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**NATIONAL BREAST
CANCER CENTRE**

Incorporating the
Ovarian Cancer Program

Clinical practice guidelines for the management and support of younger women with breast cancer



Australian Government

National Health and Medical Research Council

Clinical practice guidelines for the
management and support of
younger women with breast cancer

Prepared by the
National Breast Cancer Centre
Funded by the Department of Health and Ageing
A National Health Priority Initiative

Approved by the NHMRC
on 27 November 2003



Australian Government
National Health and Medical Research Council

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These guidelines were approved by the National Health and Medical Research Council at its 150th Session on 27 November 2003, under section 14A of the National Health and Medical Research Council Act 1992. Approval by NHMRC is granted for a period not exceeding five years, at which date the approval expires. The NHMRC expects that all guidelines will be reviewed no less than once every five years. Readers should check with the National Breast Cancer Centre for any reviews or updates of these guidelines.

The strategic intent of the NHMRC is to provide leadership and work with other relevant organisations to improve the health of all Australians by:

- fostering and supporting a high quality and internationally recognised research base;
- providing evidence based advice;
- applying research evidence to health issues thus translating research into better health practice and outcomes; and
- promoting informed debate on health and medical research, health ethics and related issues.

This document is a general guide to appropriate practice, to be followed subject to the clinician's judgement and the patient's preference in each individual case.

The guidelines are designed to provide information to assist decision-making and are based on the best evidence available at the time of publication.

This is the first edition of the *Clinical practice guidelines for the management and support of younger women with breast cancer*.

It is planned to review this Clinical Practice Guideline by 2009. For further information regarding the status of this document, please refer to the NHMRC web address: <http://www.nhmrc.gov.au>

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FOREWORD

The diagnosis of breast cancer is a blow to any woman and her family. However, for younger women in particular the impact is profound - making treatment decisions which impact on body image and sexuality, assessing the possibility of precipitation of premature menopause and enforced infertility, all underscored by the big question: "Can I beat it?"

These guidelines represent a breakthrough for younger women with breast cancer, who have long felt that their particular needs, both emotional and physical, have not been fully addressed.

In a clear and concise format, Level I evidence is presented about the enhanced survival benefit of chemotherapy in younger women, and of hormone therapy. In addition, evidence is presented outlining the reduced local recurrence for younger women who undergo boost radiotherapy. Although these treatments might come at a cost, for example by resulting in induced menopause, recommendations are made about ways in which morbidity related to this might be reduced. Furthermore, clinicians are assisted by being informed of the greater desire of younger women for active participation in decision making, and of recommendations about the promotion of wellness post-treatment.

Underpinning these guidelines is explicit information and about the emotional impact of breast cancer for younger women, and about evidence-based strategies to appropriately respond.

The implementation of these guidelines into routine clinical practice has the potential to powerfully improve outcomes for younger women with breast cancer, and I am confident they will be received with enthusiasm by health professionals and women alike.



Dr Jane Turner

Chair, Improving Care for Younger Women Working Group

LIST OF ABBREVIATIONS

ACT	Australian Capital Territory
BCAG	Breast Cancer Action Group
BCNA	Breast Cancer Network Australia
BRCA	breast cancer gene
CLE	complete local excision
CMF	cyclophosphamide, methotrexate and 5-fluorouracil
CT	computed tomography
DCIS	ductal carcinoma in situ
EIC	extensive intraductal carcinoma
ER	oestrogen receptor
FNAB	fine needle aspiration biopsy
FNB	fine needle biopsy
GnRH	gonadotropin-releasing hormone
'the guidelines'	<i>Clinical practice guidelines for the management and support of younger women with breast cancer</i> (this document)
HRT	hormone replacement therapy
IBCSG	International Breast Cancer Study Group
IBIS	International Breast Intervention Study
IVF	in vitro fertilisation
LHRH	luteinizing hormone-releasing hormone
MRI	magnetic resonance imaging
NBCC	National Breast Cancer Centre
NHMRC	National Health and Medical Research Council
NSW	New South Wales
NT	Northern Territory
PET	positron emission tomography
QLD	Queensland
SA	South Australia
TAS	Tasmania
TIS	Translating and Interpreting Service
TNM	tumour, nodes and metastases - classification
VIC	Victoria
WA	Western Australia

INTRODUCTION

Objective and scope of the guidelines

Approximately 6% of new breast cancer cases diagnosed in Australia each year are in women aged 40 years or younger. Although incidence is lower in younger women compared with their older counterparts, younger women are more likely to be diagnosed with larger, more aggressive tumours, and have worse disease-free and overall survival outcomes. Younger women are also more likely to experience psychological distress following diagnosis.

The National Breast Cancer Centre (NBCC) has produced a range of guidelines for the diagnosis and management of women with breast cancer, including:

- *Clinical practice guidelines for the management of early breast cancer*
- *Clinical practice guidelines for the management of advanced cancer*
- *Psychosocial clinical practice guidelines: information, support and counselling for women with breast cancer*
- *The investigation of a new breast symptom: a guide for general practitioners*
- *Breast imaging: a guide for practice*
- *Advice about familial aspects of breast cancer and ovarian cancer: a guide for health professionals*

The *Clinical practice guidelines for the management and support of younger women with breast cancer* ('the guidelines') have been developed to complement existing guidelines. The guidelines focus on issues that are specific to the age and/or life stage of younger women, and aim to assist younger women and their doctors in making decisions about all aspects of breast cancer care.

(Note: For the purposes of this document, younger women are defined as women aged 40 years or younger at breast cancer diagnosis, unless otherwise indicated. Section 1.1 contains more information about defining 'young' in the context of breast cancer. However, it should be recognised that many issues that are relevant to the clinical management and support of these women may also be pertinent for women of other age groups, depending on their life stage.)

This document contains recommendations for practice and is not intended to be a textbook. Clinicians seeking further information about the biology and natural history of breast cancer should consult the relevant texts. The guidelines are

neither rigid procedural paths, nor prescriptive; they aim to provide clinicians with information on which to base decisions. The guidelines will be incorporated into future revisions of clinical practice guidelines produced by the NBCC.

Development of these guidelines

The guidelines were developed by a multidisciplinary working group established by the NBCC. The working group comprised consumers and representatives from surgery, psychiatry, medical and radiation oncology, nursing, psychology, and cancer support services (see Appendix A).

The process employed to develop the guidelines is described in Appendix B.

Target audience

These guidelines were developed for use by all members of the multidisciplinary team involved in the management of women with breast cancer, which may include surgeons, radiation oncologists, medical oncologists, pathologists, radiologists, general practitioners, nurses, psychologists and social workers.

Structure of the guidelines

Guidelines are boxed throughout the text and are summarised at the beginning under 'Summary of Guidelines'. All guidelines are evidence-based and the level of evidence is clearly denoted. In addition to the guidelines, there are bullet-pointed **key points** to draw the attention of the reader to other issues of importance. Some of these key points are based on evidence derived from studies with lower levels of evidence, while others refer to areas for which there is no 'hard' evidence but which are important to the provision of care according to consensus opinion. Guidelines and key points are dispersed throughout the document with supporting and explanatory text, and are intended to be read in the order in which they are presented.

Levels of evidence ratings

A four-level rating system has been used to enable the reader to identify the strength of the evidence base for guidelines and key points. This rating system is recommended by the National Health and Medical Research Council in the

1999 publication *A guide to the development, implementation and evaluation of clinical practice guidelines*, and is as follows:

- Level I** Evidence is obtained from a systematic review of all relevant randomised controlled trials.
- Level II** Evidence is obtained from at least one properly designed randomised controlled trial.
- Level III-1** Evidence is obtained from well designed pseudo-randomised controlled trials (alternate allocation or some other method).
- Level III-2** Evidence is obtained from comparative studies with concurrent controls and allocation not randomised (cohort studies).
- Level III-3** Evidence is obtained from comparative studies with historical control, two or more single-arm studies, or interrupted time without a parallel group.
- Level IV** Evidence is obtained from case series, either post-test or pre-test and post-test.

The guidelines are based on reviews of the best available evidence. Level I evidence represents the gold standard for intervention studies; however, it is not available for all areas of practice and for some guidelines the working group considered it appropriate to utilise results from studies with lower levels of evidence. The guidelines have also been informed by expert groups.

Information for consumers

The NBCC has developed two consumer booklets: A guide for women with early breast cancer and A guide for women with metastatic breast cancer. These booklets are based on existing clinical practice guidelines for the management of early and advanced breast cancer respectively. The guides include discussion of breast cancer treatments, treatment side effects, breast reconstruction, coping with feelings, accessing psychosocial and practical support, the impact of treatment on fertility, and complementary and alternative therapies. Information in these guides that is specific to younger women will be promoted as an integral part of a media strategy at the time that these guidelines are disseminated.

SUMMARY OF GUIDELINES

Guideline	Level of evidence	Reference number
<p>Younger age has been associated with physician delay in referral for investigation of breast symptoms. For this reason, young women presenting with breast symptoms should be evaluated by means of the triple test approach to exclude or establish a diagnosis of cancer.</p>	III-2	34
<p>Assessment of emotional concerns of younger women at diagnosis of breast cancer ensures early identification of distress so that appropriate interventions can be offered.</p>	III-2	44
<p>Radiotherapy after breast conserving surgery is recommended as it significantly reduces the risk of local recurrence. For younger women, treatment with radiotherapy should also include a boost of radiation to the tumour bed, which further halves the local recurrence rate.</p>	II	79, 80
<p>Clinicians should advise younger women that the benefit of chemotherapy is greater the younger the woman's age. Chemotherapy will reduce the risk of recurrence by about one-fifth in women aged 60 to 69 years, but by nearly two-fifths in women under the age of 40.</p>	I	115
<p>Younger women with hormone receptor positive tumours should be advised that disease-free survival is significantly better when chemotherapy disrupts ovarian function, whether temporarily or permanently.</p>	III-2	119
<p>Endocrine therapy is recommended for all women aged 35 years or younger who have hormone receptor positive tumours, irrespective of whether or not they receive chemotherapy.</p>	I	15

Guideline	Level of evidence	Reference number
Combined endocrine treatment (LHRH agonist plus tamoxifen) is superior to LHRH agonist treatment alone in premenopausal women with advanced breast cancer in terms of length of survival.	I	123
Younger women should be advised about the relative effectiveness and safety of different treatments for menopausal symptoms resulting from chemotherapy or endocrine therapy.	II	187-192
Induced ovarian failure is an outcome of chemotherapy treatment for some younger women, resulting in infertility and onset of menopausal symptoms. Clinicians should openly discuss fertility before treatment, and outline the probability of menopause based on the woman's age and treatment regimen. Women who wish to consider childbearing after treatment should be offered referral to a specialist with expertise in fertility treatment <i>prior to the commencement of treatment</i> .	II	200, 201
Premenopausal women should be informed that their decision to have a child subsequent to a breast cancer diagnosis will not, as far as current evidence indicates, alter their risk of recurrence or overall survival.	III-2	223-225
Younger women, and indeed those of all ages, should be informed that moderate exercise has the potential to reduce fatigue and improve emotional wellbeing, even during radiotherapy or chemotherapy.	II	267, 268

CHAPTER 1. BREAST CANCER IN YOUNG WOMEN

1.1 DEFINING 'YOUNG'

Key point

There is no accepted definition of 'young' as it applies in the context of breast cancer. For the purposes of these guidelines, younger women are defined as women aged 40 years or less at breast cancer diagnosis, unless otherwise indicated. However, it should be recognised that many issues that are relevant to the clinical management and support of these women may also be pertinent for women of other age groups, depending on their life stage.

There are varied age classifications used for 'younger' and 'older' in the literature. For example, in clinical trials participants are often classified according to menopausal status: 'younger' women are premenopausal and/or aged less than 50 years, and 'older' women are post-menopausal and/or aged 50 years or older.¹ Many pathological studies report specific results pertaining to women aged 35 years or less; these studies suggest that disease factors appear to be different for this age group compared with older women.² A range of age classifications is also employed in the psychosocial literature. Studies variously define 'younger' as less than 60 years,³ less than 50 years,^{4,6} less than 45 years,⁷ or less than 40 years.⁸ Other researchers have avoided using chronological age, instead relying on defining indicators such as having young children, not having reached menopause, and being of child-bearing age.⁹

1.2 BREAST CANCER INCIDENCE IN YOUNGER WOMEN

Key point

In 1999 there were 10,592 new cases of breast cancer diagnosed in women in Australia. Of these, 684 cases (approximately 6%) were in women aged younger than 40 years, while 1,967 cases (approximately 19%) were in women aged between 40 and 49 years (see Table 1).¹⁰

The risk of developing breast cancer increases with age. Over the four-year period between 1992 and 1996, Australian women aged less than 30 years had a 1 in 2,298 risk of developing breast cancer, women aged 30 to 39 years had a risk of 1 in 244, and those aged 40 to 49 had a 1 in 67 risk.¹¹

Over the ten-year period between 1986 and 1996 there was a rise of 7% in the breast cancer incidence rate for women aged 15 to 39 years.¹¹ Although breast cancer incidence is lower in younger women, the years of life lost in this age group is proportionately greater due to their longer life expectancy.

1.3 DISEASE CHARACTERISTICS AND MORTALITY IN YOUNGER WOMEN

In 1999, 89 Australian women aged younger than 40 years and 347 women aged between 40 and 49 years died from breast cancer (see Table 1). Over the four-year period between 1992 and 1996, the risk of death from breast cancer was 1 in 27,517 for women aged less than 30 years, 1 in 1,317 for women aged 30 to 39 years, and 1 in 366 for women aged 40 to 49 years.¹¹ Breast cancer mortality for younger women remained relatively stable over the ten-year period between 1986 and 1996.¹¹

Table 1: Breast cancer incidence, mortality and disease characteristics by age group (data from 1999, 2001 - see references)

	Age group					
	< 30	30-39	40-49	50-59	60-69	70+
Incidence (% of total) ¹⁰	0.6	5.9	18.6	26.3	21.9	26.7
5-year relative survival (%) ¹²	72.4 †	79.8	85.8	85.7	86.1	*
Mortality (% of total) ¹⁰	0.2	3.3	13.8	20.5	19.1	43.0
Cancer size ^{**} (% per age group) ¹³						
0-10 mm	12.9	21.4	20.3	26.4	26.3	18.9
11-19 mm	29.0	35.2	34.1	36.7	37.3	34.8
20-29 mm	25.8	23.3	25.6	20.1	21.6	25.3
30+ mm	32.3	20.2	19.9	16.7	14.8	21.0
Nodal status (% per age group) ¹³						
Positive	38.2	40.0	38.0	32.2	27.2	20.9
Negative	38.2	42.2	45.3	51.9	51.0	36.5
Unknown	23.5	17.9	16.7	15.9	21.8	42.5

† Proportion reported for women aged 20 to 29 years

* Unavailable

** Excludes cases where size was not measured or information was not available

Key point

Epidemiological studies suggest that younger women with breast cancer have worse disease-free and overall survival outcomes.¹⁴⁻¹⁹ Evidence about whether independent predictors of disease-free and overall survival outcomes are similar across various age groups is inconclusive. However, positive nodes and tumour size appear to be important independent discriminators across all ages (see Table 1).

Breast cancers in younger women have a different distribution of pathological features. While there are some inconsistent findings across studies, overall there appears to be an increased incidence of several features that have been shown to predict adverse outcomes. These include larger tumour size, more positive nodes, negative steroid hormone receptors and higher histological grade.^{20,21} Poorer outcomes for younger women could be partly due to differences in these prognostic factors. There is little published population-based research to clarify the impact of young age on disease outcome; however, two well conducted studies have concluded that young age is an adverse predictor of disease outcome in certain subgroups. A Danish study found that although age was an independent predictor of outcome, the negative effect of young age was almost exclusively seen in women classified as having low-risk disease who did not receive adjuvant therapy.¹⁷ A report from the International Breast Cancer Study Group (IBCSG)¹⁵ provided data about 3,700 pre- or perimenopausal women with early stage breast cancer who received adjuvant chemotherapy in successive randomised trials between 1978 and 1993. Women aged younger than 35 had significantly shorter disease-free survival than older women and, among the younger women, positive oestrogen receptor status was associated with a particularly high risk of recurrence, possibly related to the absence of treatment with endocrine therapy.

2. PRE-DIAGNOSIS

2.1 RISK FACTORS

Key point

The causes of breast cancer are not fully understood. Ageing, genetic factors and environmental influences all appear to play a part,²² although the effects of some of these risk factors may be different for younger and older women.^{23,24} For younger women, a strong family history of breast cancer is one of the most important risk factors.²³ However, most young women who develop breast cancer do not have a family history of the disease.

Other factors that may be associated with increased breast cancer risk for younger women include: a history of proliferative benign breast disease; nulliparity, low parity, or late age at first full-term pregnancy; and short duration of breastfeeding or never having lactated.²⁴ Current or recent use of combined oral contraceptives is associated with a slightly increased risk of breast cancer, but there is no evidence of excess breast cancer risk 10 or more years after cessation of oral contraceptive use.²⁵ A link between induced abortion and breast cancer risk has been hypothesised, but the results of a large, population-based study suggest that induced abortions have no overall effect on the risk of breast cancer, regardless of age.²⁶

Family history

A history of breast and/or ovarian cancer in one or more first-degree relatives may be the strongest risk factor for younger women,²³ particularly if the affected relative was younger than 50 years at diagnosis.²⁷ In one Australian case-control study of women aged younger than 40, 12% of women with breast cancer compared with 5% of controls reported a history of the disease in a first-degree relative of any age.²³ Family history taking should include both the maternal and paternal sides of a family.

Several genes are associated with a high risk of breast or ovarian cancer. It is estimated that between 1% and 5% of all breast and ovarian cancers involve the inheritance of a mutated gene.²⁸ In younger women, the proportion of breast and ovarian cancers believed to involve an inherited mutated gene is higher.²⁹ International data from samples of women not selected for family history

suggest the prevalence of a BRCA1 mutation in women diagnosed with breast cancer before age 35 is approximately 6-11%.²⁹⁻³¹

Key point

If a woman with a family history of breast cancer wishes to clarify her genetic risk or that of her family, health professionals should discuss referral to specialist genetic services for advice, appropriate counselling and management. For more information, refer to *Advice about familial aspects of breast cancer and ovarian cancer: A guide for health professionals*.²⁸

In some circumstances, women with a very strong family history, or who are found by genetic testing to have inherited a mutated copy of a high-risk gene, may wish to explore possibilities for reducing their risk of developing breast cancer, such as prophylactic mastectomy and/or prophylactic bilateral salpingo-oophorectomy. Women who are at significantly increased risk of developing breast cancer should be referred for appropriate counselling before any therapeutic decisions are made.

Women with a family history of breast cancer may experience significant levels of distress. One study of women who had one or more first-degree relatives with breast cancer found that 27% of these women had a level of psychological distress consistent with the need for counselling.³² The *Psychosocial clinical practice guidelines* provide examples of questions health professionals can use to screen women who may be experiencing psychological distress.³³

See also Section 4.2 for more information about genetic testing after diagnosis.

2.2 DETECTION AND DIAGNOSIS

Guideline	Level of evidence	Reference number
Younger age has been associated with physician delay in referral for investigation of breast symptoms. For this reason, young women presenting with breast symptoms should be evaluated by means of the triple test approach to exclude or establish a diagnosis of cancer.	III-2	34

Most breast cancers in younger women are diagnosed as a result of the investigation of a lump or other breast symptom;³⁵ these symptoms are most often self- or partner-detected.^{36,37} While some younger women may delay in presenting with breast symptoms, evidence suggests that physician delay in referral for assessment is a key factor in delaying diagnosis.^{34,38,39} A systematic review of five studies about delayed presentation of symptomatic breast cancer reported an association between younger age and physician delay in referral in four studies involving a total of 5,146 women.⁴⁰ This may be attributable to the belief that a woman is 'too young to have breast cancer', as incidence in this population is low and breast changes in young women are common.

It is recommended that the triple test approach is used in investigating breast symptoms. The components of the triple test are clinical breast examination and medical history; breast imaging (mammography, ultrasound, or both); and non-excision biopsy (fine needle aspiration biopsy, core biopsy, or both).⁴¹ While the correct sequencing of tests is important to the overall interpretation of the results, not all breast symptoms will require investigation using all three tests. Most breast symptoms are physiological and are adequately assessed by thorough clinical breast examination with or without imaging.

Key point

As the sensitivity for mammography is lower at younger ages, ultrasound examination is recommended as the first-line imaging test for symptomatic women younger than 35 years and for women who are pregnant or lactating; however, both imaging modalities may be used as part of the triple test to provide complementary information.⁴²

If there is any suspicion of cancer on clinical examination or ultrasound, a mammogram should be performed and, in many instances, ultrasound and mammography are both used to provide complementary information. Any clinical or imaging abnormality should be further investigated with percutaneous biopsy tests. For more information, refer to *The investigation of a new breast symptom: a guide for General Practitioners*⁴³ and *Breast imaging: a guide for practice*⁴².

3. DIAGNOSIS

3.1 PSYCHOLOGICAL IMPACT OF DIAGNOSIS

Key point

Younger women appear to experience greater emotional distress than older women when diagnosed with primary breast cancer.⁴⁴

Traumatic imagery, such as intrusive thoughts about breast cancer, is more common in younger women.⁴⁵ Issues of particular concern to younger women include shock and distress at the untimeliness of the diagnosis, a sense of being different and isolated, guilt about the impact on partners, concerns for children,⁴⁶ and a sense of being a different person with different priorities.⁴⁷ Limited evidence suggests that younger women will also experience greater emotional distress when diagnosed with a recurrence,⁴⁸ as this raises fear about the future and the possibility of dying.

Guideline	Level of evidence	Reference number
Assessment of emotional concerns of younger women at diagnosis of breast cancer ensures early identification of distress so that appropriate interventions can be offered.	III-2	44

4. BEFORE DEFINITIVE TREATMENT

4.1 TREATMENT PREFERENCES AND DECISION MAKING

Key point

Many younger women prefer active involvement in treatment decision making; this is particularly the case for women with a higher level of education.⁴⁹

Clinicians should offer detailed information about treatment options and seek women's preferences.

A diagnosis of breast cancer prompts concerns about the future and survival, and fear of death and dying.⁵⁰⁻⁵² Consideration of the needs of children and family is important for young women, and there is some evidence to suggest that women with dependants may be more willing to assume risks in treatments for even small potential increases in life expectancy.⁵³ Other important issues of concern may include fertility,⁵⁴ body image,^{55,56} career and finances.⁴⁷ These issues should be identified and addressed by clinicians when providing information and discussing treatment options.

Women appear more likely to perceive greater participation in and control over decision making when clinicians encourage and facilitate their involvement.⁴⁹

4.2 GENETIC TESTING AFTER DIAGNOSIS

Following a diagnosis of breast cancer, some younger women may be concerned about the risk of breast cancer developing in their close family members, such as their mother, sisters or daughters. It is important for these women to discuss their concerns with a health professional, who may recommend referral to a specialist family cancer clinic if appropriate.

Family cancer clinics provide a service for people with a family history of cancer and their health professionals and can give an estimate of the likelihood of a woman carrying an inherited mutation in a cancer predisposing gene. Although it is now technically possible to test for mutations in some cancer predisposing genes, genetic testing is an appropriate option for only a small proportion of individuals, usually those with a strong family history of breast and/or ovarian cancer.

Genetic testing is offered only with pre- and post-test counselling to discuss the limitations of testing, plus the advantages and disadvantages of being tested, both for the woman and her family. Should a mutation be found, predictive genetic testing may be offered to unaffected adult family members (both male and female) who may also be at risk of carrying the same mutation. Women who test positive for a mutation in BRCA1 or BRCA2 are also at increased risk of developing a second primary breast cancer or ovarian cancer, and should be referred to a cancer specialist for discussion about management options.

4.3 MULTIDISCIPLINARY CARE

Key point

A multidisciplinary approach provides optimal therapy for all women with breast cancer. The disciplines represented by the core team should minimally include surgery, radiation and medical oncology, pathology, radiology and supportive care; the woman's general practitioner should also be part of the team. In treating younger women, the team may be expanded to include other health professionals such as a plastic surgeon, fertility expert, psychologist and/or psychiatrist.

Survival outcomes for patients with breast and other cancers are better if they are treated by a clinician who has access to the full range of treatment options in a multidisciplinary setting (Level III).⁵⁷ As for older women, the surgeon is usually the specialist clinician of first contact in the management of a younger woman with breast cancer. The need for a younger woman to have pre-operative consultations with a radiation oncologist and/or a medical oncologist will depend on the planning discussions held by the multidisciplinary team. Pre-operative consultation with a radiation oncologist should be considered if radiotherapy is thought to be likely.

The timing of a consultation between a younger woman and a medical oncologist should be assessed on a case-by-case basis. It is pertinent for health professionals to consider pre-operative consultation with a medical oncologist and/or gynaecologist if a woman is concerned about fertility issues (see Section 7 for more information about infertility following treatment). However, as the need for systemic therapy is usually determined by the histology of the tumour

and regional lymph nodes, it may be reasonable to involve a medical oncologist in treatment planning at a later stage.

It is pertinent for members of the multidisciplinary team to inform younger women about support services specifically catering to their needs, such as younger women's support groups. Individual women will require a varying degree of support, ranging from practical advice about obtaining breast prostheses after mastectomy to professional counselling if they are emotionally or psychologically distressed.

4.4 CLINICAL TRIALS

Key point

Australian research indicates that younger women are more likely than older women to be informed about, and offered the opportunity to participate in, clinical trials.⁵⁸

Clinical trials are an essential component of the process of finding better treatments for breast cancer, and it is appropriate for clinicians to discuss participation in clinical trials with women. Evidence suggests that women who participate in clinical trials have better survival outcomes than women given similar treatment outside trials (Level III).⁵⁹ A high participation rate will enable outstanding research questions to be answered more quickly. Information about trials for which younger women may be eligible is available from the Australian New Zealand Breast Cancer Trials Group (www.anzbctg.org) and the NHMRC Clinical Trials Centre (www.ctc.usyd.edu.au).

5. LOCAL THERAPY

5.1 IMPACT OF MASTECTOMY AND BREAST CONSERVING TREATMENT ON DISEASE OUTCOME

There have been no randomised trials designed to determine whether younger women are at increased risk of local recurrence following breast surgery compared with their older counterparts. Disease outcomes for younger women have primarily been determined by analysing data for those younger women who have participated in large trials examining risk factors for recurrence. The number of young women in these studies has been relatively small, and the comparison of results across studies has been impeded by the use of differing age classifications.

Mastectomy vs breast conservation

Key point

There are inadequate data about optimal local treatment in the very young, particularly in light of the competing increased systemic risks. Limited evidence suggests that age younger than 35 years is associated with increased risk of recurrence after breast conserving treatment, and also possibly following mastectomy. When discussing options for local therapy, clinicians should offer information about risk of recurrence based on the woman's age and disease factors. Ultimately, all treatment decisions should rest with the woman.

Although some conflicting evidence exists,^{60,61} several studies have reported an independent association between very young age (less than 35 years) and increases in local recurrence after breast conserving treatment.⁶²⁻⁶⁷ Breast cancers in younger women also carry a higher incidence of risk factors implicated in local recurrence, particularly high-grade, vascular invasion and extensive intraductal carcinoma (EIC),^{64,68-72} although the effect of EIC on local recurrence has been shown by some to be offset by obtaining clear excision margins.⁷³

Precise recurrence rates are uncertain due to the small numbers of younger women in any of these series, and differences between studies in age categories, tumour stage and grade, length of follow-up time, and statistical methods. Studies suggest the risk of recurrence for young women is approximately

12-30% per cent over a five- to 10-year period.^{64,68,74-76} Increased risk of recurrence appears to be highest for women under 30 years,⁶⁷ and rapidly declines over age 35.⁷² There are similar higher rates of distant relapse in the very young age group.

High-grade tumours and vascular invasion are also implicated in increased risk of local recurrence after mastectomy, making such a choice no real advantage in terms of local control.⁷² Age younger than 35 years features as a risk factor for local recurrence after mastectomy too, and for some there will be a benefit for post-mastectomy radiotherapy.⁷⁷ While one analysis has shown a survival advantage for mastectomy over breast conserving treatment for patients less than 35 years,⁷² other data have not shown any survival advantage for more radical surgery.^{64,76,78}

Guideline	Level of evidence	Reference number
Radiotherapy after breast conserving surgery is recommended as it significantly reduces the risk of local recurrence. For younger women, treatment with radiotherapy should also include a boost of radiation to the tumour bed, which further halves the local recurrence rate.	II	79,80

Radiotherapy

Evidence indicates that some of the increases in breast recurrences after conservative treatment are offset by delivering adequate doses of radiotherapy which includes a boost to the tumour bed. Two randomised trials have shown the importance of a radiotherapy boost, particularly in younger women where it has been shown to reduce the local recurrence rate from around 20% to 10% at five years post-treatment.^{79,80} Optimal systemic therapy is also advised for its additional effect on reducing local recurrence rates (see Section 6).^{81,82}

5.2 TIMING OF SURGERY

For premenopausal women, the effect of timing of surgery in relation to the menstrual cycle is unclear. Evidence suggests that the timing of surgical resection may be relevant to outcome, with a possible advantage to the early luteal phase (approximately days 14 to 20 of the menstrual cycle).^{83,84} However, this association is inconsistent, and available data are inadequate to provide a recommendation about timing of surgery.

5.3 BREAST RECONSTRUCTION

Key point

Younger women are more likely than older women to opt for breast reconstruction following mastectomy.^{58,85-89} Women should be provided with detailed information about immediate and delayed breast reconstruction options *before treatment commences* so they have the opportunity to consider the procedure adequately and make informed decisions.

A range of options for breast reconstruction are available, and should be explained by relevant members of the multidisciplinary team before any final decisions about surgery and radiotherapy are made. Referral to a plastic surgeon may be appropriate.

5.4 SHORT- AND LONG-TERM SIDE EFFECTS AND COMPLICATIONS OF LOCAL THERAPY

Arm morbidity

Key point

There are conflicting results about a relationship between age and arm morbidity following local therapy. Younger women may report more arm symptoms than older women because these symptoms have a greater impact upon their functioning.^{90,91} It is pertinent for health professionals to ask about arm symptoms and refer women appropriately for treatment.

Arm symptoms may include pain, discomfort, oedema, loss of strength, impaired range of motion and numbness.⁹² While recent research suggests that younger women are more likely than older women to report experiencing pain⁹³ and numbness of the arm⁹² following axillary dissection, other studies have reported an association between upper limb pain and older age.⁹⁴ In one study, women aged younger than 45 years experienced more problems doing household chores than older women following axillary lymph node dissection.⁹² Younger women and women who are engaged in paid employment have been shown to report more arm symptoms than older or non-employed women at three and 12 months following axillary dissection.⁹⁰

For more information about arm morbidity following surgery, refer to the *Clinical practice guidelines for the management of early breast cancer*.²⁸

Lymphoedema

Key point

There is no evidence to confirm age as a risk factor in the development of lymphoedema.⁹⁵

Following axillary dissection and/or irradiation a woman may experience lymphoedema of the arm. Lymphoedema can occur at any stage, even years after treatment, and can have a significant impact on both physical and psychosocial wellbeing. The predisposing factors to the development of lymphoedema remain poorly understood. Several studies have investigated age as a risk factor and while some have reported a positive association between lymphoedema risk and older age, others have found no association.⁹⁵

Lymphoedema may be more prevalent in overweight or obese women, although evidence to support this association is also inconsistent.⁹⁵ Although sentinel node biopsy has been shown to be an accurate predictor of axillary node metastasis in women with small breast cancer⁹⁶, the outcomes of clinical trials investigating mortality and morbidity in the long term are unknown. In Australia a clinical trial is currently under way to determine if sentinel node biopsy can avoid the need for axillary dissection in some women and reduce the risk of lymphoedema (Sentinel Node Axillary Clearance [SNAC] trial).

Treatment of lymphoedema requires input from medical practitioners and allied health professionals such as physiotherapists. For information about prevention and management refer to the *Clinical practice guidelines for the management of early breast cancer*.²⁸

Effect on lactation

Key point

It is unlikely that lactation will be possible from the radiotherapy treated breast.

The effect of radiotherapy on lactation is dose dependent, and the chance of lactating from the irradiated breast after the recommended 50 Gray is likely to be very low. Women who are able to lactate may produce insufficient milk from the treated breast,⁹⁷ although the contralateral breast is likely to enlarge and sufficient milk may be produced to allow a baby to be fully breastfed. There are no data to make a recommendation about feeding from the treated breast should milk be produced.

5.5 PSYCHOSOCIAL ASPECTS OF LOCAL THERAPY

Mastectomy and breast conserving treatment

Key point

Younger women appear to experience more concerns about body image,⁹⁸ greater emotional distress^{99,100} and poorer adjustment¹⁰⁰ following breast surgery than older women.

There is little evidence to suggest a substantial difference in post-operative psychological morbidity according to type of surgery.¹⁰¹ However, some research suggests that younger women experience greater distress following mastectomy than breast conserving surgery.¹⁰² Women who undergo breast conserving surgery are also more likely to report better body image than those who have a mastectomy.¹⁰³ Breast conserving surgery provides an opportunity to preserve the breast shape, facilitates a better fit of clothing, and usually avoids the need for a prosthesis or reconstructive surgery. Evidence that younger women are generally more likely to select breast conserving surgery over mastectomy^{87,101,104} suggests that concern for body image is an important consideration.

Several studies have reported that, for many young women, fear of cancer and recurrence are prevalent following surgery.⁵⁰⁻⁵² Women may also experience sexual difficulties,^{105,106} such as a reluctance to resume sexual relations, loss of libido, or feelings of sexual unattractiveness.¹⁰⁷ The *Psychosocial clinical practice guidelines* outline a range of interventions that are effective in reducing distress and promoting the adjustment of women with breast cancer.³³

Breast reconstruction

Key point

Women report a number of benefits following reconstruction, including more positive body image,¹⁰⁸ more positive partner attitudes,^{109,110} feeling more comfortable without a prosthesis,¹¹⁰ feeling 'whole' again, and thinking less about cancer.^{111,112}

There has been little systematic research about age and reconstruction. One exception is a recent study that examined age-related patient satisfaction and psychosocial morbidity following surgery. Among women aged younger than 40 years, those who had breast conserving surgery or reconstruction were less likely to feel sexually unattractive or anxious, and reported more positive body image, than those who had a mastectomy alone.¹¹³ In one small randomised trial involving 64 women aged younger than 60 years, women who received breast reconstruction had lower rates of psychological distress in the short term and improved body image at three and 12 months post-surgery compared with controls.¹¹⁴

6. SYSTEMIC THERAPY

6.1 IMPACT OF CHEMOTHERAPY AND ENDOCRINE THERAPY ON DISEASE OUTCOME

Where there remains a significant risk of distant relapse following local therapy, systemic therapy is frequently given in order to reduce this risk. At present, such adjuvant systemic therapy consists of various cytotoxic chemotherapy regimens and endocrine measures, such as tamoxifen and ovarian suppression.

Many clinical trials have been carried out to determine the extent to which giving chemotherapy, or endocrine therapy or both may reduce the risk of recurrence. Five-yearly systematic review and meta-analysis of these trials show that these treatments are effective, although endocrine treatments are only effective where the tumour expresses hormone receptors.^{1,115,116} The greater the risk of cancer recurrence, the greater the potential benefit from adjuvant therapies. For hormone receptor positive cancers, chemotherapy combined with endocrine therapy is better than either treatment alone.

Key point

Discussions between younger women and clinicians about systemic treatments should include consideration of the individual woman's underlying risk of recurrence, her treatment preference and the associated toxicities of treatment.

Chemotherapy

Key point

Women aged younger than 35 years have a particularly high risk of recurrence and should strongly consider treatment with chemotherapy.¹¹⁷

Guideline	Level of evidence	Reference number
Clinicians should advise younger women that the benefit of chemotherapy is greater the younger the woman's age. Chemotherapy will reduce the risk of recurrence by about one-fifth in women aged 60 to 69 years, but by nearly two-fifths in women under the age of 40.	I	115

The risk of recurrence never completely goes away. Clinical trials show that women aged younger than 50 years who had chemotherapy have lower rates of recurrence than those who did not, even 10 years after treatment.¹¹⁵ While a younger woman has a potentially long time at risk of recurrence, she also has a long time to accrue the benefit of adjuvant chemotherapy.

The risk of recurrence depends on a number of factors, but an average effect of chemotherapy in women less than 50 years old would be to improve 10-year disease-free survival from 80% to 87% (small node negative tumour) or from 55% to 70% (small node positive tumour).¹¹⁸

Guideline	Level of evidence	Reference number
Younger women with hormone receptor positive tumours should be advised that disease-free survival is significantly better when chemotherapy disrupts ovarian function, whether temporarily or permanently.	III-2	119

Endocrine therapy

Guideline	Level of evidence	Reference number
Endocrine therapy is recommended for all women aged 35 years or younger who have hormone receptor positive tumours, irrespective of whether or not they receive chemotherapy.	I	15

Combined data from four randomised trials involving 314 women aged less than 35 years indicate that women with hormone receptor positive tumours who did not have endocrine therapy after their chemotherapy had significantly worse disease-free survival than women with hormone receptor negative tumours.¹⁵

For premenopausal women with hormone receptor positive cancers, endocrine therapy currently comprises tamoxifen, ovarian suppression or both. Ovarian suppression can be achieved through surgical, radiotherapeutic or chemical means, which should be discussed with the woman as appropriate. Ovarian ablation by surgery or irradiation has been shown to improve long-term survival

in women aged younger than 50 years, particularly in the absence of chemotherapy.¹ Luteinizing hormone-releasing hormone (LHRH) agonists such as goserelin are effective in suppressing ovarian function chemically; this effect is potentially reversible following cessation of treatment.¹²⁰ More is known about tamoxifen, which significantly improves recurrence-free and overall survival in women of all age groups and is recommended for most women with oestrogen receptor positive tumours (Level D).¹¹⁶

Key point

Treatment with tamoxifen for five years reduces the risk of disease recurrence by up to half in premenopausal women with oestrogen receptor positive cancers.¹¹⁶ This relative reduction in risk will be translated into different absolute benefits depending on individual patient factors.

Ongoing clinical trials are examining whether treatment with tamoxifen for more than five years is beneficial. An average effect of tamoxifen alone in women less than 50 years old would be to improve 10-year disease-free survival from 80% to 85% (small node negative tumour) or from 55% to 65% (small node positive tumour).¹¹⁸

Ovarian suppression may have similar effects. Indeed, in two recently published trials temporary ovarian suppression with goserelin for two years was found to be as effective for disease-free survival as chemotherapy,¹²¹ and ovarian suppression plus tamoxifen was more effective than chemotherapy.¹²²

Chemotherapy or endocrine therapy?

However, it is important to note that the merits of chemotherapy compared with endocrine therapy for younger women are still being assessed. Trials to date have compared chemotherapy alone with endocrine therapy alone. Trials should now be designed to compare chemotherapy *followed by tamoxifen* with endocrine therapy alone. The current standard of care for women with hormone receptor positive tumours is treatment with both chemotherapy and endocrine therapy; however, some younger women with very good prognosis may decide to have endocrine therapy alone. Trials to determine the impact on disease outcome of chemotherapy plus endocrine therapy are continuing.

6.2 IMPACT OF SYSTEMIC TREATMENT FOR ADVANCED DISEASE

Guideline	Level of evidence	Reference number
Combined endocrine treatment (LHRH agonist plus tamoxifen) is superior to LHRH agonist treatment alone in premenopausal women with advanced breast cancer in terms of length of survival.	I	123

While metastatic disease is not curable, treatment can have a beneficial impact on length and quality of life.¹²⁴ Chemotherapy and endocrine therapy are often effective, and local therapies such as palliative radiotherapy may be very useful.¹²⁵ Ovarian suppression can be an effective treatment for those younger women with endocrine responsive cancers and retained ovarian function. The LHRH agonist goserelin is effective in suppressing ovarian function in premenopausal women with metastatic breast cancer, and is as beneficial as ovariectomy (oophorectomy) or ovarian irradiation in improving progression-free and overall survival.^{126,127} The combination of LHRH agonist and tamoxifen is even more effective in premenopausal women, and significantly prolongs survival compared with LHRH agonist treatment alone.¹²³

6.3 SHORT- AND LONG-TERM SIDE EFFECTS AND COMPLICATIONS

Key point

Women should be fully informed about the benefits and potential short- and long-term side effects of adjuvant therapy.

Timely discussion about benefits of treatment and all potential side effects will assist younger women to make informed treatment choices. The provision of information about treatment and treatment side effects in combination with emotional support can improve emotional and physical wellbeing for people with cancer.¹²⁸ Group-based information sessions that address issues such as the side effects of chemotherapy, body image, relationships and sexuality can also improve coping and adjustment to breast cancer,¹²⁹ even up to three years after diagnosis (Level II).¹³⁰

Chemotherapy

Despite the side effects and inconvenience of chemotherapy, studies of women who have received chemotherapy for breast cancer suggest that the majority consider it to be worthwhile even when only small improvements in survival are expected.¹³¹⁻¹³⁴ Women with dependent children, social support and milder side effects judge smaller benefits to be worthwhile.⁵³

Nausea, vomiting, alopecia (hair loss) and tiredness are the direct side effects most frequently associated with chemotherapy.¹³⁵ Newer anti-emetics have reduced the severity of nausea and vomiting.^{136,137} Temporary alopecia sufficient to require a wig is common with anthracyclines,¹³⁸ and less common in women having cyclophosphamide, methotrexate and 5-fluorouracil (CMF).¹³⁹ Alopecia may be very distressing for a woman and her family, as it is a highly visible reminder of the cancer for which she is being treated. Although hair usually grows back within three months of completing treatment, it may have a different texture and be curlier than before.

There are conflicting data about the relationship between patient age and the experience of treatment-related fatigue. A review of the literature suggests that age is unrelated to the experience of fatigue during treatment for breast cancer, but that younger women may report higher fatigue levels after treatment.¹⁴⁰

There is emerging evidence that exercise can effectively reduce the experience and intensity of fatigue in breast cancer survivors.^{141,142}

Bone loss

Key point

Premenopausal women who develop amenorrhoea following treatment are at increased risk of rapid bone loss, which may increase the subsequent risk of osteoporotic bone fractures or osteoporosis.¹⁴³ There is evidence from a number of randomised controlled trials that the oral bisphosphonates clodronate and risedronate are effective in reducing bone loss (Level II).¹⁴⁴⁻¹⁴⁶

In advanced breast cancer, early bisphosphonate use is recommended for patients with bone metastases for its role in reducing both bone symptoms and progression of bone disease. In early stage disease, the use of bisphosphonates to improve general bone health is unclear and currently under clinical trial investigation internationally. While tamoxifen may protect bone density in older

women, some evidence suggests that it may be associated with increased bone loss in premenopausal women.¹⁴⁷ The implementation of a surveillance program to monitor changes in bone density is appropriate.

Cognitive changes

Key point

Current evidence about the experience and duration of cognitive change following chemotherapy treatment is inconclusive. There are no data indicating whether younger or older women may be at higher risk of developing cognitive problems.

Chemotherapy has been associated with cognitive impairment,¹⁴⁸ although subjective concerns about cognition are not consistently reflected in abnormal neuropsychological testing. Cognitive differences between treatment and control groups do not appear to be accounted for by age, mood or educational level.¹⁴⁹ Limited evidence suggests that high-dose chemotherapy is associated with greater cognitive impairment compared with standard-dose chemotherapy,¹⁵⁰ although high-dose chemotherapy is currently not supported as standard therapy. More data are required before clear recommendations can be made about the impact of chemotherapy on cognition.

Weight gain

Key point

Premenopausal women appear particularly vulnerable to experiencing weight gain during and following treatment for breast cancer,¹⁵¹ which may be a source of distress. Evidence suggests that preventive interventions incorporating physical activity may help women reduce body fat and/or weight gain.¹⁵²⁻¹⁵⁴

The risk of weight gain appears higher in women who become menopausal during the first year after treatment,¹⁵⁵ and for those who have longer duration of chemotherapy treatment.¹⁵⁶ In one small study two-thirds of women experienced a significant weight gain in the year following treatment, and two-fifths of these women had maintained this weight gain three years after treatment.¹⁵¹ The precise mechanism for this weight gain is unclear; increased dietary intake does not appear to be a major contributor, although reduced physical activity¹⁵⁷ or metabolic changes¹⁵⁸ may contribute.

Several small studies have examined preventive approaches. The results of these studies suggest that participation in aerobic exercise programs over two to three months can reduce weight gain¹⁵³ and promote loss of body fat.¹⁵⁴ Group-based multidisciplinary programs including nutritional advice, psychosocial support and physical activity may also assist women in maintaining normal weight or losing excess weight.¹⁵² Additional benefits of exercise participation after the completion of treatment may include enhanced perceptions of physical condition and reduced concern about weight.¹⁵⁹

Please refer to Section 7 for more information about treatment-induced amenorrhoea and menopause.

Endocrine therapy

Key point

For most women, the protective effect of tamoxifen against the recurrence of breast cancer will vastly outweigh the increased risk of side effects (Level II).¹⁶⁰⁻¹⁶³

Women should be informed of the potential side effects of tamoxifen, including endometrial cancer, stroke, pulmonary embolism and deep vein thrombosis; however, these rare side effects are mainly seen in post-menopausal women and annual risks for younger women are significantly less than one per 1,000.¹⁶⁴

In a large placebo-controlled trial of tamoxifen (for breast cancer prevention), the most frequently reported side effects of treatment were hot flushes, night sweats, vaginal discharge, pain during intercourse, and cold sweats.¹⁶⁵ Recent results from the International Breast Intervention Study (IBIS-I) indicate no differences between women receiving tamoxifen and a placebo regarding the experience of headaches, fractures, eye changes, cerebrovascular effects or cardiac problems (Level II).¹⁶⁴ Although there is a perception that tamoxifen is associated with weight gain, observation of women taking tamoxifen over three to five years failed to demonstrate a difference in weight gain compared with those not taking tamoxifen.¹⁶⁶ A minority of women will experience side effects that are severe enough to prompt discontinuation of treatment. Data from the National Surgical Adjuvant Breast and Bowel Project P-1 study indicate similar rates of treatment cessation among women receiving tamoxifen (24%) and those treated with a placebo (20%).¹⁶¹

For younger women not receiving chemotherapy, some endocrine treatments have been shown to impact on sexual functioning. In one small trial involving 149 premenopausal women who had not received chemotherapy, treatment with the LHRH agonist goserelin was associated with the experience of more intense menopausal symptoms that appeared more quickly, compared with tamoxifen.¹⁶⁷ With the exception of hot flushes and sweating, the side effects of goserelin were less severe when taken in combination with tamoxifen.¹⁶⁷ An adverse effect of goserelin on sexual functioning and sexual frequency in younger women has also been documented in a recent prospective study, although this effect did appear to be reversible following cessation of treatment.¹⁶⁸ The addition of chemotherapy to endocrine treatment does not appear to exacerbate sexual dysfunction.¹⁶⁸

6.4 PSYCHOSOCIAL ASPECTS OF SYSTEMIC ADJUVANT THERAPY

Key point

Younger women who have received chemotherapy are more likely than older women to experience poorer adjustment and show more symptoms of depression up to three years post-treatment.¹⁶⁹

Younger women may be more anxious before the first chemotherapy treatment, and the experience of side effects following the first infusion is associated with increased anxiety before the second treatment.¹⁷⁰ Chemotherapy also appears to be associated with adverse quality of life,^{52,171} and several studies have documented poor sexual adjustment among younger women following treatment with chemotherapy.^{3,168,172-174} Although conflicting evidence exists,¹⁷⁵ some studies have reported that sexual difficulties or discomfort may persist for some years after treatment.^{176,177}

Evidence about the impact of tamoxifen on a woman's level of emotional distress is inconclusive.¹⁷⁸ However, the majority of studies to date have failed to find an association between tamoxifen and the development of depression or psychological morbidity.^{165,179}

A range of support interventions and psychological therapies are available to assist women who are experiencing emotional difficulties. For more detailed information, refer to the *Psychosocial clinical practice guidelines*.³³

7. OVARIAN FUNCTION AND HORMONAL ISSUES

7.1 TREATMENT-INDUCED AMENORRHOEA/MENOPAUSE

Key point

Temporary or permanent amenorrhoea can be a direct result of chemotherapy. The likelihood of developing amenorrhoea depends on the woman's age¹⁸⁰ and the type, dose and duration of chemotherapy.¹⁸¹ For women with hormone receptor positive breast cancers, temporary or permanent disruption of ovarian function is associated with improved survival.¹¹⁹

The onset of amenorrhoea adds to the effectiveness of the chemotherapy in the case of hormone receptor positive tumours, while in hormone receptor negative tumours amenorrhoea is an unwanted effect. For younger women, ovarian suppression may be a deliberate strategy to treat hormone receptor positive breast cancers, and can be achieved reversibly with LHRH agonists.¹⁸²

The average likelihood of amenorrhoea reported for CMF-type regimens is 68%.¹⁸³ Anthracycline-based regimens appear to be associated with a lower incidence of amenorrhoea, although data are limited. One study reported a 34% rate of amenorrhoea following treatment with doxorubicin and cyclophosphamide (AC).¹⁸³ Treatment with tamoxifen alone is associated with a smaller risk of developing amenorrhoea (around 13%) compared with treatment with chemotherapy alone or in combination with tamoxifen (around 84%).¹⁸⁰ For women treated with chemotherapy alone, the risk of developing amenorrhoea increases with age, rising sharply from the age of 35 (less than 20%), with subsequent risks estimated at approximately 40% at 40 years, around 70% at 45 years and over 90% by 50 years.¹⁸⁰

7.2 MENOPAUSAL SYMPTOMS

Younger women who have menopausal symptoms due to chemotherapy or endocrine therapy can experience the diverse range in severity of symptoms that occurs in natural menopause, including hot flushes, vaginal dryness, and sleep disturbance.¹⁸⁴ While data from retrospective studies suggest that the use of hormone replacement therapy (HRT) for menopausal symptoms may not impact on disease recurrence or life expectancy for women with a prior breast cancer diagnosis,¹⁸⁵ the safety of HRT use in women who have had breast cancer remains uncertain and alternatives to HRT should be considered.¹⁸⁶

Guideline	Level of evidence	Reference number
Younger women should be advised about the relative effectiveness and safety of different treatments for menopausal symptoms resulting from chemotherapy or endocrine therapy.	II	187-192

Severe hot flushes can be very disabling, and a number of treatments for hot flushes have been tested in placebo-controlled double blind randomised trials.¹⁹³ These trials indicate that clonidine¹⁸⁸ and vitamin E¹⁸⁷ do not appear to be very effective, and while the progestin megestrol acetate reduces hot flushes by about 80% compared with placebo, there remain some concerns about safety in relation to breast cancer recurrence.¹⁹⁰ The anti-depressants fluoxetine and venlafaxine have been found to impact positively on women’s experience of hot flushes, reducing their frequency and/or severity (reflected in a composite score) by up to 50%¹⁹¹ and 61%¹⁸⁹ respectively. Although the potential of such anti-depressants to lower libido¹⁹⁴ will influence treatment, this side effect appears to be dose-related.¹⁹⁵ Soy products (phyto-oestrogens) do not appear to be effective in reducing hot flushes,¹⁹² and there is also some uncertainty about the safety of these products for women with breast cancer.¹⁹⁶

There has been little research to date about the treatment of vaginal dryness and/or dyspareunia (painful intercourse) in women with breast cancer. Limited evidence suggests that both polycarbophil-based and water-soluble topical lubrication agents may be useful in reducing dryness.¹⁹⁷ Oestrogen-based vaginal

creams or tablets may also be effective,^{198,199} although the safety of these treatments for women with a prior breast cancer diagnosis has not been established.

7.3 FERTILITY

Guideline	Level of evidence	Reference number
<p>Induced ovarian failure is an outcome of chemotherapy treatment for some younger women, resulting in infertility and onset of menopausal symptoms. Clinicians should openly discuss fertility before treatment, and outline the probability of menopause based on the woman’s age and treatment regimen. Women who wish to consider child-bearing after treatment should be offered referral to a specialist with expertise in fertility treatment <i>prior to the commencement of treatment.</i></p>	<p>II</p>	<p>200,201</p>

The experience of cancer does not change the family planning aspirations of most young survivors,⁵⁴ so induced infertility has strong potential to cause distress. Concerns about fertility following treatment for breast cancer are common, and younger women require information about ways of maintaining fertility. Evidence suggests that many women do not currently receive such information: only 57% of participants in one retrospective study recalled receiving fertility-related information from their physician.⁵⁴

Currently female cancer patients have limited options for fertility preservation if chemotherapy is required. One possibility for those treated with chemotherapy is the addition of gonadotropin-releasing hormone (GnRH) agonists (such as LHRH agonists), which may be effective in preserving ovarian function in some women.²⁰² However to date the effects of GnRH agonists in combination with chemotherapy have been evaluated in only a small number of studies with few patients, and larger controlled trials are warranted. Another option for preserving fertility is in vitro fertilisation (IVF) with a stored embryo or donated

egg. Cryopreservation (freezing) of eggs or ovarian tissue is still at the experimental stage. There have been no recorded pregnancies with frozen ovarian tissue to date, and only a very small number of successful pregnancies from frozen eggs have been reported.^{203,204}

7.4 PREGNANCY

There are methodological problems inherent in research about the effect of pregnancy on breast cancer outcomes. Most data are derived from studies with retrospective designs, small sample sizes and the inability to control for factors such as the self-selection of women with good prognoses.

Diagnosis and outcome of breast cancer diagnosed during pregnancy or lactation

Key point

Women who are pregnant at diagnosis may have larger tumours²⁰⁵ and are at higher risk of presenting with advanced disease.^{206,207}

Breast masses that occur during pregnancy or lactation should be assessed as for non-pregnant or non-lactating women. As increased breast density during pregnancy can increase the rate of false negative diagnoses from mammography, ultrasound is the most useful imaging modality.⁴² Fine needle aspiration and core biopsy can be performed safely during the first or second trimesters of pregnancy, or during lactation,²⁰⁸ although fine needle aspiration has a slightly higher risk of false positive interpretation for pregnant or lactating women.^{209,210} Milk fistulas can be a complication if excisional biopsy is undertaken, but the risk of infection and fistula is reduced if lactation is suppressed or stopped prior to surgery.²⁰⁷

There are conflicting reports about breast cancer outcomes in women who are pregnant at diagnosis, with some finding no survival disadvantage²¹¹⁻²¹³ and others reporting an association between pregnancy and worse prognosis independent of other prognostic factors.^{214,215} One retrospective study of women aged 30 or younger at diagnosis compared outcomes for 22 women diagnosed during pregnancy or within one year of delivery and 205 controls.²¹⁶ Women with pregnancy-associated breast cancer had worse disease-free and overall survival

than controls, primarily due to the more advanced stage of cancer at surgery. Women with early-stage breast cancer during pregnancy had similar survival to controls.²¹⁶

There are limited data about the outcomes of pregnancies associated with breast cancer. One study reported significantly lower birth weights and higher rates of pre-term deliveries in women with breast cancer during pregnancy compared with matched controls.²⁰⁶ This was primarily due to an increased rate of elective caesarean sections to allow earlier start of cancer treatment. Women with breast cancer during pregnancy also had higher rates of stillbirths compared with healthy women.²⁰⁶

Treatment of breast cancer diagnosed during pregnancy

Surgical resection will usually be the first line treatment.²¹⁷ Mastectomy is often the preferred option, as treatment with radiotherapy during pregnancy increases the risk of adverse foetal outcome, including malignancy in childhood.²¹⁸ It is recommended that radiotherapy is avoided in pregnancy; where a diagnosis is made during the third trimester, radiotherapy can be delayed until after delivery.²¹⁹ In a study of 35 women with early stage breast cancer during pregnancy or within one year of delivery, conservative surgery with post-delivery radiotherapy was not associated with an increase in local recurrence compared with mastectomy at a median of follow-up 24 months.²²⁰ This finding should be interpreted with caution owing to the small number of women included in the study.

Chemotherapy should be considered on a case-by-case basis, bearing in mind the increased risk of haemorrhage or infection at delivery.²⁰⁷ Chemotherapy administered during the first trimester results in unacceptably high levels of foetal abnormality.^{181,217} A study involving 24 pregnant women demonstrated minimal complications at delivery for women treated with chemotherapy during the second and third trimesters.²²¹ There was also no adverse outcome for offspring during follow-up to 42 months in a study of 20 women treated with chemotherapy after the first trimester.²²² Optimal timing of delivery in relation to treatment should be decided in consultation with the woman's obstetrician, members of the multidisciplinary treatment team, and the woman. The potential ramifications of delaying treatment because of a pregnancy should be discussed in detail with the woman.

Some women may choose not to proceed with a pregnancy that is concurrent with a diagnosis of breast cancer. In such circumstances, it is appropriate for members of the treatment team to ensure the woman has adequate support in decision making and access to counselling.

Pregnancy following treatment for early breast cancer

Guideline	Level of evidence	Reference number
Premenopausal women should be informed that their decision to have a child subsequent to a breast cancer diagnosis will not, as far as current evidence indicates, alter their risk of recurrence or overall survival.	III-2	223-225

It is estimated that approximately 3-7% of younger (premenopausal) women become pregnant following a breast cancer diagnosis.^{205,217,226} Women contemplating having children after treatment may worry about a range of issues, such as the impact of a pregnancy on disease recurrence or survival, the potential for birth defects after treatment with chemotherapy or radiotherapy, or concerns about the susceptibility of children to cancer.^{54,227} However, there is currently no evidence to suggest that pregnancy after breast cancer alters survival,^{226,228,229} and some studies have suggested pregnancy has a survival advantage.^{223,224} This advantage may represent a ‘healthy mother effect’, in that women who feel well and have a good prognosis may be more likely to have children than those who are negatively affected by the disease.

Little data is available about the outcomes of children born to women who have been treated for breast cancer. Very limited evidence from three small studies does not suggest an increase in adverse outcomes such as foetal abnormalities or anatomical defects.^{228,230,231}

Key point

Younger women who are considering pregnancy following treatment for breast cancer should be informed about their risk of recurrence, based on disease stage at diagnosis and other prognostic factors.²³²

Younger women are often advised to delay pregnancy for at least two years following a diagnosis of breast cancer, because aggressive disease is considered most likely to manifest itself within that time.²⁰⁷ While there is insufficient data to confirm that short time to conception significantly worsens prognosis, very young women and those with axillary node involvement may wish to delay pregnancy for a number of years to reduce the potential risk of recurrence.^{233,234} This will be a matter of individual choice for the woman and her partner. Women should be advised to avoid becoming pregnant while taking tamoxifen, because of the potential risk to the foetus.

In general, women who become pregnant after breast cancer do not experience adverse quality of life, nor do they experience any increased stress in parenting. Having children may actually help women to move beyond the notion of survival by promoting a feeling of normalcy and fulfilling longer term life plans.^{227,230}

7.5 USE OF ORAL CONTRACEPTIVES AFTER TREATMENT

Key point

Younger women should be advised that missing a few menstrual cycles after breast cancer treatment does not necessarily imply infertility; regular menstruation may resume following treatment-induced amenorrhoea.¹⁸³ Women who wish to avoid pregnancy following treatment should employ some form of contraception unless blood tests show an established menopause.

There is currently insufficient evidence on which to make recommendations about the use of the contraceptive pill in women who have had breast cancer. However, as oral contraceptives may potentially increase the risk of breast cancer recurrence, women who wish to avoid pregnancy after treatment for breast cancer should consider using non-hormonal methods of contraception, such as condoms or a diaphragm.

8. FOLLOW-UP

It is desirable that follow-up procedures are defined to achieve specified outcomes in a cost-effective manner. Women need to be informed of the goals of follow-up, which include the early detection of local recurrence, screening for a new primary breast cancer, and detection of treatment-related toxicities. The provision of psychosocial support is also an important component; follow-up appointments provide opportunities for routine assessment of the emotional adjustment of younger women, and for providing support and offering referrals or counselling should the need arise.

Key point

Although younger women may be more anxious about disease recurrence than older women,^{50,52} it should be reinforced that there is no evidence that intensive follow-up, such as regular bone scans, CT scans, PET scans or MRI, improves survival or quality of life.^{235,236} Clinicians should inform younger women about the risks of disease recurrence, and any new symptoms should be assessed as they arise.

A minimal follow-up schedule is recommended, as there is no evidence that frequent intensive follow-up confers any survival benefit or increase in quality of life (Level II).^{235,236} Two clinical trials involving more than 2,000 women show no survival benefit for women followed intensively compared with those with a minimal follow-up schedule.^{235,236} One of these trials showed no increase in quality of life from an intensive follow-up schedule (Level II).²³⁵

The core components of follow-up are clinical review (history and examination) and mammography. For younger women who have been treated for breast cancer, mammography may be complemented by the use of ultrasound.⁴² For more information, refer to the *Clinical practice guidelines for the management of early breast cancer*.⁴¹

9. PSYCHOLOGICAL DISTRESS

9.1 THE EXPERIENCE OF PSYCHOLOGICAL DISTRESS

Key point

Younger women with breast cancer are reported as having a higher risk for significant psychological distress including mood disturbance,²³⁷ anxiety,²³⁸ depression^{4,238} and other psychosocial symptoms requiring intervention.²³⁹

A sense of the disease compromising the future is a common theme for younger women,^{6,240} a diagnosis of breast cancer confronts a woman with her own mortality. In addition, young women face changes in life perception, concerns about making treatment decisions and financial and occupational considerations.⁴⁷ Younger women appear more vulnerable to greater disruption to their daily lives, and have greater unmet practical needs, such as child care.^{240,241} The physical burden of the disease plays a prominent role; younger women who experience greater physical impact may be at higher risk for psychological distress.^{242,243} While the experience of distress in younger women is highest in close proximity to diagnosis,⁴⁴ it does appear to diminish over time.²⁴⁴ Improved psychosocial adjustment has also been reported at six months post-treatment.⁷

Women who are single may be more likely to experience emotional distress.⁹⁸ Limited evidence points to the concerns of single women about establishing new relationships, a sense of isolation and inadequate support, and fears about disclosing the illness.²⁴⁵

9.2 ONGOING PSYCHOSOCIAL ASSESSMENT

Key point

The specific concerns of younger women who have been treated for breast cancer should be explored even in longer-term follow up. Health professionals should consider referring younger women to psychosocial services if a woman's concerns are persistent or severe, or associated with disruptions in relationships and daily life.

A woman's emotional responses, needs, and expectations change over time, depending on the stage of disease and treatment and her individual characteristics and social circumstances. It is prudent for health professionals to be alert to potential psychosocial distress in younger women over time, and to continue to assess emotional adjustment regularly, including at follow-up appointments.

9.3 PSYCHOSOCIAL SUPPORT

Key point

Younger women have reported feeling socially isolated or stigmatised as a result of having breast cancer at a young age,⁹ and may find it difficult to access age-appropriate psychosocial support, including peer support.²⁴⁶

For young women and unmarried women, perceived social support has been positively associated with quality of life⁵ and adjustment to breast cancer.²⁴⁷ However, data from a population-based survey of Australian women with breast cancer indicate that women aged younger than 50 years are more likely than older women to express a need for a greater number of support services during and after treatment, including additional support for their families.⁵⁸

Key point

It is worthwhile for health professionals to provide information to women about appropriate support that is relevant to the age and disease stage of the woman, and/or to encourage women to contact their local State or Territory Cancer Council for information about support options. Health professionals should investigate what age-specific support programs exist in their local areas, and may consider developing age-specific programs for younger women if no such programs exist.

9.4 PARTNER AND FAMILY COPING

Key point

It is appropriate for health care professionals involved in the care of younger women to inquire about family coping and interpersonal problems. The impact of breast cancer can place considerable strain on partners and dependent children, especially if women are undergoing chemotherapy or have recurrent disease.

While younger women are likely to experience more concerns about relationships than older women following a diagnosis of breast cancer,^{174,177} there is limited evidence about how best to assist and support their partners and families.

The majority of women adjust after the acute phase of treatment and experience minimal disturbance in their relationships with their partners. However, potential stressors for partners may include fear of the woman dying,²⁴⁸ taking on new roles, and increased financial burden. Health professionals should discuss these stressors with the partner, if this is desired by the woman. Some women may also experience physical symptoms more frequently, including menopausal symptoms, which may impact on the functioning of their relationships.

It should be noted that research about the impact of breast cancer on partners focuses almost exclusively on heterosexual relationships. Limited evidence suggests that lesbian women with breast cancer are more likely than heterosexual women to feel that their partners make them feel loved and cared for, are willing to listen, and can be relied on to help with daily tasks.²⁴⁹ However, it cannot be assumed that this will always be the case.

9.5 NEEDS OF CHILDREN

While evidence about the impact of breast cancer on children is limited, it appears that the effects of the mother's breast cancer diagnosis depends on the developmental level of the child.^{250,251} Adolescent daughters appear to be particularly vulnerable to experiencing adjustment problems.²⁵²⁻²⁵⁴

There has been very little research conducted into the communication of a cancer diagnosis to children; however, limited evidence suggests that children who are informed about a diagnosis may be less anxious than those who are not informed.²⁵⁵ Young mothers living with breast cancer should be offered assistance about what, if and when to tell children about their cancer. Strategies to assist children need to be tailored to the specific age of the child, and children should be referred for appropriate counselling if required. State and Territory Cancer Councils can provide women with information about discussing cancer with children (phone 13 11 20).

For more information about the needs of children and relevant resources, refer to the report *Needs of children of mothers with advanced breast cancer*.²⁵¹

10. MAINTAINING WELLBEING POST-TREATMENT

10.1 COMPLEMENTARY AND ALTERNATIVE THERAPIES

Key point

Evidence indicates that younger women are more likely to use complementary and alternative therapies, although some may not inform their treating clinician that they are doing so.^{256,257} Health professionals should encourage discussion of the use of complementary and alternative therapies in an open manner.

The majority of complementary and alternative therapies have neither been tested in randomised clinical trials nor proven to be effective. Some of these therapies may be harmful under certain conditions, or interact with pharmacologic therapies in clinically significant ways. Although sometimes considered ‘alternative’, relaxation and meditation have been scientifically evaluated and have been shown to improve emotional wellbeing and to ease nausea and pain in cancer patients.^{128,258}

The use of complementary and alternative therapies has been interpreted alternatively as both a marker of distress²⁵⁹ and a positive coping mechanism,²⁶⁰

and may reflect a deficiency in conventional medicine and its style of delivery from the younger woman's viewpoint. Health professionals should broach the topic regularly, as some women may start using these therapies months and even years after diagnosis. Approaches such as, *'People use a variety of different methods to try and maintain or improve their health; What kinds of things are you doing to take care of yourself?'* may be helpful.²⁵⁶

The Memorial Sloan-Kettering Cancer Center (New York, USA) maintains a web site for health professionals that contains evidence-based information about herbs, botanicals, vitamins and other supplements (www.mskcc.org/mskcc/html/11570.cfm). The site includes a clinical summary for each agent and details about its constituents, adverse effects, interactions, and potential benefits or problems. Evaluations of alternative or unproven cancer therapies also are also provided.

10.2 DIET AND NUTRITION

Key point

Research suggests that younger women are more likely to make dietary changes than older women following a diagnosis of breast cancer.²⁶¹⁻²⁶³

There are inconsistencies in the literature concerning the effects of diet and nutrition after breast cancer diagnosis, and limited evidence about dietary factors that affect cancer progression and recurrence. However, studies suggest that significant numbers of women do make changes to their diet following a diagnosis of breast cancer.²⁶¹⁻²⁶³ In one Australian study, women aged younger than 50 years were twice as likely to have initiated dietary changes after diagnosis (61%) than older women (32%).²⁶¹ The most commonly reported dietary changes are reduced consumption of red meat and fatty foods, and increased intake of fruit, vegetable and whole grains.²⁶²⁻²⁶⁴ Some young women may feel that their diet contributed to breast cancer, and that changing their diet will improve the chance of a cure.^{261,263}

Key point

Women seeking nutritional guidance following a diagnosis of breast cancer should be informed about healthy dietary principles, such as: consuming a wide variety of vegetables and fruit; limiting intake of saturated fats; and avoiding high levels of alcohol.^{265,266}

While it has been hypothesised that the consumption of soy products may be harmful for women with a prior breast cancer diagnosis, there are inadequate data on which to base a recommendation about soy intake.¹⁹⁶

Communication between health professionals and women may prevent the use of extreme diets, and unproven and possibly harmful supplements. For women who are concerned about nutrition following treatment, referral to a dietitian is appropriate. The Dietitians Association of Australia offers a 'Find a Dietitian' service through its web site (www.daa.asn.au) which allows users to search for a practitioner in a specific location and with particular areas of interest.

10.3 PHYSICAL ACTIVITY AND EXERCISE

Guideline	Level of evidence	Reference number
Younger women, and indeed those of all ages, should be informed that moderate exercise has the potential to reduce fatigue and improve emotional wellbeing, even during radiotherapy or chemotherapy.	II	267,268

Women with breast cancer report a reduction in physical activity during the course of treatment, with an increase after active treatment has concluded. However, this post-treatment increase in exercise may not reach the level of their pre-diagnosis activity.²⁶⁹ Exercise has the benefits of reducing fatigue, improving wellbeing, reducing psychological distress and improving sleep, as well as potentially attenuating bone density loss secondary to menopause.²⁷⁰

11. SURVIVAL ISSUES

Key point

Although younger women do appear to be more concerned about the prospect of disease recurrence than their older counterparts, positive physical and emotional wellbeing has been reported among disease-free survivors up to 10 years after diagnosis.^{52,176,271} Given the potentially long survival time of younger women who have had breast cancer, clinicians should be aware of women's changing concerns over time.

Long-term survivors of younger age have reported that breast cancer has had both positive and negative impacts on their lives. Some of the positive impacts identified include changes to diet and lifestyle, exercise habits and religious belief.¹⁷⁶ Areas of life where women reported a negative impact include working life and financial situation.^{175,176} In the longer term, concerns about obtaining life insurance are also apparent.¹⁷⁵

12. THE TRANSITION FROM CURATIVE TREATMENT TO PALLIATIVE CARE

Key point

The diagnosis of progressive disease can be very distressing, particularly if the woman has been asymptomatic. Discussing the transition from curative to non-curative treatment is challenging and emotionally demanding for younger women and clinicians alike, as it involves the consideration of adverse prognosis and facing the possibility of death.

There is limited research to suggest that younger women may be more distressed when diagnosed with recurrent or metastatic disease than at the time of initial diagnosis.⁴⁸ Women with debilitating symptoms as a result of distant recurrence are more likely to experience significant emotional distress.²⁷² Evidence also suggests that many women will experience substantial difficulties in adjusting to the nature of a life-shortening condition during the progression

from early to advanced disease.^{44,273} Younger women may be confronted with feelings of distress, loss or guilt about leaving partners and young children behind. Consequently, discussions about the transition from curative treatment to palliative care, and the timing of these discussions, require careful consideration by members of the treatment team.

For many women, the transition from curative treatment to palliative care will be gradual. Depending on the extent of disease, women with advanced breast cancer may survive many years. Treatment during this time should include attention to emotional and psychosocial concerns.

Key point

A key aspect of the successful transition to palliative care is ensuring that both the health care team and the woman recognise that palliation does not preclude active treatments to improve symptom control and enhance quality of life, nor does it imply abandonment by the treatment team.

Where active treatment continues to be offered, the goal will change from cure to control of disease and disease symptoms. The symptoms of advanced disease are highly amenable to treatment. For instance, cancer pain can be treated with analgesia and other adjuvant methods such as relaxation, meditation, non-steroidal anti-inflammatories, anticonvulsants or tricyclic antidepressants. Anti-emetic regimens containing 5-HT₃ antagonists and steroids can be helpful for women receiving chemotherapy, and bisphosphonates and radiotherapy may be used in the treatment and prevention of bone pain and fracture for women with bony metastases. Where the aim of treatment is palliation, excellence of physical care can also impact positively on the woman's quality of life.^{138,274} For more detailed information, refer to the *Clinical practice guidelines for the management of advanced breast cancer*.¹²⁵

Key point

There is evidence to suggest that the early referral of young women with advanced disease to a specialist palliative care service may be warranted.^{44,273,275,276}

Evidence supports the consideration of referral at the time when the disease has progressed to a stage at which treatment is reviewed; this is a time when young women may experience substantial difficulties and may benefit from the support of a palliative care team.^{44,273} One randomised controlled trial has

shown that referral to a specialised palliative care service was associated with improved outcomes for both women living with advanced disease and their families.²⁷⁶

Unnecessary delays in referral to specialist palliative care services can lead to increased distress for the woman. Potential barriers that may delay the timely referral to a palliative care service include avoidance of discussing the issue,²⁷⁷ a lack of awareness of the components of a palliative care service, and the perception that referral means that death is imminent.²⁷⁸ Further research about how best to overcome these barriers is needed. Health care professionals may benefit from communication skills training in this area to improve the communication between a young woman, her family, and her doctor. (Communication skills training is offered by organisations including the NBCC (www.nbcc.org.au) and the Pam McLean Cancer Communications Centre (www.mcleancentre.org)).

Palliative care involves the application of good symptom control in association with particular attention to the psychological, social and spiritual wellbeing of the woman and her family and or carers.²⁷⁵ Specialist palliative care services can improve outcomes in relation to patient satisfaction, patients being cared for in their place of choice, family satisfaction, and control of pain, symptoms and family anxiety (Level I).²⁷⁹ The support of a specialised palliative care service should also be offered to a younger woman's children and partners.²⁸⁰ It has been reported that in the month before death, the families of younger women with breast cancer experience more severe anxiety than families of older patients and patients with other cancers.²⁷⁶ For some younger women living with advanced disease, it may also be helpful to be referred to a support group in which they can discuss their emotional concerns in detail (supportive-expressive therapy). One study found that while supportive-expressive group therapy did not increase survival time, all the participants reported an improvement both in their mood and in their perception of pain.²⁸¹

13. REQUIREMENTS OF SPECIAL GROUPS

Key point

It is pertinent for health professionals to consider and respond to the specific needs of women from linguistically or culturally diverse backgrounds and those from rural and remote areas.

13.1 CULTURAL SENSITIVITIES

Women from linguistically or culturally diverse backgrounds, especially those whose first language is not English, will need special strategies in place if they are to receive adequate information and be involved in decision making. While these specific needs and sensitivities will vary, there are a number of issues that are likely to be important.

Women from some cultural backgrounds may have specific beliefs that affect their attitudes to treatment. For example in some communities, cancer is viewed as fatal and/or shameful and members of the community may assume that the patient cannot function in their usual capacity, causing gradual isolation. Clinicians should also be aware of different cultural attitudes to death and dying, and the role of the woman's religious beliefs and those of her family should be explored.^{282,283} Younger women may be faced with complex issues if family members have expectations about the woman's role in making treatment decisions.

If the woman is not fluent in English, it is important to use a qualified and appropriate interpreter, rather than a family or hospital staff member. The Translating and Interpreting Service (TIS) provides telephone translating services through the Doctors Priority Line (phone 1300 131 450). Translators can be accessed straight away or booked for a later time. For doctors or specialists in private practice who are providing services that are claimable under Medicare, this translating service is free of charge. Where available, information about breast cancer should be provided to women in their own language. There may be an extra burden placed on a young woman if she has to

translate information about her health to her parents or other family members if English is not their first language.

In some communities, women may have a strong preference for care from a female health care provider. In some indigenous communities, breast cancer is perceived as women's business. Special care should be taken to discuss treatment options and to provide female doctors where possible. The use of Aboriginal Health Workers may also be of value in assisting indigenous women during treatment.

13.2 WOMEN FROM RURAL AND REMOTE AREAS

Key point

Younger women who are required to travel significant distances or to be away from home for extended periods of time may face difficulties with caring for young children, organising household responsibilities or maintaining paid work.²⁸⁴ Health professionals should explore the concerns of women living in rural and remote areas, including their ability to access assistance for travel and accommodation, which may have a direct impact on treatment decisions.

On average, women from rural and remote areas of Australia who travel for breast cancer treatment spend six weeks away from their homes during radiotherapy treatment, and three weeks away while receiving chemotherapy.²⁸⁵ Many of these women do not receive the financial assistance for travel and accommodation expenses to which they are entitled.²⁸⁶ Data from a population-based survey of Australian women with breast cancer indicate that only 30% of rural women received enough information about financial support for travel; the same proportion reported receiving enough information about accommodation.²⁸⁵ Sixty-six per cent of rural women did not receive enough information about practical and emotional support available near treatment centres. Women should be offered referral to a social worker or welfare officer for practical support, including information and advice about applying for government financial assistance for travel and accommodation costs.

14. OTHER ISSUES

14.1 CLINICIAN DISTRESS

Key point

Providing care for young women with breast cancer may be stressful for health professionals, as the diagnosis of cancer in young adults can seem particularly incongruous.²⁸⁷

Health professionals may identify with the patient ('It could be me'), feel distress and guilt about the needs of the children of such patients, and feel concerned about their own mortality. Some health professionals tend to cope by avoiding or distancing themselves in situations where they expect to experience anxiety and distress.²⁸⁸ However, there is evidence that younger patients are more vulnerable to psychosocial distress in the context of cancer.^{97,226,289} In a setting where health professionals avoid discussion of emotionally charged issues, there is the risk that this distress in younger patients is not detected or is responded to inadequately. Where available, specialised psychosocial health professionals can provide support to staff. Participation in communication skills training can also help health professionals respond to the specific needs of younger patients.²⁸⁸

14.2 INFORMATION ON THE INTERNET

Key point

Research suggests that younger women are more likely to use the Internet to find cancer-related information; this is particularly the case for women with a higher level of education.^{290,291} It is useful for clinicians and members of the treatment team to be aware of, and recommend, good-quality Internet sites.

Increasingly, women with breast cancer and their families are turning to the Internet for information about cancer and treatment. This can be a convenient way to gather information in private, but may also be a source of great confusion and anxiety for both patient and doctor. Women should be encouraged to talk with health professionals about information found on the Internet, which can be of variable quality and accuracy.

Useful Internet sites

State and Territory Cancer Councils provide information and educational resources about all types of cancers, including details about age-appropriate cancer support groups and other local services: www.cancer.org.au.

(Information can also be obtained through the Cancer Helpline, which can be accessed from anywhere in Australia for the cost of a local call: 13 11 20.) Some State and Territory Cancer Councils run initiatives specifically for younger women with breast cancer. For instance, the Queensland Cancer Fund holds meetings across the State for younger women as part of the Young Women's Network: <http://www.qldcancer.com.au/ywn/>

Breast Cancer Network Australia (BCNA) is a consumer organisation that represents Australians personally affected by breast cancer. An email-based Young Women's Networking Link has been established with the aim of keep young women informed about relevant issues: www.bcna.org.au

Breast Cancer Action Group (BCAG) NSW is a consumer group that advocates on behalf of people who have been affected by breast cancer. Young BCAG aims to ensure that the concerns and special issues of younger women are acknowledged and addressed: www.bcagnsw.org.au

Breast Cancer Care is a UK-based organisation that provides information and support to women with breast cancer, including specific information for younger women with breast cancer:

<http://www.breastcancercare.org.uk/breastcancer/Youngerwomenandbreastcancer>

The Young Survival Coalition is a US-based volunteer network of breast cancer consumers advocating for the needs of younger women with breast cancer:

<http://www.youngsurvival.org/>

APPENDIX A: NATIONAL BREAST CANCER CENTRE WORKING GROUP – IMPROVING CARE FOR YOUNGER WOMEN

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APPENDIX B: GUIDELINE DEVELOPMENT PROCESS

The *Clinical practice guidelines for the management and support of younger women with breast cancer* were prepared by the National Breast Cancer Centre (NBCC). The guidelines were developed in accordance with the NHMRC publication *A Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines* (1999), and are based on the following key principles:

- a focus on the improvement of patient outcomes
- a basis in the best available scientific evidence
- the adoption of a multidisciplinary approach which involves all stakeholders, including consumers.

Purpose and scope of the guidelines

The objective of the guidelines is to provide members of the treatment team with evidence-based recommendations for the optimal care of younger women with breast cancer, taking into account women's individual needs. The ultimate aim of the guidelines is to improve health and quality of life outcomes for younger women with breast cancer. Key outcomes may include:

- reduced rates of recurrence
- decreased morbidity and mortality
- improved quality of life and psychological wellbeing
- improved communication between patients and clinicians
- improved knowledge and access to information for patients.

The guidelines are designed to complement existing clinical practice guidelines for the management of early and advanced breast cancer, and psychosocial care for women with breast cancer.

The development of the guidelines was coordinated by a multidisciplinary Working Group convened by the NBCC. This group comprised representatives from a range of disciplines including breast surgery, psychiatry, medical

oncology, radiation oncology, psychology, palliative care and nursing, as well as consumers and breast cancer support providers (see Appendix A).

Wherever possible, the Working Group confined its scope to issues that are specific to the age and/or life stage of younger women with breast cancer. Topics covered include general principles of care, preoperative examinations, surgical management, radiotherapy and systemic adjuvant therapy, ovarian function, psychological distress, follow-up and maintaining wellbeing after treatment, and the transition to palliative care.

Processes employed

The Working Group was established in late 2001. At initial Working Group meetings, members identified known clinical problems or issues for younger women with breast cancer, relevant to their respective fields. Preliminary literature searches were undertaken to identify additional issues of importance for younger women. A list of critical topics was developed and cross-referenced to existing clinical practice guidelines to ensure non-duplication of recommendations.

Evidence pertaining to each identified topic was obtained through various avenues, including several focused literature searches using the MedLine and PsycInfo databases. Working Group members nominated topics relevant to their area of expertise and evaluated the associated evidence using a standard *pro forma* for reviewing articles. The strength of the evidence was assessed using the level of evidence rating system recommended by the NHMRC in the publication *A Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines* (1999). Summaries of the evidence for each topic were collated centrally, and several re-drafts were circulated to the Working Group for comment. Where high-level evidence existed, the Working Group developed recommendations for clinical or psychosocial management.

A draft guideline document was finalised in November 2002, and was circulated for public consultation over a five-week period during November-December 2002. The document was sent for review to relevant experts, representatives of professional colleges and organisations, Commonwealth and State/Territory health departments, and consumer representatives. Submissions were also invited from a wide range of other organisations and individuals through an

advertisement placed in the monthly NBCC publication *BreastFax*. Participants in the consultation process were provided with a *pro forma* for noting comments about the document and suggestions for action.

A total of 35 submissions were received. Comments about the draft document were recorded in a table and a sub-committee of the working group was convened to consider each comment. Each revision and action was documented. Revisions were incorporated into the guidelines where deemed appropriate, with decisions based on expert clinical judgement and whether the comments reasonably reflected best practice and the available evidence.

Dissemination, implementation and evaluation of the guidelines

The NBCC will be responsible for disseminating, implementing, evaluating and updating the guidelines, subject to resource availability.

The implementation strategy prepared by the NBCC will draw on past experience in implementing clinical practice guidelines, and the expertise of the NBCC's *Young Women's Consultative Group*. As a first step, the guidelines will be circulated free of charge to relevant stakeholders, including all relevant professional groups. The availability of the guidelines will be advertised through NBCC newsletters, which are published frequently throughout the year, and on the NBCC website.

An evaluation strategy will be drafted at the implementation stage and will include the collection of data to determine the impact of the guidelines on clinician behaviour and patient health outcomes.

List of submissions received during public consultation

- | | | |
|----|-----------------------|---|
| 01 | Professor Alan Rodger | Radiation Oncologist
William Buckland Radiotherapy Centre
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| 02 | Dr Fran Boyle | Medical Oncologist
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- | | | |
|----|---|---|
| 03 | Associate Professor
Kerstin Sandelin | Surgeon
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| 04 | Associate Professor
Christobel Saunders | Surgeon
University Department of Surgery
QEII Medical Centre
Nedlands WA |
| 05 | Ms Karen Finch | Acting Program Coordinator
Women's Cancer Prevention Program
NT Department of Health and
Community Services
Casuarina NT |
| 06 | Ms Mary Anne Hartley | Barrister at Law and Mediator
Owen Dixon Chambers West
Melbourne VIC |
| 07 | Ms Margret Ryan
Ms Ellen Kerrins
Dr Kerry Kirke | Coordinator, Cancer Support Services
Manager, Cancer Prevention Unit
Executive Director
The Cancer Council South Australia
Unley SA |
| 08 | Dr Geoff Delaney | Radiation Oncologist and Staff Specialist
Cancer Therapy Centre
Liverpool Hospital
Liverpool NSW |
| 09 | Dr Joanna Dewar | Medical Oncologist
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- 10 Ms Rosemary Bryant Executive Director
Royal College of Nursing Australia
Deakin West ACT
- 11 Mr Shane Solomon Executive Director
Metropolitan Health and Aged Care Services
Department of Human Services
Melbourne VIC
- 12 Dr Shalini Vinod Radiation Oncologist
Cancer Therapy Centre
Liverpool Hospital
Liverpool NSW
- 13 Dr Will Cairns Chairman
Australasian Chapter of Palliative Medicine
The Royal Australian College of Physicians
Sydney NSW
- 14 Mr John Collins Specialist Breast and General Surgeon
Private Medical Centre
Royal Melbourne Hospital
Parkville VIC
- 15 Ms Kim Johnstone Policy and Research Officer
Women's Health Victoria
Melbourne VIC
- 16 Dr Prue Francis Medical Oncologist
Peter MacCallum Cancer Institute
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GLOSSARY

Adjuvant therapy

A treatment that aids or assists another treatment. The term is especially used to describe the use of chemotherapy or endocrine (hormone) treatment given with or after primary surgery, the aim being to eradicate hidden cancer cells which were not removed at the operation.

Advanced disease

For breast cancer, the disease when it has advanced beyond the stage of being confined to the breast tissue alone, or the breast tissue plus armpit (axillary) lymph nodes.

Alopecia

Hair loss. In the context of breast cancer, usually caused by one of the chemotherapeutic drugs. It is usually partial and short-term and full recovery usually occurs, although new hair is often a different texture and colour from previously.

Amenorrhoea

The absence, discontinuation or abnormal stoppage of menstrual periods.

Anti-emetic medication

Used to prevent or relieve nausea and vomiting.

Anxiety

A diffuse, highly unpleasant, often vague feeling of apprehension, accompanied by bodily sensations such as pounding heart and sweating. There is an associated anticipation of future misfortune or danger, external or internal.

Axilla

Fossa axillaris; armpit.

Axillary dissection

Surgical excision of the axillary contents (fat and lymph nodes) en bloc, either with mastectomy or as an independent procedure. The extent of the axillary

dissection is further defined in the following way:

Level 1 - excision of the axillary contents up to the inferior border of the pectoralis minor muscle.

Level 2 - excision of the axillary contents up to the superior border of the pectoralis minor muscle.

Level 3 - excision of the axillary contents up to the apex of the axilla.

Benign

Not malignant; that is, not cancerous.

Biopsy

Removal of a sample of tissue or cells from the body by excision or aspiration for microscopic examination to assist in diagnosis of a disease.

Bisphosphonates

Drugs that inhibit the activity of bone-destroying cells called osteoclasts.

Body image

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

Bone scan

An investigation in which a radioactive tracer is injected and its distribution in the bones is detected by a scanning instrument. The tracer goes to areas of abnormal bone activity (such as may be caused by cancer) and shows up as a 'hot spot' on the scan. However, not all hot spots are caused by cancer, and bone scans need to be interpreted with X-rays and in clinical context.

Boost

An additional dose of radiation given to a smaller volume, usually the local excision site, after the remainder of the breast has been irradiated.

BRCA1

Breast cancer gene 1. It is identified as a gene on the long arm of chromosome 17 which is mutated or lost in 2-4% of women with breast cancer. See also familial breast cancer.

BRCA2

Breast cancer gene 2 has been identified recently on chromosome 13. See also familial breast cancer.

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 creation or insertion of a breast shape or mound using surgical techniques, after a total mastectomy.

Computed tomography (CT)/‘CT scan’

A special radiographic technique that uses a computer to convert multiple X-ray images into a two-dimensional cross-sectional image.

Chemotherapy

The use of medications (drugs) to kill cancer cells, or to prevent or slow their growth.

Clinical practice guidelines

Published guidelines issued by a central authority such as the National Breast Cancer Centre, which are aimed at informing medical practitioners of treatment and investigation methods preferred by experts and/or proven by research.

Clinical trial

Research conducted with the patient's permission which usually involves a comparison of two or more treatments or diagnostic methods. The aim is to gain better understanding of the underlying disease process and/or methods to treat it. A clinical trial is conducted with rigorous scientific method for determining the effectiveness of a proposed treatment.

Cognitive

Pertaining to the mental process of knowing, thinking, learning and judging.

Complementary therapies

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

Complete local excision (CLE)

The complete excision of an entire tumour mass, surrounded on every aspect by a margin of normal breast tissue, confirmed by histological examination of the margins.

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.

Core biopsy

The sampling of breast tissue with a cutting needle, 18-gauge or larger, to give a tiny cylinder of tissue for histological examination. This technique may involve a mechanical device to drive the cutting needle.

Counselling

Refers generically to a form of supportive care delivered by health professionals. There are differing levels of sophistication depending on the training and experience of the practitioner involved.

Cryopreservation

Maintenance of the viability of excised tissue, organs or cells by storing at low temperatures.

Depression

A pervasive and sustained lowering of mood. When used clinically, it refers to a cluster of symptoms, or syndrome, whose other features include tearfulness, guilt, irritability, reduced capacity for pleasure, lowered energy, poor concentration, poor sleep and loss of appetite.

Disease-free survival

The time from the primary treatment of the breast cancer to the first evidence of cancer recurrence.

Early breast cancer

Breast cancer confined to the breast, or breast plus axillary lymph node tissue.

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.

Endocrine therapy/hormone therapy

The use of drugs or hormones that specifically inhibit the growth of hormone-responsive cancer cells.

Extensive intraductal carcinoma (EIC)

EIC is generally said to exist when 25% or more of the primary invasive tumour mass is comprised of ductal carcinoma in situ (DCIS), and when areas of DCIS co-exist in the adjacent breast tissue. EIC is a predictor for high relapse rates following complete local excision and radiotherapy.

Estrogen receptor (ER)

See oestrogen receptor

Familial breast cancer

Breast cancer that generally occurs in the setting of a first-degree relative who has had breast cancer, particularly in pre-menopausal disease, implying an inherited disposition. The two best described syndromes of familial breast cancer are due to mutations of the BRCA1 gene on the long arm of chromosome 17 (where there may also be a predisposition to ovarian cancer) and mutations of the p53 gene (Li-Fraumeni syndrome). Familial breast cancers are thought to comprise less than 10% of all breast cancers. Recently a second gene, BRCA2, on chromosome 13, has also been identified.

Fear

Anxiety due to a consciously recognised external threat or danger.

Fine needle biopsy (FNB)/fine needle aspiration biopsy (FNA or FNAB)

The sampling of cells from breast tissue for cytological examination using a size 23-gauge needle or smaller. When suction is applied during the sampling, this is referred to as fine needle aspiration biopsy (FNA or FNAB).

Genes

The functional units of heredity, each occupying a fixed location on a chromosome within the cell nucleus.

Genetic counselling

Guidance about risks of inherited disease.

Genetic testing

Identifying carriers of gene mutations by means of DNA analysis

Grade

A relationship has been demonstrated between prognosis and degree of differentiation of breast carcinoma. This degree of differentiation is called the grade. A Grade 1 carcinoma is well differentiated and is associated with a good prognosis. A Grade 2 carcinoma is moderately differentiated and is associated with an intermediate prognosis. A Grade 3 carcinoma is poorly differentiated and is associated with a poor prognosis. Grade is assessed by a pathologist.

Gray

The modern unit of radiation dosage. Doses used in curative breast cancer management would usually vary between 45 and 65 Gray.

Group therapy

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

Histology

Assessment of cellular features by light microscopy of sections from paraffin-embedded tissue.

Hormones

Natural chemical substances that are produced by one body organ and travel through the bloodstream to other organs, where they exert their effects.

Hormone receptors

Proteins residing within the cell which specifically bind to the appropriate hormone. The resultant hormone receptor complex subsequently stimulates the cell to undergo a physiological function such as cell division. In women with breast cancer, these receptors are present in approximately 50% of all women and are powerful prognostic indicators of survival and response to hormone (or antihormonal) therapy.

Hormone replacement therapy (HRT)

The use of exogenous female hormones as a substitute for natural hormones in women.

Hormone therapy

See endocrine therapy.

Lumpectomy

Surgical removal of a lump from the breast. See complete local excision.

Luteinizing hormone-releasing hormone (LHRH) agonist

Compounds that are similar to luteinizing hormone-releasing hormone, a hormone that controls sex hormones in men and women.

Lymph nodes / lymph glands

Collections of lymphoid tissue at intervals throughout the body. A common site for the early spread of breast cancer is to the axillary lymph nodes.

Lymphoedema

Accumulation of lymph in soft tissue and swelling, caused by inflammation, obstruction or removal of lymphatic vessels.

Magnetic resonance imaging (MRI)

A special imaging technique used to image internal structures of the body, particularly soft tissues. An MRI image is often superior to a normal X-ray image.

Malignant

A tumour having the capacity to destroy tissue locally, spread, and cause death.

Mammogram

A soft tissue X-ray of the breast which may be undertaken to evaluate a clinical problem, or as a screening test in women with no symptoms of breast cancer.

Mammography

The process of obtaining soft tissue X-rays (mammograms) of the breast.

Margins of resection

The surgical margins of the excised tumour. See complete local excision.

Mastectomy

Surgical removal of the breast. May be total (all of the breast) or partial.

Meta-analysis

A quantitative synthesis of the results of two or more primary studies which have addressed the same hypothesis in the same way.

Metastasis

The process by which cancer cells are disseminated from the tumour origin (primary tumour) to form a new tumour (secondary tumour) at a distant site. Transportation of the cells is generally via lymphatic or blood vessels.

Metastatic cancer

Cancer that has spread to a site distant from the original primary 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. The disciplines represented by the core team should minimally include surgery, oncology (radiation and medical oncology), pathology, radiology and supportive care. The individual woman's general practitioner will be part of her team.

Nodal status

Indicates the histological presence or absence of metastases in the axillary nodes. Node-positive indicates one or more nodes involved; node-negative indicates no nodes involved.

Oestrogen receptor (ER)

An intracellular receptor protein that binds oestrogens and antioestrogens and mediates their effects by subsequently binding to DNA and altering the expression of specific genes. It is an indicator of responsiveness to hormonal therapies. High ER expression is associated with a good prognosis and with a response to hormonal therapy.

Oncologist

A doctor who specialises in the study and treatment of cancer.

Oncology

The branch of medicine concerned with the study of the biology and physical and chemical features of cancers. Also, the study of the cause and treatment of cancers.

Oophorectomy/ovariectomy

Surgical removal of the ovaries.

Open biopsy

A surgical procedure performed under local or general anaesthetic in which a sample of breast tissue is obtained for histological examination, using an open incision.

Ovarian ablation

Treatment that destroys ovarian function.

Ovariectomy

See oophorectomy.

Overall survival

The time from the primary treatment of the breast cancer to the death of the patient.

Palliative care

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is to achieve the best possible quality of life for patients and their families.

Palliative treatment

Treatment directed at the cancer to reduce its effects, without the intention of curing it or prolonging survival. Such treatment may include surgery, radiotherapy or chemotherapy. Investigative procedures are kept to a minimum.

Peer support

Groups composed of people with similar problems or illnesses, based on the premise that mutual sharing of experiences and information is beneficial for participants.

Pharmacologic treatments

Treatments involving the administration of drugs to alleviate symptoms, for example symptoms of depression and anxiety

Positron emission tomography (PET) / 'PET scan'

A scanning device that uses low-dose radioactive sugar to measure brain activity.

Primary

The original site where the cancer developed.

Prognostic factors

Patient or tumour parameters that are associated with, but not necessarily causally related to, better or worse disease outcomes.

Progression

The continuing growth of the cancer. Often used when discussing treatment failure. Also known as disease progression.

Prophylactic bilateral salpingo-oophorectomy

The surgical removal of the fallopian tubes and the ovaries in an effort to prevent or reduce the risk of breast cancer.

Prophylactic mastectomy

The surgical removal of one or both breasts in an effort to prevent or reduce the risk of breast cancer.

Psychosocial

Referring to the psychological, social and spiritual domains.

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 wellbeing. Quality of life encompasses symptoms of disease, side effects of treatment, relationships, occupational and social functioning and subjective evaluation of adjustment to daily life.

Radiotherapy

The use of radiation, usually X-rays or gamma rays, to kill tumour cells.

Randomised controlled trial

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

Recurrence

Return of disease after an initial response to treatment.

Relaxation therapy

A form of therapy in which emphasis is put on teaching the patient how to relax both mentally and physically, and to control breathing, with the aim of reducing emotional distress and improving control of symptoms such as anxiety or pain.

Sentinel node biopsy

Sampling of the first set of lymph nodes that receives drainage from the tumour cells. A combination of radioactive tracer and colour dye is used to localise the nodes. The biopsy technique is less extensive and can reduce the need for axillary clearance in node-negative patients. It is not, at present, a standard procedure.

Staging

Conventionally refers to the allocation of categories (0, I, II, III, IV) to groupings of tumours defined by internationally agreed criteria. Frequently these are based on the tumour, the nodes and the metastases (TNM). Staging may be based on clinical or pathological features.

Support

The existence or availability of people on whom an individual can rely for the provision of emotional caring and concern, and reinforcement of a sense of personal worth and value. Other components of support may include provision of practical or material aid, information, guidance, feedback and validation of the individual's stressful experiences and coping choices.

Supportive-expressive therapy

A form of therapy in which the therapist encourages the expression of the patients' feelings about their 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.

Symptoms

Anything physical, psychological or social that causes noticeable concern to a patient.

Systemic

Involving the whole body.

Tamoxifen

An anti-oestrogen medication, given in the form of tablets.

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.

Tumour

An abnormal growth of tissue. It may be localised (benign), or invade adjacent tissues (malignant) or distant tissues (metastatic).

Ultrasound

High-frequency sound waves above 20,000 Hz. Ultrasonic waves are reflected by deep structures in the body, allowing the visualisation of internal organs.

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