will feel
- Give the woman control, where possible, (eg ask her to tell you when she is ready to begin)
- Encourage the use of coping strategies.

**After the procedure**
- Encourage the use of coping skills (eg relaxation methods and imagery)
- Encourage the woman to state her needs
- Arrange follow-up and support.

Adapted from Cockburn J. Preparing patients for potentially threatening clinical procedures. NHMRC National Breast Cancer Centre.
PART III

PROVIDING SUPPORT AND COUNSELLING

3.1 Providing emotional and social support

A woman with breast cancer is likely to be faced with multiple concerns that can vary widely and change across time. They include coping with fears over her health and future, undergoing unpleasant treatments and coping with physical symptoms. They can also include practical concerns such as not being able to do things that are important to her, and the possible impact of her illness on employment and financial stability. Women often report feelings like ‘being in a state of shock’, ‘feeling out of control’, or being angry, fearful or helpless. Grief and loss are often key issues.

Breast cancer can be stressful for women of all ages, however younger women are likely to face unique concerns and may be particularly vulnerable (level IVa). Women may be concerned about the impact of breast cancer on their partner and children including practical issues such as the availability of childcare. There is evidence that the coping of the woman affects the whole family (level IVa).

The extent to which a woman has support and feels supported, has been identified as an important factor in women’s adjustment to breast cancer. Women with poor support are more likely to experience the additional burden of psychological difficulties (level III). Table 3.1B (page 27) summarises the recommended process for ensuring that women with breast cancer have adequate social and emotional support.

Support from the treatment team

The opportunity to discuss feelings with a member of the treatment team or counsellor decreases psychological distress (level I). Women with breast cancer, provided with an opportunity to explore feelings with a member of the treatment team or counsellor, experienced less psychosocial distress, such as body image concerns and depression, than women not provided with this opportunity (level I). (level II) Table 3.1A (page 26) identifies types of professionally led supportive interventions which have a positive impact on the well-being of women with breast cancer.

Randomised controlled trials also demonstrate that women who received supportive care from a specialist breast nurse had lower rates of psychological distress, such as depression and anxiety, and increased levels of knowledge about treatment compared to those who did not receive such care (level II).
Table 3.1A: Recommended steps involved in ensuring that all women have adequate emotional and social support.

These steps are recommended in conjunction with the general interactional skills in Table 2.1.

Support from the treatment team

- Ask the woman how she is feeling emotionally at every visit
- Ask the woman how she is feeling about treatment
- Listen to fears and concerns about treatment and prognosis
- A breast nurse or other allied health professional (e.g., social worker) may be appropriate at all phases of care
- Provide the woman with information about counselling and professionally-led support groups, and arrange a referral, if needed.

Assess support provided by family and friends

- Ask the woman about
  - Her support network and the level of support provided
  - How her family and partner are dealing with her breast cancer
  - Who she can openly discuss her thoughts and feelings about her situation
  - Who she has to assist with practical issues (e.g., childcare, cooking, cleaning...).

Support from peer support groups

- Provide the woman with information on patient support groups and services, such as the Breast Cancer Support Service (BCSS); and contact numbers for local cancer organisations.

Family and friends

Lack of support from family and friends may be associated with poorer emotional adjustment (level III). It is important to ask a woman about her key support people and define their level of involvement.

Once the level of support from a partner has been established, couple therapy with an appropriately trained counsellor may also be considered. In relation to breast cancer, couple therapy has been shown to reduce emotional distress, increase sexual satisfaction in both partners, and reduce depression in the woman (level II).

Social support

Social support has been identified as an important factor in women's adjustment to breast cancer (level III). Social support can be provided by health care professionals, family and friends, or support services like the Breast Cancer Support Service (BCSS). The BCSS describes its services as practical and emotional support to those diagnosed with breast cancer. This support is offered on a one-to-one basis and is provided by breast cancer survivors who are two years post-treatment and...
have been trained for this purpose. They are matched to the service recipient by age, treatment type, and other relevant factors.

Contact with the BCSS can be arranged through the state and territory cancer organisations; its leaflet, ‘The Breast Cancer Support Service—for health professionals’ provides a useful outline of its work (see Appendix E). The evaluation of this Australian service, and further research into its impact on the lives of women with breast cancer is currently underway.

**Peer support groups**

Unlike professionally led groups, trials of the effectiveness of self-help groups are sparse, and no randomised controlled studies have been identified. Non-randomised research suggests that peer support and self-help groups decrease feelings of social isolation, depression and anxiety (level III).\(^{118-120}\)

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**Table 3.1B: Support interventions that can improve the emotional wellbeing of women with breast cancer.**

<table>
<thead>
<tr>
<th>Type of intervention</th>
<th>Description</th>
<th>Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professionally-led group</td>
<td>Places emphasis on sharing of experiences among patients with a comparable stage of disease. Can use cognitive behavioural or supportive psychotherapy.</td>
<td>Level I(^{119}), Level II(^{121-128}), Level III(^{129})</td>
</tr>
<tr>
<td>Family</td>
<td>Enhances improved communication, cohesion and conflict resolution within the family system, including the needs of children. Can use cognitive behavioural or supportive psychotherapy.</td>
<td>Level IV(^{a130,131})</td>
</tr>
<tr>
<td>Couple</td>
<td>Targets problems and issues within the couple relationship. Can use cognitive behavioural or supportive psychotherapy.</td>
<td>Level II(^{117,132,133}), Level III(^{134})</td>
</tr>
<tr>
<td>Complementary approaches</td>
<td>Complementary therapies may include art therapies (e.g., music, painting, reading and poetry), wellness programs, etc.</td>
<td>Level II(^{121}), Level IV(^{a135})</td>
</tr>
<tr>
<td>Peer support or self-help groups</td>
<td>Supportive groups of women who have had breast cancer themselves, but run without professionals.</td>
<td>Level III(^{118-120})</td>
</tr>
<tr>
<td>Telephone counselling</td>
<td>Provides geographically-isolated patients with an opportunity for cognitive behavioural or supportive psychotherapy interventions.</td>
<td>Level II(^{136}), Level IV(^{a137})</td>
</tr>
</tbody>
</table>

\(^{*}\) where major difficulties exist, specific therapy is required, see section 3.2

For more detailed information, see report by Kissane & Burke\(^{27}\) available from the NBCC.

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Psychosocial clinical practice guidelines providing information, support and counselling for women with breast cancer 27
3.2 Providing psychological care

In addition to the general effects on a woman’s emotional well-being, breast cancer places her at risk of developing a number of specific difficulties with a high psychological impact (level IVa). These include body image and sexuality problems, interpersonal difficulties, and coping with acute and chronic physical symptoms.

Most women will experience minor or transient symptoms of anxiety and depression, and a smaller number of women with breast cancer will develop more severe problems, such as clinical depression, and will require specialised treatment. This section describes the nature, severity and prevalence of the psychological problems experienced by women with breast cancer and strategies to improve their psychological care. Guidelines are provided here to improve the detection, care and appropriate referral of women with significant psychological disturbance.

Asking about psychological problems

Although psychological problems, including body image disturbance, depression and anxiety are common in women with breast cancer, they are frequently under-recognised and under-treated (level IVb). This may be partly because many women are reluctant to mention their distress to their doctor, because they feel that depression or anxiety are signs of personal weakness. Some clinicians are also reluctant to ask about psychological problems because of their belief that depression and anxiety are a ‘normal’ response to cancer.

It is imperative that members of the treatment team monitor the emotional and psychological impact of breast cancer on women. This process begins with asking broad, open-ended questions. The following prompts are given as examples to assist clinicians frame questions according to their own style:

‘How are things going in general?’

‘How have things been emotionally since your diagnosis?’

Depending upon the initial information given by the woman, the nature, severity and impact of her concerns can then be further explored.
### Table 3.2A: Types of therapy and their impact on cancer patients

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
<th>Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive behavioural</td>
<td>Teaches skills in problem solving, reframing attitudes, coping with stress and anxiety. Relaxation therapy or cognitive skills might be used in approaching problems more effectively. Techniques to enable gradual adaptation to fears might also be included. For more detailed descriptions, refer to: Moorey &amp; Greer, 1989; Rose, 1989; Ellis, 1992; Kissane et al, 1997.</td>
<td>Level I(^{17,18}), Level II(^{157,160}), 199–201, Level III(^{202})</td>
</tr>
<tr>
<td>Supportive psychotherapy</td>
<td>Encourages the expression of emotions and tries to generate a sense of support through empathic listening and encouragement. This type of therapy is sometimes called supportive, psychodynamic, existential or supportive-expressive. For more detailed descriptions, refer to: Spiegel &amp; Spira, 1991; Mullan, 1992.</td>
<td>Level I(^{17,18}), Level II(^{206})</td>
</tr>
<tr>
<td>Psycho-educational</td>
<td>Enhances understanding and knowledge about breast cancer and associated issues such as treatment, diet, health behaviours, coping, adjustment and available services. For more detailed descriptions, refer to: Cunningham et al, 1991.</td>
<td>Level I(^{18}), Level II(^{81,206,132–3}), Level III(^{120})</td>
</tr>
</tbody>
</table>

For more detailed information, see report by Kissane & Burke\(^{27}\) available from the NBCC.

### Body image

Body image is a component of self-concept and involves the perception and evaluation of one’s body, appearance and functioning.\(^{141}\) Breast cancer, and its treatment, can significantly change the way a woman thinks and feels about her whole body and femininity, her self-esteem and the way she behaves, alone and with others. Early studies indicated that mastectomy scars, prostheses and the development of lymphoedema caused a devastating impact on the lives of almost one in four women with breast cancer (level IV\(^{a}\)).\(^{142}\) More recent data indicate that significant problems often continue (level IV\(^{a}\)).\(^{143}\)
Issues associated with appearance (cosmesis), are important factors for many women making treatment decisions and in adjusting to changes during and after treatments such as surgery and chemotherapy. Although it is thought that cosmesis may be particularly important for women under 55 years of age (level IVa), body image issues should not be discounted in older women. For some women, concerns about body image, fear of deformity and mutilation, and loss of femininity are significant factors in choosing breast conservation, in some cases even against their doctor’s advice (level IVa).

Asking about body image concerns

Clinicians should be alert to a woman’s body image concerns throughout treatment. The clinician can explore whether the woman has significant concerns about the impact of treatments on her body or sense of self by asking questions like:

‘Although it is often hard to talk about, many women worry about how they will look and feel about themselves after treatment. Can you tell me how you feel about these changes?’

This may then be followed with a question such as:

‘Have you discussed any concerns with your partner?’

After treatment, it is important to explore sensitively how the woman is coping with her altered appearance. It can be helpful to ask about the degree of distress this is causing, and the extent to which she avoids situations such as catching sight of herself, allowing her partner to see her naked or undressing in public changing rooms.

When a woman is worried about the changes to her body, it is important to assess the nature, severity and impact of these concerns. Support and education from a specialist breast nurse may help with adjustment difficulties but in more severe cases, the woman may be referred to a clinical psychologist or psychiatrist for appropriate interventions such as cognitive behavioural, supportive or crisis therapy (see Tables 3.2A and 3.2B).

The clinician needs to be aware that a woman may also avoid sight of her altered breast or be disturbed by images of it because of fear of recurrence and fear of the cancer. In either case, it is important that she is offered a referral to a trained specialist who is able to assess these difficulties thoroughly and provide treatment as needed.

Fertility and childbearing

During the treatment of women with breast cancer a number of fertility issues may arise, including the selection of appropriate contraception and the potential for loss of fertility. These issues are of concern to many women and their partners. Loss of fertility may be the source of psychological distress. Although there is insufficient evidence to make specific recommendations on the discussion of fertility issues, awareness of fertility issues by clinicians and providing an opportunity for sensitive
discussion, may allow women to consider the potential impact of treatment on their fertility.

For those women whose breast cancer is diagnosed during pregnancy or after childbirth particular concerns such as breastfeeding or the impact on the child may be an issue. These women may benefit from support and professional assistance. This may also be the case for women who have young children, as there is evidence that these women are at increased risk of emotional distress (level III). 144–146

**Sexuality**

Estimates of the proportion of women experiencing sexual problems following the diagnosis and treatment of breast cancer range from 10 per cent to 50 per cent (level II), 94 (level III), 147 (level IVa). 98,148 In a report of the psychosocial morbidity among Australian women with early stage breast cancer, significant disturbance in sexual functioning has been reported (level IVa). 149 Women who have had a mastectomy are particularly vulnerable to sexual problems, even one to two years after surgery (level II), 94 (level III), 147 (level IVa). 148 Research also shows that women under 50 years of age, who had a mastectomy were twice as likely as women over 50 years of age to experience sexual difficulties (level IVa). 148

Adjuvant chemotherapy may also affect sexual response by interfering with the production of oestrogen and testosterone (level IVa). 150 Furthermore, chemical menopause may produce atrophic vaginitis and dyspareunia, while changes in androgens alter libido and orgasm (level IVa). 151

**Asking about sexual difficulties**

Questions about sexual adjustment should be part of routine clinical care and follow-up. Skilful communication can make it easier for women to disclose sexual concerns. However, many women will feel reluctant to broach the subject of sexual difficulties and may be more willing to discuss issues of sexuality with certain members of the treatment team if they feel comfortable with them. Comments such as the following may help put women at ease whilst initiating assessment of sexual adjustment:

‘Having had breast cancer affects many aspects of women’s lives. One concern women often have, but which they may find hard to talk about, is their sex life, and their intimate relationships. Can you tell me if anything like that is worrying you?’

This may need to be followed by more specific questions. The clinician should consider referring women who are experiencing sexual difficulties to personal and/or couple counselling and for endocrine assessment if a hormonal basis for the problem appears likely. In addition, women should be informed of resources on breast cancer and sexuality, available from the NBCC or state and territory cancer organisations.
Interpersonal problems

The impact of breast cancer can place considerable strain on relationships, particularly in cases where difficulties existed before the diagnosis of breast cancer. Poor marital or family functioning may place a women with breast cancer at increased risk of psychological problems (level IVa). Women may feel reluctant to discuss their interpersonal problems because they feel embarrassed that they are not coping, or because they feel that nothing can be done. There is however, evidence to indicate that appropriate psychological interventions are effective in the management of interpersonal problems (see Table 3.1A).

Asking about interpersonal problems

Discussing interpersonal problems is easier for the woman if the clinician makes a prefacing comment, such as:

‘A diagnosis and treatment for breast cancer is often stressful for the whole family.’

This can then be followed by,

‘Can you tell me how things are at home, and whether you’re getting the practical and emotional support you need?’

and/or,

‘How do you think your partner and family are coping with your illness?’

Women experiencing interpersonal problems may be offered a referral to couple or family counselling. In addition, family members should also be offered the opportunity to discuss concerns with the clinician or be referred to an appropriate counsellor.

Coping with physical symptoms

Women with breast cancer experience a number of illness and treatment-related physical symptoms that may significantly affect their quality of life and increase the risk of developing more serious levels of anxiety and depression. These include nausea and vomiting (level IVa), acute and chronic pain (level IVa), fatigue (level IVa), and lymphoedema (level III).

Psychological interventions may be helpful to reduce the distress and impairment associated with these symptoms and, in some cases, to reduce the severity of the symptom itself (level I).

Chemotherapy-induced nausea and vomiting

Despite recent improvements in anti-emetics, chemotherapy-induced nausea and vomiting continue to cause significant suffering. In some cases, women will develop habitual nausea and vomiting which affects them over and above the direct effects of the chemotherapy. The habitual nausea and vomiting may occur prior to a scheduled administration of chemotherapy ( anticipatory nausea and vomiting) or in
response to stimuli, such as tastes, smells and locations that have become
associated with the chemotherapy (conditioned nausea and vomiting). Recent data
indicate that up to 24 per cent of patients undergoing chemotherapy experience
moderate to severe anticipatory and conditioned nausea and vomiting (level IVa).

Women suffering from persistent nausea and vomiting may benefit from
psychological interventions, including cognitive-behavioural techniques such as
progressive muscle relaxation, guided imagery and systematic desensitisation,
supportive interventions and education, all of which have been shown to help
(level I), (level II) (level III) (see Table 3.2B).

Pain

Pain may arise for a number of reasons in women with breast cancer. History-
taking, examination, and appropriate investigation and treatment of pain are key
aspects of clinical care. Pain also has an emotional dimension and for patients
with serious illness, the interpretation of the meaning of the pain may influence the
way the individual deals with it, as may social, family, personality and cultural
factors (Level III).

There are a number of psychological approaches, which have been shown to be
efficacious in the management of acute and chronic pain in women with breast
cancer. These include progressive muscle relaxation, guided imagery and other
techniques (Level IVb). In addition, antidepressant medication may be a useful
adjunct when treatment with opioid analgesia is required. Please refer to further
discussion of psychological therapies and pharmacotherapy later in this section.

Fatigue

There is increasing recognition of the impact of fatigue on a woman’s psychological
wellbeing during and after treatment for breast cancer. Some studies have reported
an association between treatment related fatigue and depressed mood, with both
radiotherapy (level IVa) and chemotherapy (level IVa). Frequent use of
quality of life questionnaires that include measures of fatigue, will assist in the
understanding of its relationship to psychological morbidity, and its prevalence
as a chronic condition persisting beyond treatment cessation.

Lymphoedema

The precise incidence of lymphoedema is unclear, but is of considerable concern to
women who have been treated for breast cancer (level IVa). Lymphoedema
usually occurs between the acute and palliative care phase. The diagnosis of
lymphoedema may be a time of considerable stress. In some cases, the woman may
avoid seeking help because she fears that the lymphoedema symptoms are an
indicator that the cancer has recurred.

Women who have lymphoedema report that the condition is debilitating. For
example, performing ordinary tasks becomes difficult (level IVa) and
psychological distress may be experienced (level III). The presence of other arm
symptoms including weakness, limitation in range of movement, stiffness and pain
also have a negative impact on quality of life for women with breast cancer (level III). A recent study suggests that coping with lymphoedema is affected by the presence of pain and the availability of social support, as well as the severity of physical symptoms (level IVa).

Inquiring about the presence of arm swelling or other symptoms is important, with clinical assessment and referral (for physiotherapy, for example), as necessary. Women may benefit from education about the early symptoms of lymphoedema and the availability of treatment. Contact details for lymphoedema associations and support groups are listed in Appendix E.

**Cognitive problems**

Impaired thinking, described as poor concentration, confusion or memory problems, is a common symptom reported anecdotally by women with breast cancer, which can be especially distressing. Few detailed studies have been conducted to confirm these experiences using valid and reliable neuropsychological tests. In one such study, women with early stage breast cancer were assessed, on average, six months after adjuvant chemotherapy was completed (level IVa). The study found that 75 per cent of women had moderate impairment in multiple aspects of cognitive functioning. Difficulties observed included attention, concentration, memory and mental flexibility. Determining causality is often problematic, particularly for subtle impairment that may be a sign of treatment side effects, metastatic disease or symptomatic of an anxiety or depressive conditions or fatigue (level IVa). Additional longitudinal research is needed in this area to determine prevalence, natural course and causal factors associated with cognitive impairment.

**Emotional disturbances**

Women vary in their emotional responses to the circumstances surrounding the diagnosis and treatment of breast cancer. A woman’s level of distress may also change over time. The response required by members of the treatment team to a women’s emotional disturbance also varies, and is often determined by the extent to which the woman feels able to manage her emotions and how much these concerns impair her daily living.

It can be part of the normal range of responses to a stressful event to experience episodically intense, unpleasant and distressing emotions such as tearfulness, being frightened and anger. These reactions are very common, are usually occasional, tend to be time-limited, rarely lasting more than a day or two, and are not inappropriate responses to significant health concerns. The woman’s existing coping strategies, as well as the provision of appropriate information, reassurance, and emotional support from the treatment team, family and support groups are useful strategies for dealing with these emotional responses.

Stress and adjustment problems include stronger feelings that can last for a week or more, and these can be difficult and disruptive to a woman’s life. Despite this, most women still exercise some control and can continue to function well enough.
However, if such problems are left undetected and unacknowledged, some can develop into more serious emotional states.

Major psychological disturbances include a major depressive episode, anxiety disorder, or an emotional, behavioural or cognitive state that is overwhelming, lasts longer than a couple of weeks, causes significant impairment in functioning and over which the woman feels she has little or no control.

The following section identifies types of emotional disturbance, and strategies and interventions which have been demonstrated to improve the psychological adjustment of women with breast cancer. Identification of particular personality characteristics and coping strategies likely to be associated with more successful psychological adjustment is less clear in the literature. Research currently underway in Australia, may yield useful information about specific techniques for promoting coping and psychological well-being.

**Stress and adjustment reactions**

Stress and adjustment reactions describe a moderate level of emotional and psychological disturbance that includes significant symptoms of anxiety and depression. However, these are either time-limited or do not have as great an impact on functioning as disorders such as a major depressive episode.

Between a quarter and a third of women will experience moderate stress and adjustment problems as a result of their diagnosis and treatment. An Australian study demonstrated that 29 per cent of women suffered from significant adjustment problems and had depressive and/or anxiety symptoms at 3 months post-surgery *(level III)*. There is however, insufficient longitudinal data to describe the long-term course of significant adjustment problems in women with breast cancer.

Women may be particularly vulnerable to high levels of stress at the following times:

- at diagnosis or disease recurrence;
- when facing the prospect of having surgery, be it mastectomy or breast-conserving; *(level II),*(94) *(level III),*(95,96,176) *(level IVa),*(97–99);
- during adjuvant therapy *(level III);
- around the time of medical check up; and
- living with advanced breast cancer *(level III),*(15) *(level IVa). *(177)

Adjustment problems compromise psychological health, functioning and quality of life. Referral of women experiencing adjustment problems for appropriate intervention may prevent the development of more enduring or disabling emotional disturbances, such as depression. Appropriate interventions include cognitive behavioural, supportive or psycho-educational interventions (see Table 3.2B page 36).
Table 3.2B: Impact of different intervention techniques on specific psychological problems.

<table>
<thead>
<tr>
<th>Problem</th>
<th>Effective intervention techniques</th>
<th>Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>Relaxation therapy, guided imagery, systematic desensitisation, problem solving, crisis intervention, supportive interventions, other combinations of education and behavioural or non-behavioural interventions, and anti-anxiety medications.</td>
<td>Level I\textsuperscript{18,19} Level II\textsuperscript{200,210}</td>
</tr>
<tr>
<td>Depression</td>
<td>Relaxation therapy, guided imagery, psycho-education, problem solving, supportive interventions, other combinations of education and behavioural or non-behavioural interventions, and anti-depressants and cognitive behavioural therapy.</td>
<td>Level I\textsuperscript{18,19} Level II\textsuperscript{116,200,133,211,212}</td>
</tr>
<tr>
<td>Physical symptoms</td>
<td>Relaxation therapy, guided imagery, systematic desensitisation, supportive interventions and education together with cognitive-behavioural interventions; complementary therapies.</td>
<td>Level I\textsuperscript{18} Level II\textsuperscript{102,121,162,163,200}</td>
</tr>
<tr>
<td>Body image concerns</td>
<td>Cognitive behavioural interventions, supportive interventions, crisis interventions, complementary therapies.</td>
<td>Level II\textsuperscript{104}</td>
</tr>
</tbody>
</table>

**Anxiety**

Although some anxiety in response to a stressful life event is normal, in some cases anxiety can interfere with relationships, social or occupational functioning and health-related behaviours. Symptoms associated with anxiety include heightened physical arousal, sleep disturbance, impaired concentration and decision-making, agitation and anger. Avoidance of distressing issues and situations, and excessive reassurance-seeking, may also indicate anxiety problems. These responses can have a major impact on the woman as well as her family's functioning.

When anxiety problems become severe, specialist treatment may be required. Severe problems may include panic attacks, pervasive and generalised worry, treatment phobias (e.g., needle phobias), social anxiety and post-traumatic stress reactions. Estimates of the prevalence of anxiety problems among women with breast cancer range from 12 per cent to 30 per cent (level IV\textsuperscript{a}). In Australia, research on women with early breast cancer has found rates of anxiety ranging from 12 per cent to 23 per cent (level IV\textsuperscript{a}). In the few studies done to date, the disorder has been reported to occur in 8 per cent of women with early stage breast cancer (level III).\textsuperscript{179,180}
Anxiety disorders in women with breast cancer may be related to a number of different factors. These include: reaction to the stress of the diagnosis and treatment; response to cancer-related medical problems, such as uncontrolled pain; response to drug treatment, such as steroids; response to investigations, such as CT scans and MRI; and specific fears and phobias (e.g., needle phobias), which existed before the cancer diagnosis, but which have been exacerbated by it (level IVb). Anxiety may also be a symptom of other medical conditions, such as thyroid disease, and is commonly associated with alcohol or benzodiazepine withdrawal.

**Asking about anxiety**

When talking to women with breast cancer about their concerns and psychological well-being, it is helpful to ask specifically about anxiety. For example:

‘Not surprisingly, many women with breast cancer experience some level of anxiety. If you like, we can discuss any anxiety you’ve been feeling.’

For the woman who raises concerns, further questions will clarify the extent of anxiety symptoms and their impact:

‘What makes you feel anxious?’

‘Are there any particular times when you feel anxious?’

‘How often do you feel this way?’

‘Are there any times when the feelings are overwhelming?’

‘Do the anxious feelings interfere with your daily life, or your relationships?’

‘Is there anything you’re avoiding because of this anxiety?’

Women reporting intrusive or difficult-to-manage anxiety problems should be offered further specialist assessment by a clinical psychologist or psychiatrist.

When an acute anxiety state or panic threatens to impede or complicate treatment, prompt consultation with a psychiatrist or clinical psychologist is recommended (level IVb). The treatment team also needs to be alert to signs of chronic anxiety disorders developing, and consultation should be sought before enduring and disabling conditions develop.

Cognitive and behavioural techniques (see Table 3.2A page 29 and 3.2B page 36) have been demonstrated to be effective in the treatment of anxiety (level III). In some cases, however, anxiolytic medication is also required, appropriate medications are discussed later in this section.

**Depression**

The key symptoms of depression include low or flat mood or a loss of interest in things that used to be enjoyable. The diagnosis of a major depressive episode in physically healthy patients relies heavily on symptoms such as anorexia, insomnia,
anergia, fatigue, weight loss and reduced interest in sex, but in cancer patients, these symptoms may also be related to the disease process or treatment side-effects.

Thus, a diagnosis of a major depressive episode in patients is best evaluated by the severity of depressed mood, loss of interest and pleasure, the degree of feelings of hopelessness, guilt and worthlessness, and the presence of suicidal thoughts (level IVb). Another symptom, recurrent tearfulness is often accompanied by social withdrawal and loss of motivation. The woman may feel she is unable to control the negative feelings and these feelings begin to dominate the day, on most days for two weeks or more.

How common is depression in women with breast cancer?

Estimates of the proportion of women with breast cancer suffering from depression vary. At three months post-diagnosis, 10 per cent to 17 per cent suffer major depression. At 12–24 months post-diagnosis, the estimates of depression are 5 per cent to 20 per cent for major depression (level II), (level III), (level IVa). Much of the variation in estimates of the prevalence of depression can be attributed to the different measurement methods used, with structured diagnostic interviews providing greater accuracy. For example, in Australia, research measuring depression with brief, self report questionnaires have found low rates of depression among women with breast cancer (level IVa); however, research using a diagnostic interview found rates of depression ranging from 10 per cent for major depression to 27 per cent for minor depression at two to six months post-diagnosis (level IVa).

Asking about depression

Due to its high prevalence, all members of the treatment team need to be alert for signs of clinical depression in women with breast cancer. Clinicians can indicate they are interested in the woman’s adjustment and coping, by making statements such as:

‘Apart from the physical effects of breast cancer, we’re aware of the emotional toll it can take on you and your family.’

This can then be followed with open-ended questions, such as:

‘How are you bearing up emotionally?’

This should be followed with clarifying questions about the depth of any mood disturbance which, in severe cases, the woman will often describe in terms such as ‘hopeless’ or ‘helpless’. It is also important to enquire about whether these feelings are transient (‘a bad day’) or more frequent and lasting. If the clinician is concerned that the woman may be becoming depressed, she should be informed that depression is common and that there are many effective treatments. She should be referred for further assessment, preferably to a psychiatrist or clinical psychologist.
Asking about suicidal thoughts

Suicide may be a risk for the severely depressed woman. Risk factors for suicide include severely depressed mood, a family history of completed suicide, past history of self-harm and a history of alcohol or other substance abuse. Lack of any hope for the future is a risk factor for suicide.

There is no evidence that asking about suicidal thoughts will prompt them in someone who had not previously considered the possibility of suicide (level IVb). Sensitive exploration of suicidal thoughts, plans and access to means is crucial. Introductory questions might be along the lines of:

‘Sometimes when things seem hopeless, it can feel too hard to keep going on. Have you ever felt like that?’

This can be followed by clarifying questions such as:

‘Would you describe any of these feelings as suicidal?’ (If yes), ‘What do you think about doing?’

Urgent psychiatric consultation should be considered for any woman who appears at risk of suicide.

Screening for major psychological disturbance

Clinicians should routinely ask about, and document, risk factors which have been found to predict adverse psychological outcomes (Table 3.2C page 40). These include: young age at onset of disease; having children under 21 years of age; economic adversity; psychiatric history; poor social support, poor family and/or marital functioning; cumulative stressful life events; and increased treatment side-effects (level III). 15,31,112,144–146,184,185

Monitoring risk factors and anxiety and depression symptoms may assist in early identification of serious psychological disturbance (level III). 15,31,146,184 Screening for the nature and severity of psychological distress should also be done in consultations at times of diagnosis and recurrence. Based on more general research about clinical depression, early diagnosis can lead to more effective treatment. (Tables 3.2D page 41 and 3.2E page 42) outline recommended procedures for the routine screening of women for psychological problems.
Table 3.2C: Factors associated with an increased risk of psychosocial problems.

<table>
<thead>
<tr>
<th>Characteristics of the woman:</th>
<th>Research studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>• younger</td>
<td>Level III 31,112,113,144-146, 184,185</td>
</tr>
<tr>
<td>• single, separated, divorced or widowed</td>
<td>Level IVb 2</td>
</tr>
<tr>
<td>• children younger than 21 years</td>
<td></td>
</tr>
<tr>
<td>• economic adversity</td>
<td></td>
</tr>
<tr>
<td>• perceived poor social support</td>
<td></td>
</tr>
<tr>
<td>• poor marital or family functioning</td>
<td></td>
</tr>
<tr>
<td>• history of psychiatric problems</td>
<td></td>
</tr>
<tr>
<td>• cumulative stressful life events</td>
<td></td>
</tr>
<tr>
<td>• past history of alcohol or other substance abuse.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Characteristics/stages of disease and treatment:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• at the time of diagnosis and recurrence</td>
<td>Level III 15,213,172,171,214</td>
</tr>
<tr>
<td>• during advanced stage of the disease</td>
<td>Level IVb 2</td>
</tr>
<tr>
<td>• more treatment side-effects</td>
<td></td>
</tr>
<tr>
<td>• experiencing lymphoedema</td>
<td></td>
</tr>
<tr>
<td>• experiencing chronic pain</td>
<td></td>
</tr>
</tbody>
</table>

For more detailed information, see report by Turner et al.²⁹ available from the NBCC.

Using self-report questionnaires for screening and monitoring anxiety and depression

Medical practitioners in both medical oncology and general practice settings have been found to have difficulties identifying patients with depression (level III),¹⁸⁶ (level IVa),¹⁸⁷,¹⁸⁸ (level IVb).¹⁸⁹ Clinical audit and prospective studies indicate that clinicians are frequently unaware of psychological disturbance, such as sexual problems and depression, experienced by their patients (level III).¹⁸⁶ In one study, oncology staff correctly identified 79 per cent of anxiety problems but misdiagnosed 40 per cent of patients as anxious who were not, and only identified 40 per cent of patients with a depressive illness (level IVa).²⁸

The use of questionnaires in oncology settings has been suggested as a way of improving the identification of women most likely to be clinically anxious or depressed. There are a number of self-report questionnaires that have been used in research and clinical settings to monitor change in anxiety and depression symptoms, and to detect women likely to meet criteria for an anxiety or mood disorder. These include the Hospital Anxiety and Depression Scale (HADS),¹⁸⁸ the General Health Questionnaire (GHQ28 or GHQ12),¹⁸⁰ and the Rotterdam Symptom Check List (RSCL).¹⁹¹

However, attempts to establish the validity of the use of self-report psychological questionnaires as psychiatric screening instruments in oncology, have so far had mixed results (level III).¹⁹² One multi-centred trial, however, found that the best results in detecting women with major psychological problems were obtained by matching the type of questionnaire with the woman’s current disease and treatment.
Further work needs to be done before specific recommendations can be made. Any use of questionnaires for this purpose should be done in consultation with a psychologist who is trained in questionnaire use and analysis.

**Table 3.2D: Recommended steps for screening women with breast cancer for significant clinical problems.**

These steps are recommended in conjunction with the general interactional skills in Table 2.1.

**Identify and document high risk factors (Table 3.2C)**
- high risk characteristics of the woman
- high risk disease characteristics.

**Ask a woman about her general psychological and emotional wellbeing**

**Ask about specific clinical issues including**
- Anxiety
- Depression
- Interpersonal functioning
- Coping with physical symptoms
- Body image and sexuality.

**Referral for counselling**

If you or the woman are concerned about her emotional well-being you should consider a referral for counselling:
- Tell the woman about the benefits of both individual and group counselling and ask her if she has any questions
- Provide the woman information about available individual or group counselling
- Ask the woman if she would like a referral and assistance arranging the appointment
- Consider endocrine assessment if a treatment-induced hormonal dysfunction is likely.

**Referring women for psychological treatment**

There are a range of referral sources for the clinician who is concerned about the emotional well-being of the woman and/or her family members.

Most oncology wards have a social worker who has expertise in counselling cancer patients, as well as practical knowledge which may be of value to women and their families. An increasing number of oncology services also have access to a clinical psychologist who is either employed directly by the oncology unit or in the hospital’s Department of Psychology.

Most large metropolitan hospitals also have a psychiatric consultation-liaison service, staffed by psychiatrists, clinical psychologists, registered mental health nurses and sometimes occupational therapists who are qualified in counselling.
These services exist not only to assess medically ill patients with mental illness, but also to provide assessment and advice about interventions for those coping with debilitating or life-threatening illness. In many cases, these services can arrange appropriate longer-term follow-up, if that is indicated.

For those who work within the private health sector, the lack of ready access to an existing multi-disciplinary team may mean that provision of psychosocial support for women poses some difficulty. Given the significant contribution of psychosocial factors to overall quality of life, it is crucial that those clinicians are sensitive to the psychosocial needs of women.

All clinicians need to develop their own referral network for supportive care. This would comprise individuals with expertise in the areas of breast cancer (e.g. psychiatrists, clinical psychologists and/or social workers) with whom they feel able to communicate about their patients.

Table 3.2E: Example clinician questions to screen for psychological difficulties.

<table>
<thead>
<tr>
<th>General emotional wellbeing questions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• ‘In addition to looking at the medical/surgical issues, I am interested in hearing how things are going more generally for you’</td>
</tr>
<tr>
<td>• ‘How have you been feeling emotionally?’</td>
</tr>
<tr>
<td>• ‘Could you tell me how your mood is?’</td>
</tr>
<tr>
<td>• ‘How are you handling the diagnosis and treatment?’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Specific clinical issues:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• ‘Diagnosis and treatment for breast cancer is often stressful for the couple and members of the family. Can you tell me how things are at home? How are your partner and family handling it?’</td>
</tr>
<tr>
<td>• ‘Some women find that they get quite depressed during treatment, if that is the case, there are a number of treatments available. Have there been times lately when you have felt down?’</td>
</tr>
<tr>
<td>• ‘Many women feel particularly anxious about their diagnosis and treatment. How are you feeling? Have there been any times when you have found it hard to cope with feelings of anxiety?’</td>
</tr>
<tr>
<td>• ‘Although it is often hard to talk about, many women feel concerned about how they will look and feel about their bodies after treatment. How do you feel about the changes you are facing to your appearance? Is this playing an important role in your treatment decisions?’</td>
</tr>
<tr>
<td>• ‘I know this might be difficult to discuss, but self-image and intimate relationships are often affected by breast cancer. Can you tell me if there are any things like that that are worrying you?’</td>
</tr>
</tbody>
</table>
Psychological therapies for women with breast cancer

A number of studies have evaluated the impact of providing various types of counselling or psychological interventions to women diagnosed with breast cancer. As shown in Tables 3.2A page 29 and 3.2B page 36, the majority of these studies have found that psychological intervention improves the well-being of women. Psychosocial interventions may include, cognitive-behavioural therapy, psychotherapy, psycho-educational therapy, group therapy, and family and/or couple therapy (see Tables 3.1B page 27 and 3.2A page 29).

In a meta-analysis of 45 randomised controlled trials with adults with cancer, those receiving psychological therapies had on average a significant improvement of 12 per cent in emotional adjustment, 10 per cent in social functioning, 14 per cent in treatment and disease-related symptoms, and 14 per cent in overall improvement in their quality of life compared to those not receiving psychological therapy (level I). In most trials, the therapy was provided by a specially trained counsellor, nurse, social worker or psychologist. However, greater effects have been demonstrated when psychological therapies were conducted by more highly trained therapists and continued for longer periods of time (level I).

Otherwise, trials comparing the relative effectiveness of different types of psychological interventions have indicated that most therapies have a similar effect (level I). It is evident, for example, that professionally-led group therapies are as effective as individual-based therapy (level I). It may be that the features of therapy common to all psychological interventions such as an empathic manner, listening, affirmation, reassurance and support generate the observed outcome.

All women with breast cancer should be informed that counselling is available for those who request it or who have particular needs. Choice of psychological therapy is always individually determined, dependent on the issues at hand and the skills of the therapist. Therapies may be delivered individually, or via a group or family model. While some women will be more comfortable with the privacy of individual counselling, other women will benefit from group counselling where they can gain from sharing the commonality of their experience.

The use of medication for psychological disturbance in women with breast cancer

The following section describes a range of pharmacological agents which have been shown to have an effective role in the management of anxiety or depressive disorders. There are few comparative studies of the efficacy of these medications, so recommendations cannot be made for any one agent over another. Selection of the particular medication depends on the individual characteristics and needs of the woman with breast cancer, and her medical status. In many instances a psychiatrist will initiate treatment with these medications. It is important for all members of the treatment team to recognise the potential role of medication as part of the comprehensive treatment of psychological disturbance in women with breast cancer.
Anxiety

In many cases in oncology, the management of acute anxiety states and anxiety disorders requires pharmacotherapy in addition to relaxation or other psychological interventions. The drugs used for treatment of anxiety include benzodiazepines, antipsychotics, antihistamines and antidepressants. Choice of a particular agent depends on the acuteness or chronicity of the anxiety state, the drug’s absorption rate, the available route for administration, concurrent medical problems and drug side-effects (level IVb).

- **Benzodiazepines:** These are the mainstay of pharmacological treatment of acute anxiety. Shorter-acting benzodiazepines, such as alprazolam, are safest but there may be breakthrough anxiety, necessitating substitution with a longer-acting benzodiazepine, such as diazepam. For those with hepatic disease, drugs such as oxazepam are safest (level IVb). Long term use of benzodiazepines has been associated with dependence. Benzodiazepines should never be ceased abruptly because of the risk of withdrawal symptoms, which may include seizures.

- **Neuroleptics:** In cases of extreme agitation, low doses of antipsychotics, such as thioridazine or haloperidol may be used, bearing in mind the risk of extrapyramidal side-effects (level IVb).

Depression

The optimal management of a major depressive episode in women with breast cancer should incorporate a combination of supportive psychotherapy, cognitive and behavioural techniques, and pharmacotherapy.

The concern that antidepressant therapy poses an unacceptable side-effect burden, is not supported by research. In one study, about 80 per cent of cancer patients receiving antidepressants showed a good clinical response, and the majority had no significant adverse effects (level IVa).

The choice of antidepressant medication should include consideration of the specific symptoms which are distressing the person, the potential for side-effects, and risk of exacerbating current medical problems and the potential for drug interactions. It is generally appropriate to commence with a low dose and to increase this slowly.

- **Tricyclic antidepressants:** The tricyclic antidepressants have been used for many years for the treatment of depression. Their sedating properties are particularly useful for management of the agitated, depressed person with insomnia (level IVb). Their potentiation and enhancement of opioid analgesia is also useful for those with pain (level IVb).

Anticholinergic side-effects may aggravate stomatitis secondary to chemotherapy and may exacerbate constipation. These drugs also have the potential to affect cardiac rhythm. Cancer patients may respond to tricyclic antidepressants at a lower dose than physically healthy people.
• **Selective serotonin reuptake inhibitors (SSRIs):** Unlike the tricyclic antidepressants, the SSRIs are a newer class of drugs, and there have been fewer studies of their effectiveness in cancer patients. One study of 115 people with cancer (level II) showed some benefit from the use of fluoxetine. The half-life of fluoxetine, however, is long, with active metabolites, and in those with hepatic or renal dysfunction, short-acting drugs, such as sertraline and paroxetine, are preferable.

The SSRIs have fewer anticholinergic or cardiovascular side-effects and are less sedating than the tricyclic antidepressants, but may be associated with some exacerbation of anxiety or insomnia. Nausea may be a limiting side-effect in cancer patients. The potential for drug interactions, such as with warfarin, may limit the use of SSRIs.

• **Selective noradrenergic reuptake inhibitors (SNRIs):** New agents, like venlafaxine, provide both selective noradrenergic and serotonergic reuptake inhibition, with fewer anticholinergic, histaminic, adrenergic effects, and no monoamine oxidase inhibition. They are likely to have a helpful role in cancer care.

• **Psychostimulants:** Limited research suggests that patients with advanced cancer may experience some improvement in depressed mood, appetite and well-being when treated with low-dose psychostimulants (level IVb). Side-effects include nervousness, over-stimulation, mild increases in blood pressure and pulse rate, and tremor (level IVb). Long-term use of these drugs is associated with tolerance and dependence.

3.3 **Practical needs and financial issues**

During the period following diagnosis and treatment, women will need information about practical issues which may influence their treatment and well-being (see Table 3.3). The following section provides information which may be of assistance.

**Cost of diagnosis and treatment**

Most women will pay something towards the cost of their diagnosis and treatment (level IVb). Women should be informed that costs for treatment vary depending upon a number of factors and that information is available from state and territory cancer organisations, or National Breast Cancer Centre publications. Concerns about additional financial burdens and the impact of treatment on employment should be discussed with the social worker or welfare worker.

**Cost, availability and types of prostheses**

The cost of prostheses varies between public and private hospitals, as well as between the states and territories (level IVb). Some women may be entitled to various financial assistance schemes. Information on cost, availability, types and fitting of prostheses can be obtained from local state and territory cancer organisations.
organisations, the local Breast Cancer Support Service, specialist breast nurses, community health nurses and some hospital social workers.

**Breast reconstruction**

Information on the appropriate time for breast reconstruction, and the advantages and disadvantages of the various types of breast reconstruction, should be provided to all women who have had a mastectomy, regardless of age, family situation or location (level IVa). Information resources are available from each state and territory cancer organisation. Women should be advised about the local availability and likely cost of the operation, and they should be referred to a surgeon experienced in breast reconstruction for advice if they are considering the operation.

**Lymphoedema**

Women with lymphoedema may require referral for physiotherapy, access to compression garments and additional support services. Treatment of lymphoedema is available through major hospitals and in private practices throughout Australia. Information about trained therapists, treatment locations, compression sleeve costs and fitting, and assistance with costs can be obtained from state and territory cancer organisations, lymphoedema associations and the Breast Cancer Support Service. Contact details for these resources are listed in Appendix E. Health funds can also provide advice on coverage for private treatment costs.

**Travel and accommodation**

Research has shown that women in Australia travelling for breast cancer treatment spend an average of over six weeks away from their homes, and many do not receive the financial assistance to which they are entitled (level IVa). Women travelling to the city for treatment may be eligible for a government scheme to provide financial assistance for travel and accommodation expenses. However, many women are unaware of their eligibility for this support (level IVb). Women in rural and remote areas should be referred to a social worker or welfare worker for advice and an application form as soon as possible following diagnosis. The travel and accommodation scheme has a different name in each state and territory (see appendix F). Ambulance travel may be necessary at certain times. Women are advised to check their entitlements for ambulance travel as there may be variations across states.

**Other support**

In some cases, additional support may be available. For example, some states offer assistance with child care, meals, home help and sickness allowance while the woman is recovering from surgery, and during radiation and/or chemotherapy. Information about these types of services should be available from the local councils, community health centres, hospital social workers or cancer organisations in each state and territory. Social workers may also be able to offer advice regarding leave entitlements and other employment benefits.
The out of pocket expenses for women diagnosed and treated with breast cancer in Australia will vary for each woman (level IVb). Further information about the range of costs for screening, medical procedures, support services such as physiotherapy and counselling, prostheses, and travel and accommodation can be found in publications available from the National Breast Cancer Centre.

Each state and territory cancer organisation and the local Breast Cancer Support Service will be able to provide direction in obtaining information regarding other practical issues. Contact details are listed in Appendix E.

### Table 3.3: Recommended steps involved in dealing with practical issues.

**Dealing with practical issues**

- Consider (as appropriate) issues involving transport, child-minding, sick leave, wigs, clothing, and sources of information.
- Inform the woman that she will probably need to pay something towards the cost of her treatment, and that the local cancer organisation or NBCC publications can provide information on costs.
- Inform the woman that the cost of prostheses vary and that information on cost, availability and types is available from local cancer organisations, local BCSS, community health nurses, social workers and some hospital staff.
- Inform the woman about breast reconstruction, including information on timing, cost, advantages and disadvantages, and that more information is available from her local cancer organisation or NBCC publications.
- Inform the woman that she may be eligible for financial assistance for travel and accommodation during breast cancer treatment, and that the local cancer organisation or NBCC publications can provide information on this.
- Ask the woman how practical issues (i.e. money, time away from home) are influencing her treatment decisions.
- Be alert to signs/symptoms that a woman may be developing lymphoedema and arrange referral to a treatment centre.
- Women with lymphoedema may also want practical information such as the fitting of a compression garment.
- Provide the woman with a contact number for her local cancer organisation and other support services.
- Refer the woman to a specialist breast nurse or social worker for practical assistance, as required.

### 3.4 Dealing with cultural issues

**Cultural and linguistic diversity**

Women from linguistically or culturally diverse backgrounds, especially those whose English is poor, will need special strategies put in place if they are to receive adequate information and be involved in decision-making. While the specific needs
and sensitivities of women from diverse cultural and linguistic backgrounds will vary, there are a number of issues that are likely to be important to most communities (see Table 3.4, page 52).

**Using interpreters**

When using an interpreter, the role of the interpreter should be explained. Women need to agree to the interpreter being present at the consultation and understand that the service is confidential. Interpreted consultations are most effective if the health professional talks directly to the woman, rather than to the interpreter, keeping sentences short and pausing after a few sentences to allow time for the interpretation.

Professional interpreters are strongly preferred over the use of family members, friends or other unqualified people. The reasons for this include issues surrounding the accuracy of information passed on (family/friends may seek to censor or alter in some way the information in order to make it more palatable or less frightening to the woman) and to protect the woman’s confidentiality. Alternatively, a woman may have a general practitioner who speaks her language and is available to attend the consultation.

The professional interpreting services available in each state and territory vary. NSW, Victoria and the ACT for instance, have health care interpreters who specialise in providing interpreter services (telephone and on-site) for the health sector. South Australia provides interpreters through its own state service. See Appendix C for the contact details of these services. Interpreters need to be booked before a consultation. This is particularly important if requesting an interpreter to be present at the consultation, and/or if requesting an interpreter in a minority language.

A telephone interpreter through the Translating and Interpreting Service (TIS) can usually be provided promptly, although giving some notice is preferable. To effectively use a telephone interpreter from the TIS, a hands-free speaker phone or a dual handset phone is all that is needed. On-site interpreters through TIS can be pre-booked, and a specific time will need to be arranged for the interpreter to be present. If at all possible, TIS recommends block bookings to maximise the use of interpreters’ time.

**Provision of information**

Where available, information on breast cancer should be provided to women in their own language (**level IVa**). Written information, including community language booklets are available from the National Breast Cancer Centre. For details on other sources of written information, see Appendix E.

The Multicultural Breast Cancer Information Service (MBCIS) is a telephone service provided to NSW and Victorian residents as part of a joint project between the NSW Cancer Council and the Anti-Cancer Council of Victoria. This service provides information and emotional support for women with breast cancer, their families and friends, in five languages—Arabic, Cantonese, Greek, Italian and Mandarin. Health
professionals and community workers can also make use of the service. The MBCIS is confidential, provided entirely by women and can be accessed by NSW and Victorian callers for the cost of a local call. Contact details are included in Appendix D.

Cultural sensitivities

It is important to be aware that women from linguistically or culturally diverse backgrounds may have a number of cultural sensitivities (level IVa), (level IVb). There may also be diversity within cultural groups, as well as between cultures. Some of these cultural issues will be similar across a number of ethnic groups, while others may be relevant to one group only.

A recent report which examined cultural issues relating to breast cancer, identified several issues that may be relevant across a number of groups (level IVa). These include the following:

- many women prefer a female medical professional. If that is not possible, a female nurse or counsellor should be present during the consultation;
- a diagnosis of breast cancer may be viewed as a death sentence whatever the prognosis might be. Some ethnic communities believe that breast cancer can have ‘male’ and ‘female’ characteristics, where the ‘male’ type is perceived as curable and ‘female’ type as fatal. Reassurance and emphasis on the positive aspects of the diagnosis will be especially important with these women;
- a diagnosis of cancer may be viewed as shameful, so reassurance that having cancer is not the fault of the women, and is not something to be ashamed of, may be required;
- religion may play a fundamental role in the woman’s attitude toward her disease and treatment. Spiritual support from her religious group may be important; and
- family and extended families have a central role in many cultures. Rights, responsibilities and decision-making are often shared by family members, and this may influence choice of treatment.

Support

The concept of support is often not easily understood by women from linguistically or culturally diverse backgrounds. Therefore, it will be important to explain what it means, and to give examples of the types of support available. Encourage women to seek support from family and friends, and community, ethnic and religious organisations, if appropriate. Wherever possible, offer the woman the opportunity to bring family members/friends with her to consultations and treatment.

A number of formal support services exist for women with breast cancer, some of which have support workers from ethnic backgrounds. In some cultures, it is not considered appropriate to seek support from outside the family. It is important to explain that formal support services offer detailed information about breast cancer,
and often the opportunity to talk to someone who has actually experienced the disease themselves. In some states, the Breast Cancer Support Service (BCSS) offers volunteers from a number of ethnic backgrounds, so it may be possible for women to talk with someone from a similar background who has breast cancer.

**Women from Aboriginal and Torres Strait Islander backgrounds**

Aboriginal and Torres Strait Islander women often do not receive culturally appropriate management and support (level IVb). While there is great diversity amongst these communities, awareness and consideration of the following issues are recommended.

**Community links—awareness, networking and utilisation**

A range of different health workers are available to support, interpret, advocate and explain on behalf of Aboriginal and Torres Strait Islander women. In different areas these health workers may include Aboriginal Health Workers, Aboriginal Liaison Officers, Aboriginal Health Education Officers and Aboriginal Nurses. They can be contacted through:

- Office for Aboriginal and Torres Strait Islander Health Services (OATSIS);
- Aboriginal Health Branches in each state and territory Department of Health;
- Aboriginal Health Coordinators in each state and territory area or regional health service;
- Aboriginal Liaison Officers at major hospitals;
- National Aboriginal Community-Controlled Health Organisations (NACCHO)—there are also state and territory equivalents;
- Aboriginal Medical Services (AMS); and
- Aboriginal land councils.

**Provision of information**

There is very little culturally-specific information written for Aboriginal and Torres Strait Islander women, which makes it difficult for women to access adequate information about treatment options (level IVb). The above contacts, as well as some state and territory cancer organisations, have information on what is available, and where to obtain it.

**Cultural sensitivities**

It is important to be aware that women from Aboriginal and Torres Strait Islander backgrounds may have a number of cultural sensitivities. Ignoring these cultural values can threaten the identity, security and ease of the woman, and have significant consequences on the provision of treatment for her breast cancer (level IVb).
Issues that may be relevant to a number of Aboriginal and Torres Strait Islander women include the following:

- many women may be concerned about how, and if, their personal information is protected from other health professionals, researchers and members of their own community. Clinicians should not only ensure confidentiality, but also explain how this is achieved;

- breast cancer is considered to be part of the realm of women’s business. Consequently, the use of female health professionals would improve acceptability of care;

- the significance of ‘shame’ for Aboriginal people is not well understood. It is more than a sense of guilt or disgrace—it is a powerful emotion resulting from the loss of the extended self, that is, identity in terms of kinship, ritual and spiritual relationships, and responsibilities. Shame may be experienced when a person acts, or is forced to act, in a manner not sanctioned by the group and that is in conflict with social and spiritual obligations. It may also be experienced when an individual is singled out for either praise or blame. In the health care setting, shame is perhaps the most complex and sensitive Aboriginal issue of which to be aware;

- family and kinship is central to the well-being of Aboriginal and Torres Strait Islander people. Clinicians should be aware that family responsibilities may impact greatly on treatment decisions and that involving family in the decision-making process may increase the acceptability of treatment options, as well as completion of, and compliance with, treatments;

- the concept of ‘support’ is often not well understood; therefore, an explanation of social support, including examples of available services (such as the BCSS) and how they can be accessed, should be given to Aboriginal and Torres Strait Islander women; and

- Aboriginal people understand individual illness in terms of its impact on a person’s ability to fulfil social and spiritual commitments. If treatment is seen to have a negative impact on a person’s social or spiritual role, it is not uncommon for it to be refused or discontinued (level IVa). \(^{22}\)
Table 3.4: Recommended steps involved in dealing with cultural issues.

Dealing with cultural issues
- Book a trained interpreter from the Translating and Interpreting Services (TIS) if the woman is not proficient in English—Ph: 13 14 50.
- Explain the role of the interpreter and ensure that the woman agrees to their presence.
- Talk directly to the woman rather than the interpreter, keep sentences short and pause after a few seconds to allow for interpretation.
- Provide culturally-appropriate health care workers, when possible.
- Provide a female medical professional or nurse, when possible.
- Explain how confidentiality is achieved within the medical setting.
- Ask how the woman feels about her disease and treatment, and what meaning it has for her within her culture.
- Assess the woman’s understanding of her disease, treatment and prognosis.
- Ask about cultural or religious issues which may influence treatment.
- Offer to discuss issues and treatment options with the woman’s family.
- Explain the importance of social support and encourage the woman to seek support from family, friends, support services and local cancer organisations.
- Provide written information in the appropriate language, if available.
- Arrange follow-up and support.
- Always be aware of culturally-specific and individually-specific values, beliefs and modes of behaviour.

3.5 Ensuring continuity of care

Women with breast cancer continue to report a lack of continuity of care (level IVa). In Australia, there is a mixed model of care, with public and private sectors, urban and rural/remote locations, and state and federal funding for health. Given that this model is likely to continue, various methods of improving continuity of care, described below, should be provided to women with breast cancer. See Table 3.5 (page 55), for a summary of these recommendations.

Identification of a coordinator of care

The identification of a coordinator of care, often a general practitioner, can be useful in ensuring continuity of care (level IVa). General practitioners often have knowledge of a patient’s background, such as family and social history, usual responses to illness, and medical history, which would be helpful to a specialist. The general practitioner may also look after the family throughout the woman’s illness and follow-up. In rural and remote areas in particular, the general practitioner may play a key role in ongoing care.
The coordinator of care could also be the treating surgeon or another member of the treatment team, and should be selected by the women in consultation with the treatment team. The coordinator of care needs to be informed of all consultations, treatment plans and treatment outcomes.

Specialist breast nurses

The role of a specialist breast nurse is to provide ongoing counselling, information and support relating to all aspects of breast care for women with breast cancer, and clarify or reinforce information and provide continuity of care throughout the treatment process ([level II](#)). Women may also feel less constrained by time pressures and therefore more able to ask questions with a specialist breast nurse as opposed to a clinician.

Interdisciplinary communication

Treatment team members from several disciplines, such as medical and radiation oncology, surgery, general practice, nursing and social work are typically involved in the care of women with breast cancer. Sometimes the team members may physically work in the same location, at other times they may not. Optimal care depends on timely exchange of pertinent information between these team members. When interdisciplinary communication breaks down, the results may disrupt the continuity of patient care and cause unnecessary repetition of clinical/diagnostic tests, and consequent patient confusion, anxiety and dissatisfaction ([level IVa](#)).

A vital prerequisite to effective interdisciplinary communication is a well-functioning team. During a recent series of consensus workshops held by the NSW Cancer Council, inclusion of the interdisciplinary team and active efforts to promote communication among health professionals were nominated as the most important steps to ensure ethical decision-making in the oncology setting ([level IVb](#)).

By far the most common means of interdisciplinary communication is the referral letter and letter of reply. The role of these letters has been described as not only an exchange of information, but also a means of influencing consultant attitudes, educating general practitioners, equipping clinicians to better treat the patient, ensuring consistency in what is said to the patient, and a formal record for future reference.

A general survey of specialists ([level IVa](#)) has indicated that the following items are most desirable features of letters of communication:

- a clear and explicit statement of the reason for referral;
- history of the problem;
- a medical history;
- current medication;
- the referring doctor’s expectations from the referral;
• findings on examination;
• findings on investigation; and
• whether this is a new or re-referral.

Additional important content items identified from a recently completed Australian survey of medical and radiation oncologists (level IVa) were
• copies of test results, eg pathology report, x-ray films;
• a provisional diagnosis;
• what the patient has been told;
• whether an interpreter is required;
• any factors mitigating against certain treatments or treatment arrangements;
• intercurrent medical conditions;
• involvement of other doctors;
• the referring doctors’ continuing role; and
• any concerns about psychiatric or social problems.

Several studies have explored information preferences of referring doctors for letters of reply (level III) and (level IVa). The most desired information includes
• diagnosis and staging;
• findings on examination and investigation;
• treatment options;
• treatment/therapy recommendation and rationale;
• benefits of treatment;
• likely short- and long-term side-effects;
• follow-up arrangements;
• involvement of other doctors in the case;
• prognosis;
• what the patient and/or relative has been told;
• anything specific the oncologist would like the referring doctor to do;
• concerns about patient understanding and coping behaviour; and
• the patient’s wishes/expectations regarding information disclosure, decision-making and treatment.
Patient-held records

Although research on patient-held records is only beginning to emerge, patient-held records are a promising mechanism for improving continuity of care for women with breast cancer. Research has shown that patient-held records are beneficial for patients \( \text{(level II)} \)\(^7\) and have considerable medico-legal benefits, such as documentation of doctor-patient communication, with no substantial practical drawbacks \( \text{(level IVa)} \).\(^{231}\)

<table>
<thead>
<tr>
<th>Table 3.5: Recommended steps for establishing continuity of care.</th>
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</thead>
<tbody>
<tr>
<td><strong>Ensuring continuity of care</strong></td>
</tr>
<tr>
<td>• Ask the woman who she would like to coordinate her care (ie general practitioner, specialist, breast nurse, etc.).</td>
</tr>
<tr>
<td>• Document coordinator of care in medical notes and/or patient-held record.</td>
</tr>
<tr>
<td>• The coordinator of care should inform specialists and members of the treatment team of any known psychosocial or medical risk factors which may influence treatment.</td>
</tr>
<tr>
<td>• Notify the coordinator of care promptly after each visit to a specialist or when there are any changes in treatment. Options include a phone call, a fax, or a letter carried by the patient.</td>
</tr>
<tr>
<td>• Notify the coordinator of care of any interspecialist referrals. A phone call or fax message may be sufficient (or even preferable), rather than sending the patient back and forth.</td>
</tr>
<tr>
<td>• Provide letters of referral and letters of reply with relevant information to members of the treatment team.</td>
</tr>
<tr>
<td>• Forward all relevant health information to the coordinator of care; however, the patient should be encouraged to contact the appropriate member of the treatment team for clarification and further information.</td>
</tr>
</tbody>
</table>

Adapted from *The clinical practice guidelines for the management of advanced breast cancer. NHMRC National Breast Cancer Centre.*\(^{22}\)

3.6 Support in palliative care

When a woman has breast cancer, maintaining quality of life and minimising the psychosocial impact of both the cancer and treatment side-effects should be a major focus of management. In women with advanced breast cancer, quality of life has been shown to be a significant, independent prognostic predictor of survival in clinical trials \( \text{(level III)} \).\(^{232,233}\) Valid and reliable quality of life assessment is important as it may influence decision making about the type of treatments used. Clinicians need to be aware of the potential impact of the disease on quality of life for the woman and her family, and have monitoring strategies in place so that appropriate interventions can be implemented (see Table 3.6).
Physical issues

Quality of life is affected by symptoms, loss of function and curtailment of activity due to the disease and physical effects of treatment (level IVb). Symptoms affecting quality of life may be related to the cancer and/or treatment, and include nausea, pain, dyspnoea, tiredness, anorexia, vomiting, constipation, abdominal bloating and lymphoedema.

Loss of function relates to the inability to perform a variety of activities that are normal for most people. These activities include self-care activities (feeding, dressing, bathing), mobility (ability to move indoors/outdoors), physical activities (walking, lifting, bending) and role activities (work, school, household activities). When women with advanced breast cancer are asked to rank quality of life issues in terms of importance, general health items such as self-care, mobility, physical activity, appetite and sleep are ranked in the upper quartile (level IVa).

When women with advanced breast cancer enter the phase of palliative care, pain and a variety of other symptoms require active treatment. When pain and fatigue are not well controlled, psychological distress increases and physical and social functioning decrease (level IVa). Women with metastatic disease have been shown to have significantly more unmet needs in the area of help with physical aspects of daily living when compared with the needs of women in remission (level IVa).

Psychological issues

A number of studies have shown that 25–50 per cent of women show clinically significant levels of anxiety and depression when a diagnosis of recurrence of breast cancer is made (level III), (level IVa). Studies also indicate that 50–75 per cent of women rate the diagnosis of recurrence as more devastating than the original diagnosis (level III), (level IVa). The diagnosis of recurrence challenges women to confront their mortality more than at any other stage of the cancer illness (level IVa). For many women, distress increases as the cancer progresses (level IVa).

For the woman and her family, dealing with the grief and concerns associated with disease progression may be very difficult. Recognition of this grief and the provision of the opportunity to discuss concerns is an integral aspect of care. This is discussed in more detail in the advanced breast cancer clinical practice guidelines.

Social issues

There are a number of ways in which cancer and cancer treatment can disrupt social relationships. Functional problems due to pain or fatigue may diminish the individual’s ability to pursue normal activities. Similarly, the demands of treatment regimens may seriously limit the ability to maintain social contacts, and psychological reactions and concerns may lead to restricted social interactions. Friends and family may also decrease the level of contact because they fear that the woman will be unable to manage the demands of social contact.
A study which examined the experience of cancer patients in their final year of life found that a good death was associated with the following features: the social life of the dying person, the creation of open awareness, the adjustment to and personal preparation for death, and the public preparation, such as arrangements relating to work and final farewells. Given the opportunity, clinicians should ask their patient what their expectations of dying and death are.

**Existential and spiritual issues**

Existential issues such as concerns about death, freedom, isolation and the question of meaning may become increasingly important to people with advanced cancer. They may, in fact, become as important as the physical, psychological and social support domains in determining quality of life.

There is evidence that as the physical condition deteriorates, spiritual issues gain importance as determinants of quality of life. In the spiritual domain, the basic human need for transcendence, ‘to step back and move beyond what is’, may manifest as a search for meaning in the illness. Spiritual considerations may also assist the individual to endure present discomforts and, if need be, to face death with courage and dignity.

**Impact on the family**

The diagnosis of recurrence of disease has been shown to impact negatively on marital and other relationships. Some women may feel their partner fails to appreciate the devastating impact of disease progression, thus failing to meet their needs. Many families may be even more distressed by the diagnosis than the woman, and some family members may avoid discussion about recurrence of disease or dying because they are uncertain about what to say.

Families play a major role in the woman’s coping with breast cancer and open communication styles and expression of feelings generally facilitate adjustment. There is no evidence that being upset will worsen the prognosis, in fact, there is evidence that expression of feelings may improve adjustment. Therefore, women should be encouraged, where possible, to express fears and feelings and maintain open communication with her family and friends.

A review commissioned by the National Breast Cancer Centre for the development of the Advanced Breast Cancer Guidelines found that there is little specific evidence regarding the impact on children of women with advanced breast cancer. Most studies relate more generally to children of a parent with cancer. This review, available from the National Breast Cancer Centre, identifies the following key issues:

- the child’s developmental age is a major factor affecting adjustment to his/her mother having cancer;
- younger children are often concerned with the disintegration of the family, and are worried about the vulnerability of the well parent.
• guilt about their own possible contribution to parental illness (level IVa);
• for adolescents, disruption to social networks and leisure activities and increased domestic responsibilities are prominent issues (level IVa);
• adolescent daughters of women with breast cancer are particularly emotionally vulnerable (level III); (level IVa). This vulnerability may relate in part to identification with their mother, and changes in role expectation; and
• parents coping with cancer may fail to recognise emotional distress in their children (level IVa). further, some research reports that children perceive that their families offer them little support (level IVa).

Families may benefit from being informed about support services and groups that can provide practical assistance, support and counselling. Information on local services for families can be obtained from the Cancer Information Service, the Breast Cancer Support Service, and hospital social workers.

The impact on the clinician

Dealing with people who have cancer has been acknowledged as stressful for many clinicians, however, it is only recently that the origins of this stress have been examined in the literature. Clinicians may experience frustration and a sense of professional failure in their dealings with patients with cancer, (level IVa) some of whom have a poor prognosis. Major areas of concern for oncologists include dealing with the patient’s suffering, and being involved with decisions about treatments that are increasingly complex and potentially toxic. These issues occur against a background of organisational responsibilities which may conflict with clinical demands, and concerns about the impact of overwork on home life (level III). The ethical and legal issues which arise in patient care add a further dimension to the management of clinical work.

Exposure to dying patients may pose conflicts between curative goals, which underpin much medical education, and the need to adopt the palliative or supportive roles of cancer care. This same medical training often provides little preparation for the intensity of grief, anger, frustration and resentment displayed by patients and their families (level IVa).

Understanding clinician stress involves consideration of the individual’s personality style and their capacity to develop priorities in their professional and private lives (level IVb). It is important for those working in oncology to draw on the expertise of members of the multidisciplinary team in dealing with complex clinical problems (level IVa).

It is also important that clinicians talk to colleagues about the stresses of their daily work, and that they seek professional help when required. Another strategy for reducing stress is to improve communication skills, as there is evidence that health professionals who feel insufficiently trained in communication and management skills have significantly higher levels of stress (level III).
Table 3.6: Recommended steps involved in providing support in palliative care.

These steps are recommended in conjunction with the general interactional skills in Table 2.1.

**Planning care**
- Ask about the woman’s understanding of her disease status, including her current needs and priorities.
- Discuss plan of future management and monitoring, including understanding of short and medium term outcome goals.
- Keep the woman, her partner, children, and significant others continually informed about issues of most importance to them, such as the likely course of the disease, symptom management and service availability.

**Physical issues**
- Introduce the notion of active treatment of symptoms and the importance of its role in ongoing care.
- Discuss and clarify the current targets of symptom management and actively enquire about the woman’s symptoms, particularly pain and fatigue.
- Provide the woman and her family with information about specific measures available for symptom relief.
- Provide the woman and her family with information about practical support services such as volunteers, Meals on Wheels, home help, community nurses, palliative care domiciliary services, etc.

**Psychological issues**
- Actively encourage the woman to discuss how she and her family are coping with the disease and how others’ reaction to the disease is impacting on the woman’s well-being.
- Where appropriate, make specific arrangements for counselling/support/information to be given to the woman and her family.

**Social issues**
- Actively encourage the woman to discuss how her disease is impacting on her relationships and social life, and whether her family is influencing her level of social interaction.
- Where appropriate, provide information about counselling and support, including support groups.
- Encourage open communication and expression of feelings and fears in relationships with family and friends.
- Discuss issues related to dying and death and encourage the woman to discuss these issues with family and friends.
- Encourage early involvement with palliative care services to access their range of supportive personnel and therapies.

**Other issues**
- Ask about practical care needs, including financial and legal issues.
- Enquire about spiritual needs and offer referral for pastoral care, if desired.
- Discuss your availability for future advice and support.
APPENDICES

APPENDIX A: NBCC PSYCHOSOCIAL WORKING GROUP

The NHMRC National Breast Cancer Centre (NBCC) was established in 1995. One of its goals is to ensure that all women diagnosed with breast cancer and their families receive adequate psychological, physical and practical support.

The Psychosocial Working Group was established with a national and multidisciplinary membership to assist the centre in its efforts to achieve this goal.

Terms of Reference

To critically evaluate existing research and clinical evidence for optimal psychosocial support for women with breast cancer.

To identify the type, availability and efficacy of models providing psychosocial support to women with breast cancer in the following areas:

• within the treatment team;
• from other sources including professional counsellors, self help groups/volunteers, specialised psycho-oncology units, breast cancer support services; and
• support strategies for women with advanced breast cancer versus early breast cancer.

To develop recommendations for the identification of women who require psychosocial support.

To develop psychosocial clinical practice guidelines for health care providers as part of an overall training package for use by medical practitioners.

The clinical practice guidelines will be developed, implemented and evaluated following the procedures recommended by the Quality of Care and Health Outcomes Committee’s draft first edition of Guidelines for the Development and Implementation of Clinical Practice Guidelines.

Membership of the NBCC Psychosocial Working Group

Dr Jane Turner (Chair)             Department of Psychiatry
Psychiatrist                      University of Queensland
                                   Royal Brisbane Hospital, Herston, QLD

Dr Fran Boyle                        The Bill Walsh Cancer Research Laboratory
Medical Oncologist                  Department of Clinical Oncology
                                   Royal North Shore Hospital, NSW
Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer

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Professor Jill Cockburn
Head, School Population Health Sciences
University of Newcastle, Wallsend, NSW

Behavioural Scientist

Professor David Kissane
Psychiatrist
Director, Centre for Palliative Care
University of Melbourne, VIC

Ms Penny La Sette
Consumer Representative
Darwin, NT

Dr Amanda McBride
General Practitioner
North Sydney, NSW

Miss Suzanne Neil
Breast Surgeon
Balaclava, VIC

Ms Marcia O’Keefe
Breast Cancer Consumer/Advocate
Engineer (Deceased October 1997)

Professor Sally Redman
Director
NHMRC National Breast Cancer Centre
Woollahra, NSW

Professor Martin Tattersall
Medical Oncologist
Professor of Cancer Medicine
Department of Cancer Medicine
University of Sydney, NSW

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Social Work
Director of Social Work
Canberra Hospital, Canberra, ACT

Ms Kate White
Nursing
Senior Lecturer in Nursing
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Consumer
Consumer/Counsellor Breast Screen
Western Parramatta, NSW
Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer

**NBCC Secretariat**

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APPENDIX B: PROCESS FOR GUIDELINE DEVELOPMENT AND EVALUATION

The guidelines were funded and developed by the NHMRC National Breast Cancer Centre, through its multi-disciplinary Psychosocial Working Group and secretariat staff (see Appendix A) in a manner consistent with that prescribed by the NHMRC, and according to the standards indicated by the QCHOC.

Purpose and scope of the guidelines

National significance

In 1994, the House of Representatives Standing Committee on Community Affairs convened an Inquiry into the Treatment and Management of Women with Breast Cancer. The report, tabled in 1995, concluded that:

‘Despite the proven, high incidence of serious psycho-morbidity in breast cancer patients, in Australia at least very little has been done to either investigate the extent and severity of that morbidity or to provide a suitable means of addressing it either as a preventative measure or as a therapeutic measure.’ (page 34)

This high level of need was observed across all aspects of psychosocial care in clinical practice, including the provision of information, access to adequate counselling, and practical support for women from rural and remote settings.

Need for evidenced based clinical practice guidelines

Despite the high level of need and evidence that demonstrates that psychosocial intervention can benefit emotional adjustment and social functioning in cancer patients, there are few guidelines available for the supportive care of women with breast cancer.

- Neither the NBCC nor its international advisory board was aware of any specific and comprehensive clinical practice guidelines for the provision of information, support and counselling for women with breast cancer
- The NHMRC Clinical Practice Guidelines for the Management of Early Breast Cancer indicated the importance of psychosocial support, but provided only general information about optimal standards of care in this area
- Some consensus guidelines have been developed for specific aspects of information-giving in cancer care (eg NSW Cancer Council’s Breaking Bad News).

Target audience

These psychosocial clinical practice guidelines were developed to equip the treatment team with evidence-based recommendations for optimal psychosocial care throughout treatment, according to individual needs.
Scope of the guidelines

The objective of the guidelines is to assist clinician and patient decisions about psychosocial care by providing a framework within which to apply a clinician’s judgement and to assess and consider the woman’s individual needs and circumstances.

The guidelines are confined to the psychosocial aspects of care in both early and advanced breast cancer. Topics covered include, the way information on diagnosis and treatment may be delivered to a woman and her family, how the members of the treatment team can provide emotional support, how they can screen for, acknowledge and where necessary refer on more significant psychological problems, and practical issues such as the use of interpreters and the availability of financial assistance.

Outcome focussed

The primary focus of the psychosocial clinical practice guidelines for the care of women with breast cancer is to improve psychosocial and quality of life outcomes of the woman and her family. Key outcomes may include the following:

Information and satisfaction with care

The guidelines make evidence-based recommendations regarding the provision of information to enable greater levels of satisfaction with all aspects of care. Measurable outcomes include consumers’ ratings of satisfaction with care and information, and changes in the number of health complaints made on the basis of communication issues. Improved information giving has also previously been found to affect outcomes such as treatment compliance.

Psychological outcomes

The guidelines recommend evidence-based strategies to improve the early detection, referral and treatment of women with elevated levels of anxiety and depression, as well as specific psychological conditions, such as body image disturbances. The guidelines also make recommendations to assist in the reduction of event-specific distress, such as communication of news of diagnosis or preparation for a treatment. It is anticipated, therefore, that measurable psychological outcomes may include, levels of anxiety and depression, the prevalence, severity and chronicity of body image and sexual disturbance, interpersonal problems, and changes to the psychosocial component of chronic and impairing physical symptoms associated with breast cancer and its treatments.

Social functioning

The guidelines make recommendations to aid the provision of information about practical and financial support for women with breast cancer, particularly those from rural and remote settings and those from cultural groups with special needs. Improved social functioning includes reduced impact on the family, particularly when a woman is required to travel away from home.
Best available evidence

The NHMRC National Breast Cancer Centre commissioned comprehensive reviews of the published and unpublished literature with regard to psychosocial aspects of breast cancer as the basis for the psychosocial guidelines.

The reviews included the following aspects of psychosocial care:

- the nature, severity and impact of breast cancer on the emotional well-being of women with breast cancer, including how to identify women who may benefit from additional psychosocial support;
- psychosocial support that is appropriately offered by members of the treatment team;
- psychosocial support that is appropriately to offered by groups outside the treatment team; and
- strategies for information-giving for health professionals providing care for women with breast cancer, including telling a woman she has breast cancer, discussion of treatment options and prognosis.

The reviews examined the design and quality of the studies and rated the level of evidence in the prescribed method. As a result, extensive reviews of the material were collated and in some cases independently published.

Studies from breast cancer, general oncology and health literatures were examined during the review process. In many cases the supporting research is very specifically related to breast cancer, for example assisting a woman to make a treatment choice. In other instances the clinical issue has relevance to cancers in general, for example discussing the diagnosis of cancer. In such cases, the supporting research evidence cited in these Guidelines may include other oncology samples. In rare instances isolated studies included in the reviewed meta-analyses may not have included a sample of women with breast cancer. These studies have only been included if the clinical issue of interest was generic—for example the benefits of psychoeducational groups. The working group considered that it was inappropriate to exclude generic data relating to clinically important issues, particularly as it is the best available evidence.

The reader is referred to the primary review documents for detailed descriptions of the review methodology and a comprehensive discussion of the reviewed literature. The primary reviews are available from the National Breast Cancer Centre on request. The completed reviews include:

- Psychosocial impact of breast cancer: a summary of the literature 1986–1996 by Dr Jane Turner et al
- Psychosocial support for breast cancer patients provided by members of the treatment team by Dr Susie Burke and Professor David Kissane 1976–96

RESERVED
Psychosocial support for breast cancer patients: a review of interventions by specialist providers—A summary of the literature 1976–1996, by Dr Susie Burke and Professor David Kissane

Supporting research reviews by Dr Billie Bonevski and Dr Jill Cockburn:
• Breaking bad news: a review of the literature
• Effectively discussing treatment options for women with breast cancer: a review of the literature
• Preparing women diagnosed with breast cancer for mastectomy or breast conserving therapy: a review of the literature.

Talking about prognosis with women with early breast cancer by Ms Elizabeth Lobb, Dr Phyllis Butow et al.

Consultation process
There has been extensive consultation with stakeholders and interested parties with a series of meetings, surveys and calls for written reviews undertaken since the start of 1997. The consultation process included members of the relevant professions and consumers, as summarised in the following table.

Consumer representation has been sought throughout the consensus process. Consumers are permanent members of the psychosocial working group which have overseen the development of the guidelines. Consumers were also consulted at a number of junctures in the guideline development process, as summarised below.

Key aspects of the consultation process underpinning the guideline development
• Meeting of the National Breast Cancer Centre Psychosocial Working Group to consider the review process on 13 December, 1996.
• Consensus meetings on 6 February, 1997 in Brisbane and 11 February, 1997 in Melbourne. Participants represented professions involved in all aspects of cancer care; considering recommendations of the key reviews.
• A survey of consumer opinions, conducted by CERP in September/December 1997. 313 women were invited to participate and 143 completed the study.
• A review of the guidelines by the National Breast Cancer Centre Consumer Advisory Group in September, 1997. Consumer opinion has been incorporated in subsequent reviews, through their representation on the Psychosocial Working group, and in the review process described below.
• An ‘NHMRC first round equivalent’ of consultation, initiated on Nov 21 1997. The guidelines were sent out to relevant experts, representatives of the professional college and consumer representatives and modifications were made, based on replies received from reviewers by the end of January, 1998 (listed below).
• Modifications to the guidelines were presented to the Psychosocial Working Group again in March and June 1998 with subsequent modifications by the working group panel.
• Final drafts were reviewed by the National Breast Cancer Centre Clinical Advisers in January 1999.
Initial consensus meetings arising from research reviews

Organising Group

Professor Sally Redman  Director, National Breast Cancer Centre, NSW
Dr Afaf Girgis (chair)  Behavioural Scientist, National Breast Cancer Centre, NSW
Professor David Kissane  Director, Centre for Palliative Care VIC
Psychiatrist
Dr Jane Turner  University of Queensland QLD
Psychiatrist

Consensus meeting, Brisbane, 6 February 1997

Mr Colin Furnival  Surgeon, Wesley Medical Centre, QLD
Dr Ken Pittman  Medical Oncologist, Royal Brisbane Hospital, QLD
Ms Anne Fletcher  Oncology/Breast Nurse, Breast Link, QLD (now Cheltenham, VIC)
Dr Sue Harbison  General Practitioner, Ashgrove Avenue Family Practice
Ms Pat Neely  Social Worker, Mater Hospital, NSW
Dr Marguerite Robertson  Palliative Care Specialist, Mt Olivett Hospice QLD
Dr Brian Kelly  Psychiatrist, Princess Alexandra Hospital
Miss Olive McMahon  Consumer Representative, QLD
Ms Leonie Young  Consumer Representative, QLD
Dr Wendy Ochtman  Palliative Care Physician, Mt Olivett Hospice QLD
Ms Jenn Scott  Clinical Psychologist, Griffith University QLD

Consensus Meeting in Melbourne, 11 February, 1997

Dr Ray Snyder  Chair, Medical Oncologist Group of Australia, St Vincent’s Hospital VIC
Dr Roslyn Drummond  Radiation Oncologist, Peter MacCallum Cancer Institute VIC
Ms Mary Harvey  Breast nurse, VIC
Ms Carrie Lethborg  Social Worker, St Vincent’s Hospital, VIC

Psychosocial clinical practice guidelines providing information, support and counselling for women with breast cancer  69
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Psychologist  
Monash Medical Centre, VIC

Ms Lyn Swinburne  
Consumer Representative, VIC

Ms Diane Ferguson  
Consumer, VIC

Ms Susie Burke  
Psychologist  
Centre for Palliative Care Studies

‘NHMRC First Round Equivalent, Nov 1997-Jan 1998’

Submissions received

Dr Barbara Jones  
Acting State Director  
RACGP Training program  
COORPAROO, QLD

Ms Sue Lockwood  
Breast Cancer Action Group  
BLACKBURN, VIC

Mr Peter Malycha  
Chair, Breast Section,  
Royal Australian and New Zealand College of Surgeons  
ADELAIDE, SA

Mr James Kollias  
Surgeon  
ADELAIDE, SA

Professor Alan Rodger  
Board of the Faculty of Radiation Oncology  
C/- William Buckland Radiotherapy Centre  
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Ms Anne Fletcher  
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Breast Link, QLD  
(now Cheltenham, VIC)

Ms Lillian Dailey  
NSW College of Nursing, NSW

Dr Dianne Hastrich  
Breast and General Surgeon  
Mount Medical Centre, PERTH, WA

Mr Sean Hamilton  
Surgeon, WEMBLEY, WA

Professor Linda Kristjanson  
Professor of Nursing  
Edith Cowan University  
CHURCHLANDS, WA

Mr Colin Furnival  
General Surgeon  
Wesley Medical Centre  
AUCHENFLOWER, QLD
Implementation and dissemination plans

The NHMRC National Breast Cancer Centre will be responsible for disseminating, implementing, evaluating and updating the guidelines.

The psychosocial clinical practice guidelines affect the clinical practices of a number of different professions, and strategies have been developed to target both general and specific needs. The implementation plan has also been developed on the basis of the experience obtained through the implementation of the NHMRC-developed companion, Clinical practice guidelines for the management of early breast cancer.

The implementation plan includes the following strategies:

Pretesting and piloting

The psychosocial guidelines have been pilot tested throughout 1998 as guidelines for clinical practice in a multicentred trial of a Specialist Breast Nurse model of care at treatment centres in Melbourne, Perth, Adelaide and Dubbo in rural NSW.

The draft psychosocial guidelines have been incorporated into communication skills training programs for senior oncologists. These workshops have been conducted nationally throughout 1998 and early 1999.

Endorsement

The guidelines have been submitted to the NHMRC for endorsement and will be circulated to relevant stakeholders as a critical first step to aid dissemination and implementation.

Dissemination

An initial print run of 10,000 copies of the guidelines will be disseminated to relevant professional groups free of charge. Additionally copies will be made available to allied health organisations, state and territory health authorities, breast cancer treatment centres, consumer groups, patient support groups, professional colleges and associations.

Secondly, the guidelines will be made available on the internet through the NBCC’s homepage. The availability of the guidelines will also be advertised through the NBCC’s newsletters, published frequently throughout the year, and will be distributed through professional colleges nationally.
Thirdly, an A3-sized summary card of the key evidenced statements and recommendations will be produced for distribution to relevant health professionals nationally.

Fourthly, the guidelines will be promoted through national seminar series, presentations at relevant professional meetings and conferences and submissions to professional journals.

Training members of the treatment team

The National Breast Cancer Centre have undertaken to facilitate the development of training programs, including partnerships with key groups and organisations, to assist the implementation of the guideline recommendations. These include:

- communication skills training programs, already developed by the NBCC to assist health professionals implement information aspects of the guidelines;
- the ‘specialist breast nurse demonstration project’ has enabled the recognition of factors affecting the implementation of the guidelines and how to evaluate outcomes;
- the NBCC has also undertaken to facilitate the development of communication skills training programs for registrars in oncology; and
- workshops and seminars will be conducted for health care professionals involved in the treatment and support of women with breast cancer.

Consideration of local conditions and resource constraints

The guidelines have been framed in a manner that is flexible and mindful of the variation in local conditions and resource considerations. In some instances specific projects have been undertaken to investigate the needs of local groups and the effects of local conditions and constraints on the psychosocial wellbeing of women with breast cancer and their families.

Economic implications

Some of the recommendations in these guidelines are more independent of resource constraints than others. The majority of the recommendations reflect changes in clinician-consumer interaction and therefore incur no or trivial costs. A number of recommendations also guide health professionals and consumers to information about available local resources and resources that may be underutilised such as financial assistance for women travelling to city treatment centres from rural settings.

Certain of these recommendations may lead to the women themselves incurring costs for their psychological care. An additional resource available from the NBCC, details out of pocket expenses incurred by Australian women during the diagnosis and treatment of breast cancer and includes the costs of psychological services (level IVb).215
There are some recommendations that may be difficult to implement within current resource arrangements, including the provision of trained professionals, such as psychiatrists or clinical psychologists. The NBCC has initiated a number of projects to explore what is required to meet needs and develop resources, such as specialist breast nurses, in diverse treatment settings.

**Evaluation plan**

An essential part of the development and implementation of these guidelines is the evaluation of their effectiveness. A strategy for evaluating these guidelines will be drafted at the implementation stage and will include the collection of data to determine the impact of these guidelines on the care of women with breast cancer.

The National Breast Cancer Centre has already undertaken key steps to facilitate this process. Baseline data has already been collected on women’s perceptions of care and psychosocial needs through the NBCC National Consumer Survey (NCS). The NCS was based on a representative national sample of women treated for breast cancer in the preceding 12 months. It is intended that this survey be repeated after the release of the guidelines to evaluate their impact. Additional baseline data has been collected on 360 women treated at 4 national treatment centres collaborating in projects to improve psychosocial care through specialist breast nurse model of care.

A protocol has also been drafted to examine the effects of the guidelines on psychosocial clinical practices and outcomes in care around the time of breast cancer surgery.

**Revising the guidelines**

The psychosocial clinical practice guidelines reflect the best available knowledge at the time of their publication. Collaboration between the National Breast Cancer Centre’s Behavioural Scientist and Psychosocial Working Group (which meets quarterly) provides an established mechanism to review advances in the field and implications for revising the guidelines. In addition, the National Breast Cancer Centre will continue to foster close links with the Sydney-based Cochrane Collaboration Review Group in Breast Cancer, which will facilitate the guideline review process.

**Further research**

As a result of the review process, a number of areas of supportive care have been identified as requiring additional research before stronger evidence-based recommendations can be made. These include:

- sexuality and body image;
- psychological intervention in palliative care;
- strategies to improve the detection of psychological difficulties in women with breast cancer;
• psychosocial needs of women with advanced cancer;
• management of chronic physical and cognitive symptoms, such as post treatment fatigue;
• the development of a research action plan and a network of collaborative researchers to investigate the measurement, prevalence, prevention, and management of lymphoedema; and
• the information and support needs of the children of women with breast cancer.

The National Breast Cancer Centre has initiated the further investigation of a number of these key issues.
The Translating and Interpreting Service (TIS) is a national service with offices in each state and territory. The service offers both telephone and face-to-face interpreting. If you need an interpreter to attend an appointment, you will need to book a few days in advance. TIS is available 24 hours a day, 7 days a week. The TIS can be contacted from anywhere in Australia, for the cost of a local telephone call, on 13 14 50.

Some states and territories also have other interpreter services available in a range of community languages. Some have health interpreters who are specially trained to interpret medical terms and procedures. The service is usually free of charge in public hospitals. In addition to the interpreter services listed below, you could ask your doctor or check with your local Department of Social Security for other services that may be available in your area.

**National**

Translating and Interpreting Service (TIS) 13 14 50 (local call cost, 24 hour)

**ACT**

ACT Health Care Interpreters (02) 6205 3333

**NSW**

Health Care Interpreter Service (available Sydney, Hunter & Illawarra areas):

- Northern Sydney (02) 9926 7560
- Central, Eastern & Southern Sydney (02) 9516 6999
- South Western Sydney (02) 9757 1800
- Western Sydney (02) 9840 3456
- Illawarra (02) 4274 4211
- Hunter (02) 4924 6285 (02) 4924 6286

**NT**

Northern Territory Interpreter and Translator Service

- Darwin (08) 8999 7566
- Alice Springs (08) 8951 5389

**QLD**

No other accredited interpreter services - call TIS 13 14 50
SA
Interpreting and Translating Centre, Multicultural and Ethnic Affairs Commission
(08) 8226 1990

TAS
No other accredited interpreter services - call TIS 13 14 50

VIC
Central Health Interpreting Service (CHIS) (03) 9370 1222

WA
No other accredited interpreter services - call TIS 13 14 50
APPENDIX D: MULTICULTURAL BREAST CANCER INFORMATION SERVICE (MBCIS)

This is a telephone service in Arabic, Chinese, Greek and Italian for those diagnosed with breast cancer and their families.

What does the service provide?

- Information about breast cancer in Arabic, Cantonese, Mandarin, Greek and Italian to those diagnosed with breast cancer and their families.
- A confidential telephone service.
- Female information workers who speak Arabic, Cantonese, Mandarin, Greek and Italian. Each information worker also speaks English.
- Emotional support for women diagnosed with breast cancer and their families and friends.
- Information about referral to other services related to breast cancer.
- Information about breast cancer including investigations and treatment options.
- Information on attitudes and beliefs related to breast cancer in women from non-English speaking backgrounds for health care providers and community workers.
- Feedback to doctors and other health care providers about the woman’s concerns (at the woman’s request).

About the Information Workers

The information workers are trained in the clinical, cultural and psychosocial aspects of breast cancer. They have a background in nursing, social work and counselling. The information workers receive regular debriefing sessions by a psychologist or counsellor.

For further details, contact Marisa Toscano, Co-ordinator, MBCIS on (02) 9334 1971.

Contact details for the Bilingual Information Workers:

These numbers may be called from NSW and Victoria for the cost of a local call.

- Arabic: Monday & Tuesday 1300 301 625
- Cantonese and Mandarin: Monday to Thursday 1300 300 935
- Greek: Thursday & Friday 1300 301 449
- Italian: Thursday & Friday 1300 301 431
APPENDIX E: RESOURCES AND CONTACTS FOR WOMEN AND THE TREATMENT TEAM

Resources for women

The resources listed below are available from the National Breast Cancer Centre.

- A consumer’s guide: early breast cancer (booklet)
- All about early breast cancer (booklet)
- All about early breast cancer (cassette)
- Breast cancer and family history: what you need to know (booklet)
- Breast changes: what you need to know (booklet)
- Familial breast cancer (video)
- Healthy breasts (booklet in Arabic, Greek, Italian and Polish)
- Women and breast cancer (set of five radio programs on cassette)
- Breast reconstruction: your decision (tape)
- When the woman you love has early breast cancer (cassette)
- When the woman you love has advanced breast cancer (cassette)
- Information for the adolescents of women with breast cancer (cassette in production).

NOTE: A full catalogue of resources on breast health and breast cancer is updated regularly and is available from the National Breast Cancer Centre on request.

State or territory cancer organisations will have other resources about treatment options, radiotherapy, chemotherapy, prosthesis, lymphoedema and post-surgery exercises.

- The Beacon is the newsletter of the Breast Cancer Network Australia and can be obtained by writing to Lyn Swinburne PO Box 4082, Auburn South, Victoria, 3123.

Resources for clinicians

The resources listed below are available from the National Breast Cancer Centre.

Guidelines and recommendations

- NHMRC Clinical practice guidelines for the management of early breast cancer
- Current best advice about familial aspects of breast cancer: a guide for general practitioners (card)
• The investigation of a new breast symptom: a guide for general practitioners (card)

• The management of early breast cancer for GPs: action based on evidence (card)

• National best practice guidelines for familial cancer clinics


• Clinical practice guidelines for the management of advanced breast cancer, (Draft).

Numerous research and data reviews, reports and discussion papers are also available from the National Breast Cancer Centre on topics such as Aboriginal and Torres Strait Islander women, women from linguistically or culturally diverse backgrounds, cultural attitudes to breast cancer, satisfaction with breast cancer care, genetic testing and clinical trials.

For women and clinicians
The following books may be available in local bookshops or libraries:


A complete list of Australian resources about breast cancer can be found in the Catalogue of Resources on Breast Health and Breast Cancer. Part 1: Australian Resources. Woolloomooloo, NSW: National Breast Cancer Centre, 1996. This catalogue is an annual publication and can be found in public libraries.

The internet also has a lot of information about breast cancer. A good place to start searching the internet is through the National Breast Cancer Centre website. Through the National Breast Cancer Centre website, information from Australia and throughout the world can be accessed. The address for this is www.nbcc.org.au

Contacts
To learn more about breast cancer and the services and support available to a woman and her family, the following contacts may be helpful:

Nationally
National Breast Cancer Centre
PO Box 572, Kings Cross NSW 1340
(02) 9334 1700
Cancer Information Service
The CIS provides general information as well as information on local resources. This service can be accessed from anywhere in Australia for the cost of a local call, connecting to local cancer organisations.
13 11 20 (1300 361 366 in Queensland)

Breast Cancer Support Service (BCSS)
This service extends practical and one-to-one social support to women diagnosed with breast cancer. BCSS support workers are themselves breast cancer survivors who are matched to the woman according to relevant social and treatment characteristics.
13 11 20 (1300 361 366 in Queensland)

BreastScreen Australia
BreastScreen Australia is a Commonwealth initiative supported by all state and territory governments. It aims to detect breast cancer at an early stage in women age 50 years and over. Some BreastScreen centres have designated counsellors available. Information on local BreastScreen services can be accessed from anywhere in Australia for the cost of a local call, 13 20 50

State and territory cancer organisations and associated numbers
State and territory Cancer Councils provide information and educational resources on all types of cancers. Some have lending libraries. Many cancer organisations also have developed their own publications about cancer and treatments. To find out about breast cancer support groups and other local services, state or territory cancer organisations and the Cancer Information Service should be contacted.

Australian Capital Territory Cancer Society
159 Maribyrnong Avenue
Kaleen ACT 2617
(02) 6262 2222

Anti-Cancer Council of Victoria
1 Rathdowne St
Carlton South VIC 3053
(03) 9279 1111
Can-Help: 13 11 20

Anti-Cancer Foundation of South Australia
202 Greenhill Rd
Eastwood SA 5063
(08) 8291 4111
www.acf.org.au

Cancer Help Line
1800 188 070 (toll free outside Adelaide)
Cancer Council of Tasmania
13 Liverpool Street
Hobart TAS 7000
(03) 6233 2030

Cancer Foundation of Western Australia
334 Rokeby Rd
Subiaco WA 6008
(08) 9381 4515

Cancer Council of the Northern Territory
Casi House
23 Vanderlin Dr
Casuarina NT 0810
(08) 8927 4888
1800 678 123 (toll free outside Darwin)

NSW Cancer Council
153 Dowling St
Woolloomooloo NSW 2011
(02) 9334 1900
www.nswcc.org.au

Cancer Information Service
13 11 20
1800 422 760 (toll free outside Sydney)
TTY (02) 9334 1865

Queensland Cancer Fund
553 Gregory Terrace
Fortitude Valley QLD 4006
(07) 3258 2200

Cancer Information Network
1300 361 366 (toll free outside Brisbane)
Other breast cancer services for women

Breast Cancer Network Australia
Breast Cancer Network Australia (BCNA) is the national umbrella group which links individual women with breast cancer and support and advocacy groups around Australia. The BCNA also publishes a free, quarterly newsletter, The Beacon, which details and discusses issues, information and resources for women with breast cancer. There is a BCNA representative in every state and territory, who can be contacted through:

Lyn Swinburne
PO Box 4082
Auburn South, Vic 3122
Ph (03) 9660 6865
Fax (03) 9662 3861
Email bcan@bigpond.com
www.users.bigpond.com/bcan

Breast Cancer Action Group (ACT)
Contact: Anna Wellings Booth
3 Belah Street
O’Connor ACT 2602
Ph (02) 6247 8470
Email wbfamily@interact.net.au

Breast Cancer Action Group (VIC)
Contact: Sue Lockwood
PO Box 281,
Fairfield VIC 3078
Ph (03) 9878 0736
Fax (03) 9894 4411
Email bcan@bigpond.com

Breast Cancer Action Group (NSW)
Contact: Sally Crossing,
Ph (02) 9436 1755
Email crossings@bigpond.com

Action for Breast Cancer South Australia
Contact: Carlene Butavicius
11 Lanor Avenue
Millswood SA 5034
Ph (08) 8272 2895
Email butavic@chariot.net.au
NT Breast Cancer Voice
Contact: Susan Tully
GPO Box 3987, Darwin NT 0801
Ph (08) 8927 3327
Email tullynt@msn.com.au

Breast Cancer Action Group (QLD)
Contact: Leonie Young/Janelle Gamble
PO Box 53
Aspley QLD 4034
Ph (07) 3353 4151 (Janelle Gamble business hours)
Ph (07) 3341 7570 (Leonie Young after hours)
Email medusa_998@yahoo.com

Breast Cancer Action Group (WA)
Contact: Carol Bishop
Ph (08) 9381 2070
Fax (08) 9382 3348

Cancer Foundation
334 Rokeby Road
Subiaco WA 6008
Email carol@cancerwa.asn.au

Breast Cancer Action Group (TAS)
Contact: Pat Mathew
51 Macphee Street
Devonport TAS 7310
Ph (03) 6423 3637
Email mathewp@southcom.com.au

Lymphoedema associations and support groups
These groups provide information on lymphoedema, local services and resources and support. Some states and territories also have regional and special interest support groups. Contact numbers are available from the state or territory lymphoedema organisations.

The Australian Lymphology Association
C/- Beverley Mirolo
Wesley Clinic
1st Floor Wesley Medical centre
40 Chasely Street
Auchenflower QLD 4066

ACT Lymphoedema Support Group
66 Bindaga Street
Aranda 2614
Ph (02) 6251 1294
Darwin Lymphoedema Support Group
PO Box 4127
Casuarina 0811
Ph (08) 8927 4888
Fax (08) 8927 4990

Lymphoedema Support Group of NSW
79 Beechworth Rd
Pymble 2073
Ph (02) 9402 5625

Lymphoedema Support Group of SA
PO Box 1006
Kent Town 5071
Ph (08) 8204 4711

Tasmanian Lymphoedema Support Group
C/- 42 Stanley Street
Bellerive Hobart TAS 7018
Ph (03) 6244 4634

Lymphoedema Association of Victoria
3 Murray Drive
Point Leo 3916
Ph (03) 9801 7547

Lymphoedema Association of Western Australia
PO Box 2037
Claremont North WA 6010
Ph 0500 576 000

Lymphoedema Association of Queensland
PO Box 68
Bracken Ridge QLD 4017
Ph (07) 3269 4376
Fax (07) 3269 1498
APPENDIX F: FINANCIAL ASSISTANCE FOR TRAVEL AND ACCOMMODATION

Women travelling to the city for treatment may be eligible for a government scheme to provide financial assistance for travel and accommodation expenses. However, many women are unaware of their eligibility for this support. This scheme has a different name in each state and territory:

- ACT Interstate Patient’s Travel Assistance Scheme (IPTAS)
- NSW Isolated Patients’ Travel and Accommodation Assistance Scheme (IPTAAS)
- NT Patient Assistance Travel Scheme (PATS)
- QLD Patient Transfer Assistance Scheme (PTAS)
- SA Patient Assistance Transport Scheme (PATS)
- TAS Patient Travel Assistance Program (PTAP)
- VIC Victorian Patient Transport Assistance Scheme (VPTAS)
- WA Patients Assisted Travel Scheme (PATS)

Women should be advised that they may need to claim in advance in some states. In some states, support is available for family members, and some states also have patient accommodation available through the cancer organisations or hospitals at reduced costs. A list of available resources can be attained from each state and territory cancer organisation or local hospital.
G L O S S A R Y

Alopecia
Hair loss. It is usually partial, although it can be complete. Full recovery usually occurs fairly quickly when its cause has been chemotherapy.

Anti-emetic medication
Used to prevent or relieve nausea and vomiting.

Anticipatory concern
Anxiety or worry regarding a possible future event.

Aromatherapy
Therapy using the extracted essence of flowers to improve mood and increase well being.

Axillary dissection
Surgery to remove fat and lymph nodes from the armpit. It can be done either at the same time as breast surgery or as a separate operation. It can be partial or complete.

Body image
A person’s conception of and feelings about her/his body—its form, size, shape and the way it fits society’s norms. Self-esteem and sexuality are linked with body image.

Breast-conserving surgery
Surgery in which the cancer is removed, together with a margin of normal breast tissue. The whole breast is not removed.

Breast reconstruction
The formation of a breast shape after a total mastectomy.

Breastcare centres
Clinical services that specialise in the care of patients with breast disease.

Chemotherapy medication
Drugs used to kill cancer cells, or prevent or slow their growth.

Chemotherapy induced nausea
Nausea which arises as a consequence of the drugs used in chemotherapy treatments.
Chronic illness
Illness of slow onset and long, continued duration.

Cognitive-behavioural interventions
Interventions which use methods focused on changing specific thoughts or behaviours, or on learning specific coping skills. Included in this category are progressive muscle relaxation training, meditation, hypnotherapy, systematic desensitisation, biofeedback, behaviour modification or reinforcement.

Cognitively-oriented intervention
Interventions which focus on changing specific thoughts.

Community-based domiciliary palliative care
Care provided by a multi-disciplinary team in the patient’s home during the latter phase of the woman’s life and extending to bereavement care for her family.

Complementary therapies
A range of approaches to care provision aimed at enhancement of quality of life, including physiotherapy, music, art, massage, aroma, and dietary therapies, and other wellness or socialisation programs.

Conflict resolution
A technique of resolving conflict between two or more people which involves all parties expressing their needs and wants, and brainstorming possible solutions to meet everyone’s needs.

Continuity of care
Maintenance of knowledge about the patient and family through consistency of care provision.

Coping
A measure of a person’s ability to deal with the stress of daily life and unusual challenges posed by chronic disease, disability, and pain.

Coping skills training
A program that teaches a range of strategies used to enhance adjustment.

Coping style
A particular pattern of thoughts, feelings and behaviours which a person adopts in response to their illness.
Counselling
A generic form of supportive care delivered by all healthcare providers. There are differing levels of sophistication depending on the training and experience of the practitioner involved.

Depression
A pervasive and sustained lowering of mood. When used clinically, it is a cluster of symptoms, or syndrome, whose other features include tearfulness, guilt, irritability, loss of interest in life, loss of energy, poor concentration, poor sleep and loss of appetite.

Disease-related symptoms
Symptoms which arise as a consequence of the illness rather than the treatment.

Dysfunctional attitude
A belief or thought which is based on an irrational premise, and which can lead to an unnecessary increase in distress.

Early stage cancer
Cancer which has not spread from the original site, and which is not very large.

Eclectic psychological therapy
Selecting and combining different types of psychological therapies which are considered to be best for particular purposes.

Educational and informational intervention
Interventions primarily providing sensory, procedural, medical information or coping information.

Emotional adjustment
A person’s emotional response to the illness, treatment and coping strategies. This includes mood state, fear and anxiety, depression, denial or repression, self-esteem, sense of control, satisfaction with medical care, other attitudes, personality traits, and any other type of emotion or distress.

Empathy
The realisation and understanding of another person’s feelings, needs, and suffering.

Epidemiology
Study of the patterns of distribution and causation.
Existential therapy
Therapy which addresses problems of being or being-in-the-world. The patient’s relationship to the world of things, to other people, and to her own internal world of consciousness is explored. The goal of therapy is to facilitate a transformation in the meaning and values of life, and to assist the person to find a new model of being, thus freeing themselves from former ways of being. Emphasis is on the present and the future, not on the past.

Family therapy
Treatment of the members of a family together, rather than an individual “patient”; the family unit is viewed as a social system important to all of its members.

Genetic counselling
Guidance about risks of inherited disease.

Group therapy
Any form of collective therapeutic treatment. Frequently the process involves group meetings of patients with a therapist who acts as leader.

Guided imagery
A technique in which a person uses their imagination to picture a desired state with the goal of bringing that state into reality.

Hormone therapy
The use of drugs or hormones which specifically inhibit the growth of hormone responsive cancer cells.

Informed consent
Competent and voluntary permission for a medical procedure, test or medication. The consent is given based on understanding the nature, risks, and alternatives of the procedure or test.

Lymphoedema
Lymphoedema may be a side effect of breast cancer treatment, experienced by some women, that results in chronic and [often] debilitating arm swelling. The cause of lymphoedema is the destruction of the lymphatic vessels during the removal of the nodes under the arm, or during radiation therapy to that area after surgery. (Smith, 1998 American Cancer Society Lymphoedema Workshop)

Medical model of treatment
Approach to care usually involving doctor and nurse but without complete consideration of social, psychological, cultural and spiritual aspects.
Meta-analysis
A statistical technique used to aggregate research on a particular issue so that a global outcome is identified without the vagrancies of an individual study.

Metastatic disease
Cancer which has spread to a site distant from the original site.

Mood
A pervasive and sustained emotion that may have a major influence on a person’s perception of the world. Examples of mood include depression, anger, anxiety, joy and elation.

Morbidity
The outcome or consequence of a process or treatment.

Multidisciplinary team
A team of health providers from a number of different disciplines. These might include general practitioners, surgeons, radiation oncologists, medical oncologists, nursing staff, psychiatrists, psychologists, social workers, physiotherapists, members of the clergy, pharmacists, occupational therapists and palliative care specialists.

Music therapy
The use of music to enhance quality of life and sometimes to alleviate pain.

Oncologist
A doctor who specialises in treating cancer.

Oncology
The study of the biology and physical and chemical features of cancers. Also the study of the cause and treatment of cancers.

Palliative care
Treatment directed at alleviating symptoms due to the disease, without prospect of cure.

Paraesthesiae
An abnormal sensation, such as prickling or itching.

Patient or peer support groups
Groups composed of people with similar problems or illnesses. The absence of a formally trained, professional leader is a common characteristic of these groups.
Pharmacological treatments
Treatments involving the administration of drugs to alleviate symptoms, for example, of depression and anxiety.

Probabilistic
Likelihood of something happening.

Problem solving
A technique which involves developing a sequence of alternatives leading to a goal or solution.

Professionally-led groups
Therapeutic or educational groups which are facilitated by a professional leader who is formally trained in the form of therapy, or who is regarded as having expert knowledge in cancer and/or specific treatments.

Progressive or advanced cancer
Cancer which is spreading beyond the original site, and which is not being controlled by treatments.

Psychiatric disorders
Illnesses classified within the discipline of mental disorders.

Psychodynamic
Pertaining to the branch of psychology which understands developmental processes that influence current happenings.

Psychoeducational programs
Programs with both psychological (eg supportive group therapy) and educational (eg coping skills training, stress management, education about disease and treatment) components.

Psychosexual difficulties
Sexual difficulties in the broadest sense, including both physical, mental and emotional aspects.

Psychosocial intervention
Treatment which is intended to address psychological, social and some spiritual needs.

Psychosocial support
The culturally-sensitive provision of psychological, social and spiritual care.
Quality of life
An individual’s overall appraisal of their situation and subjective sense of well being. Quality of life encompasses symptoms of disease, side effects of treatment, relationships, how well you get on at work and play, and how you cope with daily life.

Radiotherapy
The use of radiation beams to kill tumour cells.

Randomised controlled trial
A trial which is conducted using subjects who have been selected in such a way that all known selective or biasing factors have been eliminated, and which compares an experimental group with another group of subjects, equal in all respects, who do not undergo the treatment being trialled.

Recurrence
Return of disease after an initial response to treatment.

Reframing
Altering a particular way of thinking about something in order to see from a different perspective.

Relaxation therapy
A form of therapy in which emphasis is put on teaching the patient how to relax, on the assumption that muscular relaxation will help bring about a lessening of psychological tensions.

Self-esteem
One’s personal evaluation or view of self, generally thought to influence feelings and behaviours.

Self-help groups
Groups in which volunteers or fellow patients provide support to each other. See peer support groups.

Social functioning
Patient’s ability to function in a social environment.

Specialist breast nurse
A specially trained nurse who works as a member of the multidisciplinary team, giving specialist advice, education and support to women with breast cancer and their families.
Specialist providers
In the context of psychosocial cancer care this includes specialised psycho-oncology units, professional counsellors (including psychologists and psychiatrists) and breast cancer support services.

Support network
A collection of people known to the patient, usually family members and friends, who are recognised as able to provide emotional, psychological, and practical care to the patient.

Supportive psychotherapy
Professionally-based counselling that includes psychodynamic, existential, supportive-expressive, grief and crisis therapies. It includes family, group and individual therapies but excludes interventions with a significant cognitive-behavioural component.

Supportive-expressive therapy
A form of therapy in which the therapist encourages the expression of the patient's feelings about her situation, and provides support and encouragement.

Survivors
A term used to refer to patients who have undergone treatment for their cancer and are deemed to be free of cancer.

Systematic desensitisation
A technique in which the patient imagines a hierarchy of anxiety-producing situations under conditions of physical relaxation with the goal of weakening the anxiety responses.

Time-limited groups
A group which has a pre-determined end-point. This may vary from a few weeks to several months or even years. It is contrasted from an open-ended group format, which has no stated end-point at its conception.

Trait anxiety
Anxiety which is characteristic of an individual as opposed to arising in response to a particular experience.

Treatment modality
A specific type of treatment. Examples of different treatment modalities include radiation therapy, chemotherapy and psychological therapy.
Treatment team
Generic health professionals who are directly involved in the provision of medical treatment to the patient. This includes general practitioners, surgeons, medical and radiation oncologists, and the specialist nursing and allied health staff involved in surgery, radiotherapy, and chemotherapy. It also includes the medical staff directly involved in the less common breast cancer treatments such as blood transfusions, reconstructive surgery, treatment for lymphoedema, etc.

Treatment-related symptoms
Symptoms which arise as a consequence of a particular treatment, rather than from the disease itself.

Volunteer programs
Many cancer organisations train volunteers, who are often former cancer patients, to provide support for patients. This might involve telephone contact, hospital or home visits, and include advice giving, sharing of resources, and general support.
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Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer


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INDEX

adjustment 2, 8, 12, 25, 26, 34-36, 57

anxiety
prevalence vii, ix, 1, 36
identification 28, 37-42
post-traumatic stress disorder 36
treatments/therapies 6, 36, 37, 43-44
see also psychological concerns, treatments/interventions for psychological problems

body image 1, 28-30, 36
Breast Cancer Support Service 26-27
children- see family, fertility issues
clinical trials 21-22
clinician see treatment team
complementary therapies 23, 27
see also treatments/interventions for psychological problems, palliative care, quality of life
contact details
cancer organisations 81-82
other services for women 82-85
continuity of care 6, 11, 52-55
interdisciplinary communication 53-54
identifying the co-ordinator of care 52-53
patient held records 6, 55
coping 2, 10, 24, 25, 57-58
counselling see treatments/interventions for psychological problems, referring for psychological treatments
cultural diversity and needs vii, 1, 47-52, 75-76
using interpreters 48, 50, 75-76
providing culturally appropriate information 48-49, 50
support issues 49-51
community links 50-51
awareness of cultural sensitivities 49-51
Multicultural Breast Cancer Information Service (MBCIS) 77
depression
prevalence vii, ix, 1, 38
Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer

identification 28,37-42
suicidal thoughts 39
treatment/therapies 6,36,43,45
see also psychological concerns, treatments/interventions for psychological problems

diagnosis
  discussing 9-11
  emotional and supportive role 10-11
  impact on family 57
  impact on women 1-2,9,17
  recurrence 1-2,9-11
  women's preference for information ix,10-11

distress see anxiety, depression psychological concerns

distress see anxiety, depression psychological concerns

evidence see Psychosocial Guidelines

family
  26,57-58
  xi,25,1,57-58
  impact on partner/children
  role changes 1,25
  support needs 46,58
  support services 58

fertility and childbearing 30-31

financial issues see practical needs

glossary 89-97

information see general interactional skills, diagnosis, treatment, continuity of care

informed consent 17,21

interactional skills
  general skills 5,7,13-16,17-19
  see also diagnosis, prognosis, treatment

interpersonal issues 31
  see also family

local resources 3,72

mood disorder see anxiety, depression, psychological concerns

palliative care 55-59
  existential/spiritual issues 57
physical issues 56,59
psychological issues 1,56
social issues 55-56
referral to
see also family

partner see family

physical symptoms 32-34,36,56
fatigue 33
lymphoedema 33-34,46,84-85
nausea & vomiting 32-33
pain 33,56

practical needs xiii, ix, 1,20,45-47
costs of treatments/procedures 45-46
prostheses 45-46
occupational concerns xiii,1,46,56
tavel and accommodation 46,87
other needs 46-47

procedures see treatments

prognosis 5,12-16
discussing prognosis 5,12-16
emotional and supportive role 13
impact on women 14
women's preference for information 12-13,35
see also treatment ix,13

psychiatric disorders see anxiety, depression, psychological concerns

psychological care 17,28-45

psychological concerns 1,25,28-45,55-56
cognitive problems 34
emotional disturbances 17,23,34-45,56
identifying psychological problems 28,39,40-41,42
prevalence of 1,2
risk factors 39,40
stress and adjustment problems 35
see also anxiety, depression

psychosocial guidelines ix,2,4,65-74
aims vii,3,65-66
consultation process 68-71
dissemination/ implementation 71-72
evaluation plan 73
evidence 4,5-6,67-68
<table>
<thead>
<tr>
<th><strong>NBCC Psychosocial Working Group</strong></th>
<th>vii,61-63</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>target audience</strong></td>
<td>3,65</td>
</tr>
</tbody>
</table>

**quality of life** 2, 3,33,34,40,55-57

**recurrence** see diagnosis, treatments and procedures

**references** 99-116

**referring for assessment/treatment of psychological problems** 30,31,32, 37,39,41-43

**resources and services**

- **constraints** 3,72
- **for clinicians** 75-76,79-85
- **for women** 79-85,87

**screening for psychological problems** see psychological concerns, anxiety, depression

**sexuality** 31

**specialist breast nurse** 3,6,8,9,18,23,25,47,53,73

**supportive role**

- **benefits of** 2,25-27
- **treatment team** 2,6,13-14,22,23,25-26
- **specialist providers** 6,26,27,43
- **peer support groups** 26-27
- **family and friends** 25-27

**see also practical needs**

**treatments and procedures**

- **discussing options** 12-15,17-22
- **impact on women** 1,8,23,35,28-35
- **treatment decision making** vii, 13-14,18,19-22
- **preparing women for procedures** ix,6,23-24
- **side effects** 1,23,55
- **women’s preferences for information** vii,xi,17-19

**see also anxiety, depression, referring for psychological treatments, physical symptoms**

**treatments/interventions for psychological problems** ix,2,6,25, 27,29,33,43-45

- **cognitive-behavioural therapy** 2,29
- **family therapy** 27
- **psycho-education** 2,29
- **medications** 33,37,43-45
- **supportive therapies** 2,26,27,29
- **types of therapies** 27,29,36

**see also referring for psychological treatments**

---

120 **Psychosocial clinical practice guidelines; providing information, support and counselling for women with breast cancer**
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