

Clinical practice guidelines for the psychosocial care of adults with cancer



**NATIONAL BREAST
CANCER CENTRE**

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CONTROL
INITIATIVE**

Clinical practice guidelines for the psychosocial care of adults with cancer

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

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NHMRC

*National Health &
Medical Research Council*

INVESTING IN AUSTRALIA'S HEALTH

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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 psychosocial care of adults with cancer*. These guidelines are based on the *Psychosocial clinical practice guidelines: providing information support and counselling for women with breast cancer*, published in 2000 by the National Breast Cancer Centre.

It is planned to review the *Clinical practice guidelines for the psychosocial care of adults with cancer* by 2008. For further information regarding the status of this document, please refer to the NHMRC website: <http://www.nhmrc.gov.au>

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FOREWORD

Optimal care of the patient with cancer incorporates effective *physical* and *psychological* care. There are currently several clinical practice guidelines available documenting evidence-based information and treatment recommendations for the physical care of people with cancer, many of which are also available in consumer versions. Some of these treatment guidelines include chapters devoted to psychosocial care.

People with cancer suffer significant emotional morbidity. In addition to the distress, fear and grief consequent upon diagnosis, up to 30% experience clinically significant anxiety disorders and prevalence rates for depression range from 20%-35%. These disorders have a major impact on the person's functioning, and that of their family, as well as posing a major occupational and economic burden. In addition, such disorders adversely impact on capacity to cope with disease burden, and may reduce patient adherence to recommended treatments.

People with cancer continue to request more information in order to better understand their cancer, its impact on them and their family, and the treatment options available. Patients are only able to participate as they wish in clinical decision-making if they have access to appropriate information. For people from rural areas, and those from particular cultural groups, access to such information and services represents a major unmet need.

In an era of evidence-based medical practice, health professionals desire accurate information about the emotional impact of cancer on patients and their families, and clear recommendations about strategies to reduce the emotional burden. The specialist medical Colleges also are increasingly endorsing the need for enhanced communication skills training for members, to improve the provision of information and emotional support for patients and their families.

The *Psychosocial clinical practice guidelines: providing information support and counselling for women with breast cancer* was published in 2000. These evidence-based guidelines were developed to assist health professionals in providing optimal evidence-based psychosocial care of women with breast cancer. This is the only comprehensive psychosocial guidelines document currently available in Australia. To date there have been no comparable generic guidelines that would be applicable to all adult patients with cancer.

Emerging evidence in the discipline of psycho-oncology suggests there are similar themes in the psychological needs of patients with cancer at different cancer sites. Therefore there is potential clinical value in developing generic psychosocial guidelines.

The *Clinical practice guidelines for the psychosocial care of adults with cancer* have been developed by the National Breast Cancer Centre and the National Cancer Control Initiative in response to this need. A multidisciplinary Steering Group with representatives from various cancer areas was established to oversee the development of the Guidelines. The group used the original psychosocial guidelines for women with breast cancer as a template for the expansion of information, and further development of recommendations regarding clinical care of all adult patients with cancer.

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

These guidelines provide clear recommendations, predominantly based on Level I and Level II evidence. I am confident that their successful implementation in routine clinical practice will help to promote well-being and reduce the distress of all patients and their families as they cope with cancer. Further, the issues discussed are an integral facet of medical practice and, as such, it is expected that they will become incorporated into medical training.

Dr Jane Turner

Chair,

Clinical practice guidelines for the psychosocial care of adults with cancer

Steering Group

IMPORTANT NOTICE

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.

EXECUTIVE SUMMARY

Cancer has a significant impact on the lives of many Australians. Excluding non-melanocytic skin cancers, there were 80,864 new cancer cases and 34,270 deaths due to cancer in Australia in 1998. Based on 1998 rates, it is expected that one in three men and one in four women will be directly affected by cancer by age 75. Recent Australian survival data shows that approximately 60% of people diagnosed with cancer are still alive five years later. This excludes non-melanocytic skin cancers, which have a relatively low mortality rate.

Many people diagnosed with cancer face practical, emotional and psychological demands in addition to their physical treatment. These psychosocial needs are significant, and frequently go undetected and unmet. Up to 66% of people with cancer experience long term psychological distress: up to 30% experience clinically significant anxiety problems, and prevalence rates for depression range from 20%-35%. Many people report inadequate information to guide decision-making, and others are disadvantaged because of a lack of knowledge about practical support, even when such services are available. The impact on families of those with cancer is considerable.

These *Clinical practice guidelines for the psychosocial care of adults with cancer* were developed to expand on the existing *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer*. Health professionals and consumers have found the existing guidelines to be valuable in the provision of evidence based psychosocial care. These Guidelines for adults with cancer were developed by the National Breast Cancer Centre and the National Cancer Control Initiative, and overseen by a multidisciplinary Steering Group. The guidelines are based on comprehensive and systematic reviews of the research and an extensive consultative process to ensure their clinical relevance.

Many of the recommendations are based on Level I (meta-analyses) and Level II (randomised controlled trial) evidence, particularly those relating to information provision, psychological interventions and emotional and social support (see 1.5, Summary of Evidence). For example, there is Level I evidence that psychological preparation for surgery improves both physical and psychological outcomes after surgery. There is also Level I evidence that appropriate psychological interventions do reduce the high levels of psychological morbidity experienced by people with cancer.

The guidelines also provide a valuable resource for: facilitating the practical care of people with cancer including information about financial assistance and services for people with specific needs; ensuring continuity of care; as well as strategies to facilitate adjustment to disease progression, including moving from curative to palliative treatment goals. The guidelines also address specific issues such as culture, age and particular needs of rural patients.

Implementation of these guidelines has the potential to improve healthcare outcomes, including a reduction in psychological morbidity and emotional distress, improved wellbeing and satisfaction with care. Many of the guideline recommendations require no new service delivery infrastructure or additional resources. These guidelines therefore represent an important resource to improve the care of patients with cancer, and their families, in diverse treatment settings throughout Australia.

CHAPTER 1 INTRODUCTION AND BACKGROUND

1.1 THE IMPACT OF CANCER

Cancer has a significant impact on the lives of many Australians. Excluding non-melanocytic skin cancers, there were 80,864 new cases and 34,270 deaths due to cancer in Australia in 1998. Based on 1998 rates, it is expected that one in three men and one in four women will be directly affected by cancer by age 75.¹ Recent Australian survival data shows that approximately 60% of people diagnosed with cancer are still alive five years later.² This excludes non-melanocytic skin cancers, which have a relatively low mortality rate.

The diagnosis of cancer may be made after symptoms are investigated, or when a patient undergoes routine screening, eg mammogram, pap smear, etc. Patients who seek treatment after their diagnosis represent the full demographic spectrum of the Australian population, including diverse cultural and religious backgrounds, urban, rural or remote communities, and traditional or non-traditional families. Many patients will have pre-existing medical problems, be coping with social adversity or have a mental illness, which may influence the impact of cancer and will need to be taken into consideration. In addition, individuals diagnosed with cancer will be cared for in a range of settings, including home, hospitals, residential aged care facilities, or for some, palliative care units.

Each patient will experience a range of practical, psychological and emotional challenges as a result of their diagnosis and treatment-related adverse effects. Each patient's life may be further disrupted by changes in role and family functioning, occupational or employment status, and financial status. Some patients will have to come to terms with progressive illness and approaching death, others may be faced with the physical, emotional and social challenges of survival.

The psychological impact of cancer is significant. The prevalence of long-term psychological distress in patients with cancer ranges from 20% to 66%, according to the few available estimates.³ While most people with cancer experience symptoms of anxiety, evidence suggests that 12%-30% experience clinically significant anxiety problems.⁴

Australian Bureau of Statistics report that 17% of Australians in the general community will experience an anxiety or depressive disorder in a 12-month period,⁵ while a US study estimated that 5.8% of the general population will develop clinical depression at some point in their lives.⁶ There is some evidence from studies of patients with breast cancer that depression is at least twice as common in people undergoing surgery for cancer as in those without cancer.^{7,8} Studies of patients with breast cancer and studies with patients with various other cancer types also show that those who have undergone chemotherapy, adjuvant therapy or radiation therapy are at increased risk for depression.^{9,11} Some studies report clinical depression in up to 40% of patients with cancer with progressive disease in palliative care.¹²

The experience of cancer may continue to have an emotional impact on some people long after their initial diagnosis. Residual concerns about recurrence and fear of checkups may last for many years after the original diagnosis. The diagnosis of a recurrence causes significant stress. For instance, recurrence is associated with psychiatric disorders in up to 50% of women with breast cancer.^{13,14}

The benefits of support for patients with cancer

Health professionals can help to reduce patient and family distress substantially following diagnosis and treatment of cancer. Each patient will draw on individual coping resources that have helped in the past, such as religious faith or specific problem-solving techniques. All members of the treatment team may also play a role in strengthening the patient's own resources by providing additional emotional, informational and practical assistance, and appropriately fostering a sense of hope or optimism.

Evidence is accumulating that psychological therapies improve emotional adjustment and social functioning, and reduce both treatment- and disease-related distress in patients with cancer. Meta-analyses of randomised controlled trials demonstrate the efficacy of both supportive and cognitive behavioural therapies in the treatment of depressive disorders in patients with cancer (**Level I**),^{15,16} and the efficacy of both individual and group therapies (**Level I**).¹⁶

In a meta-analysis of 45 randomised controlled trials in patients with cancer, those receiving psychological therapies showed, on average, a significant improvement of 12% in measures of emotional adjustment, 10% in social functioning, 14% in treatment and disease-related symptoms, and 14% in overall improvement in their quality of life, compared with those not receiving psychological therapies (**Level I**).¹⁷ A meta-analysis of 116 intervention studies found that patients with cancer receiving psycho-educational or psychosocial interventions showed much lower rates of anxiety, depression, mood disorders, nausea, vomiting and pain, and significantly greater knowledge about disease and treatment, than the control group (**Level I**).¹⁵

1.2 DEVELOPMENT OF THESE GUIDELINES

Need for generic evidenced based psychosocial clinical practice guidelines

The *Psychosocial clinical practice guidelines: providing information support and counselling for women with breast cancer*, published in 2000, is the only comprehensive psychosocial guidelines document currently available in Australia. To date there have been no comparable generic guidelines that would be applicable to patients with any cancer type. Emerging evidence in the discipline of psycho-oncology suggests there are similar themes in the psychological needs of patients with cancer at different cancer sites. Therefore there is potential clinical value in developing generic psycho-social guidelines.¹⁸

The *Clinical practice guidelines for the psychosocial care of adults with cancers*, have been developed following the steps and parameters recommended by the NHMRC¹⁹ in response to this need.

Objective and scope of the guidelines

The objective of these guidelines is to assist health professionals in providing optimal, evidence-based psychosocial care of adults with cancer, and their families. Accordingly, the best available evidence is presented, and used as a basis for providing recommendations about clinical practice.

Optimal care of the patient with cancer incorporates effective *physical* and *psychological* care. Evidence-based information and treatment recommendations are documented in a series of clinical practice guidelines (see Appendix E), many of which are also available in a consumer version. Some of these guidelines include chapters devoted to psychosocial care, such as the guidelines for colorectal cancer.

The *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer* supplied a template for these guidelines, which provide generic evidence based recommendations about:

- the provision of information
- the integration of quality-of-life issues into the care of patients with cancer
- minimising the social, and psychological impact of cancer on a patient and their family
- strategies for the identification and management of patients experiencing significant emotional distress.

These guidelines identify key themes in the provision of psychological care which ideally, may be incorporated into routine clinical care. However, the opportunity to implement some of the recommendations may be limited by local circumstances and the availability of resources such as access to psychiatrists, clinical psychologists or specialist oncology nurses.

Recommendations are drawn from the best available evidence. However, limited research in some cancer types and thematic areas has resulted in an imbalance in the available evidence. In such instances, the best available evidence is cited, and any major deficiencies in the evidence-base are noted. The reader's judgement is required in applying the evidence or recommendation to individual patients.

These guidelines are not rigid procedural paths. They are designed to provide guidance, but flexibility is required in their implementation, depending on available resources, the characteristics of the particular treatment centre, and the applicability of recommendations to individual patients.

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

Target Audience

These guidelines were developed for use by all members of the diagnostic and treatment team, which may include surgeons, radiation oncologists, medical oncologists, general practitioners, nurses, social workers, psychologists, psychiatrists, physiotherapists and occupational therapists.

While most aspects of psychosocial care are common to all cancers, there are some aspects that will be relevant to specific cancers and to specific stages of treatment. It is recognised that while some aspects of psychosocial care are common to all the health professionals involved in a patient's treatment and care, different members of the treatment team will be responsible for specific aspects of the psychosocial care of people with cancer.

Development of these guidelines

The development of these guidelines has been overseen by a Steering Group of representatives from various clinical disciplines and cancer areas. Information included in the *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer* was extensively revised and expanded to create a document that is applicable to all adult patients with cancer. The Steering Group has utilised the comprehensive literature reviews that formed the basis of the psychosocial guidelines for breast cancer, as well as the specific studies commissioned by the National Breast Cancer Centre (NBCC) Psychosocial Working Group to investigate areas of need identified in the reviews. These reviews and studies to some extent still form the basis of the current document.

In keeping with NHMRC recommendations,¹⁹ the literature reviews covered the scientific literature prior to 1997,^{20,26} and identified and synthesised the best available scientific evidence about the key, practice related issues. Comprehensive literature searches were also conducted to identify additional relevant studies from 1997 to 2001 (see Appendix C for details). Evidence was predominately obtained from research in the following cancers known to be the most frequently occurring cancers in Australia: colorectal, breast, prostate, melanoma, lung, gynaecological and Non-Hodgkin's lymphoma (see Appendix D for full incidence details). Head and neck cancers, which results in high levels of impairment, and pancreatic cancer, which has a high mortality, were also included (see Appendix D for full details).

The evidence rating system used in the guidelines is based on the recommendations for interventions studies by the NHMRC's Standing Committee on Quality of Care and Health Outcomes (QCHOC),²⁷ which was adapted from the rating system developed by the US Preventive Services Task Force.

- 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), case control studies, or interrupted time series with a control group.
- Level III-3** Evidence is obtained from comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel group.
- Level IV** Evidence is obtained from case studies, either post-test or pre- and post-test.

For intervention studies, Level I represents the gold standard of evidence. Recommendations based on lower levels of evidence have been included in this document because of the insight offered by well-conducted research or clinical consensus on pertinent issues that have not been subject to investigation using randomised control trial methodology.

Appendix C further details the process for the development, implementation and evaluation of these guidelines.

1.3 STRUCTURE OF THESE GUIDELINES

Structure of these guidelines

The framework for the guidelines is predominately based on symptoms or patient concerns rather than specific cancer sites, due to the considerable overlap in themes across different cancers and for ease of clinical use. Cancer site-specific issues are included in the document where applicable. Within each section, when citing evidence in text, a generic statement is made followed by examples from various cancers.

In most instances, recommendations made are applicable to all adults with cancer. Differences may apply in some instances, depending on stage of treatment, type of cancer, gender, age or social circumstances of the patient. Therefore, within each chapter or section of these guidelines, recommendations are made based on the following hierarchy:

- general (generic) recommendation
- recommendation based on stage of treatment
- recommendation for specific cancer.

Further, where recommendations are likely to be affected by gender differences, this has been noted.

Identification of research sources

Studies with patient samples from several different cancer sites are considered heterogenous and identified as 'studies of patients with different types of cancers' throughout the document.

Studies of patient samples from one or two cancer groups are identified by type, eg. 'a study of patients with prostate cancer' or 'a study of patients with breast cancer and gynaecological cancer'.

Management of gender issues

The psychosocial guidelines for women with breast cancer²⁸ drew on a large body of evidence covering needs assessment and effective strategies for these patients. While it has been suggested there are commonalities in the psychological needs of patients with cancer at different cancer sites,¹⁸ it is possible that there may be differences in effective psychosocial strategies between sub-populations. Throughout the document, likely gender differences in the way people react to cancer, psychosocial support needs, and successful strategies to meet these needs, have been noted.

1.4 ISSUES AFFECTING HEALTH PROFESSIONALS WHO TREAT PATIENTS WITH CANCER

These guidelines have been developed to promote awareness of the psychosocial needs of patients and inform health professionals of those evidence-based interventions that may improve adjustment and outcome for patients. However, the psychosocial care of patients is not conducted in a vacuum, and the training, skills, attitudes and beliefs of health professionals will affect clinical care, often in subtle ways. Furthermore, the clinical care of patients with severe, disabling or life-threatening conditions such as cancer, poses special burdens for staff – an issue that is often neglected. Recognition and understanding of the emotional issues for

health professionals allows strategies to be developed to address these concerns, a process likely to lead to improved therapeutic relationships, enhanced professional satisfaction and reduced stress and burnout.

High levels of stress are reported amongst oncologists²⁹ and oncology nursing staff. Levels are higher among staff who are younger, who feel less supported in the ward^{30,31} and more recent graduates.³² Informing patients of the diagnosis of cancer, and providing emotional support for patients and their families are common sources of stress,^{33,34} yet are areas of training largely neglected until recently. Concerns about the toxicity of treatments and the potential for treatment errors³⁵ pose a burden, as does the conflict between clinical demands and concerns about the impact of this on family life.³⁵ Treating the dying, especially when patients' and families' suffering cannot be relieved as fully as one would wish, is recognised as a potent source of stress.³⁶ Staff who are faced with deaths of large numbers of patients³⁷ often feel immersed in suffering, with little respite from the demands of displaying warmth and empathy towards others.³⁸ In work environments in which there are high levels of organisational responsibilities, stress is also likely to be high.³⁵

Strategies for coping must include attention to the training of health professionals that traditionally has offered little preparation for the intensity of grief, anger, frustration and resentment displayed by patients and their families, particularly when faced with a devastating diagnosis and high disease burden.³⁹ It is important for those who work in oncology to draw on the expertise of members of the multidisciplinary team in dealing with complex clinical problems,⁴⁰ especially when these pose emotional stress. Participation in communication skills training also appears to be a valuable strategy, given evidence that those health professionals who feel insufficiently trained in communication and management skills have higher levels of stress.³⁵ It may be necessary for health professionals to challenge unrealistic expectations of professional performance. Investing in interpersonal relationships is likely to improve coping ability, since supportive relationships appear to protect against burnout.⁴¹ Finally, given the evidence of high rates of emotional morbidity in health professionals,⁴² it is important that depression and anxiety are not attributed to 'work-stress', but that affected staff receive assistance, support and appropriate treatment.

1.5 SUMMARY OF EVIDENCE

The following table summarises guideline statements that are supported by Level I and Level II evidence. The corresponding sections in the text expand on the context of this evidence, including discussion of significant, clinically relevant recommendations based on evidence from other than Level I or Level II study designs.

Summary Statements with Level I and II evidence

General interactional skills – Chapter 3.1	Level	Evidence
The way a clinician and the treatment team relates to, and communicates with a patient can significantly benefit the patient and their family, including improvements in psychosocial adjustment, decision-making, treatment compliance and satisfaction with care	I	15
Expressing empathy and listening actively improves psychological adjustment	I	393
A patient's understanding, recall and/or satisfaction with care increases when techniques such as the following are used:		
<ul style="list-style-type: none"> • taping of the consultation 	II	398,399
<ul style="list-style-type: none"> • a general informational tape 	II	369
<ul style="list-style-type: none"> • a summary letter as a 'follow up' to the consultation 	II	400
<ul style="list-style-type: none"> • the presence of a support person (healthcare professional, family, friend) 	II	401
<ul style="list-style-type: none"> • actively encouraging questions 	II	396
Discussing prognosis – Chapter 3.2.2	Level	Evidence
The way in which prognosis is communicated, eg use of words or numbers, survival or death as the outcome, and the time taken to explain information, influence a patient's decision about treatment	II	429,430
	II	441
Discussing treatment options: Providing information and choice – Chapter 3.2.3	Level	Evidence
Appropriate detailed information promotes understanding and increases the psychological well-being of people with cancer	I	15
For women with breast cancer, discussions with a specialist breast nurse reduce psychological morbidity, and increase understanding of breast cancer, recall of information and perceptions of support	II	243,401 466,467
Patients' recall of information increases when they are provided with individualised information	I II	471 399,400 476,477 478,479

Providing question prompt sheet to patients with cancer during an initial consultation promotes patient questions, reduces anxiety, improves recall and shortens the consultation	II	350
Preparing patients for potentially threatening procedures and treatment – Chapter 3.2.4	Level	Evidence
Providing patients with information about the procedure they are about to undergo reduces emotional distress and improves psychological and physical recovery	I	523,524
	II	525,526
Providing patients with practical details about the procedure (procedural information), a booklet and/or videotape decreases anxiety, and psychological distress. This information can be provided by a clinician, or other health professional such as a specialist nurse	II	401,525 526,527 528,529
Providing patients with information about what they are likely to experience before, during, and after a procedure (sensory information), decreases anxiety	I	524
	II	530
Providing patients with psychosocial support before undergoing surgery reduces psychological distress	I	17
Emotional and social support – Chapter 3.3	Level	Evidence
Appropriate counselling improves the well-being of people with cancer	I	15
The opportunity to discuss feelings with a member of the treatment team or counsellor decreases psychosocial distress	I	15
Participation in psycho-educational programs decreases anxiety and depression and increases knowledge	II	477,478 479
Participation in peer support programs is beneficial for patients with poor perceived social support	II	559
Successful strategies for meeting psychosocial support needs may differ for men and women and when the delivery method is inappropriate or insensitive, men may not participate or not gain a benefit	II	362
Ensuring continuity of care – Chapter 3.5	Level	Evidence
Specialist breast nurses improve understanding and provide continuity of care throughout the treatment process for women with breast cancer	II	401,466 569
Patient-held records improve continuity of care	II	475

Support towards the end of life – Chapter 3.6	Level	Evidence
Pain can be significantly controlled by relaxation therapy, and educational programs, aimed at enhancing pain control, improve adherence to treatment	I II	15 578
The expression of feelings improves adjustment	II	401
Psychological interventions can improve quality of life in areas such as mood, self-esteem, coping, sense of personal control, and physical and functional adjustment	I II	15,17 579,580
<hr/>		
Exploring and responding to specific concerns – Chapter 3.7	Level	Evidence
Referring people who have risk factors to specialised psychological services minimises the likelihood of their developing significant distress	I	359
A range of interventions, such as psycho-educational interventions and anxiety reduction strategies are useful for decreasing distress in patients with cancer	I	15
Cognitive and behavioural techniques, eg muscle relaxation and imagery, are effective treatments for anxiety. However, when anxiety or panic impedes or complicates treatment, prompt assessment from a psychiatrist or clinical psychologist is required	I	15,16,17
Cognitive and behavioural techniques, eg muscle relaxation and imagery, are effective in reducing symptoms	I	15,16,17
A range of psychological interventions including cognitive behavioural techniques such as progressive muscle relaxation, guided imagery and systematic desensitisation, supportive interventions, meditation, exercise, and education are effective in reducing a patient's level of nausea and vomiting	I II	15 525,607 608,609 610,611
Cognitive behavioural techniques such as progressive muscle relaxation and guided imagery, and other therapies such as prayer and meditation are efficacious in the management of acute and chronic pain	I II	15 616
Numerous strategies including education, and nutrition therapies have been found to be useful in improving nutritional status and quality of life	II	273,274
Exercises in breathing control, activity pacing and relaxation techniques are beneficial for patients experiencing respiratory difficulties	II	628

Types and benefits of specialised care - Chapter 4.1	Level	Evidence
A variety of psychological interventions, including cognitive behavioural, supportive, group, family and couples therapy, as well as relaxation techniques, reduce psychological distress	I	15,16,17
	II	548,564 565,568 607,611 659,660 661,662 667,668 669,670 671
Cognitive behavioural, supportive and crisis interventions, as well as combinations of education and behavioural or non behavioural interventions and anti-anxiety medications, are effective in the treatment of anxiety	I	15,16
	II	661,681
Cognitive behavioural, psycho-educational, and supportive interventions, as well as combinations of education and behavioural or non behavioural interventions and cognitive behavioural and anti-depressants, are effective in the treatment of depression	I	15,16
	II	149,569 580,661 671,682
Supportive psychotherapy, in combination with antidepressants such as selective serotonin reuptake inhibitors is effective for the management of post-traumatic stress disorder	I	683
Relaxation therapy, guided imagery, systematic desensitisation, supportive interventions, and education together with cognitive behavioural interventions, are beneficial for patients with physical symptoms	I	15
	II	525,607 608,609 611,661
Greater beneficial effects are observed when therapies are longer and conducted by more highly trained therapists	I	16
Cognitive behavioural, supportive and crisis interventions and relaxation techniques, are beneficial for people experiencing body image concerns	II	527
Personal and/or couple therapy is beneficial for people experiencing sexuality concerns	II	548
Interventions that provide support for partners of patients are effective in reducing distress in both patients and partners	I	654
Treatment of anxiety and depression - Chapter 4.2	Level	Evidence
Depression can be managed by incorporating a combination of supportive psychotherapy, cognitive and behavioural techniques, and pharmacotherapy	I	149,15,17, 690
	II	695,697
There is no evidence that any particular antidepressant is superior to another in the management of depression in people with cancer	I	692

CHAPTER 2 UNDERSTANDING THE CHALLENGES OF CANCER AND HOW PEOPLE REACT

Optimal psychosocial care of people with cancer is best provided when all those involved have a detailed understanding of the challenges faced by a person with cancer, including potential reactions to these problems. This chapter provides a brief but comprehensive overview of these issues. A summary of the issues and the cancer sites for which they may be relevant is provided in Table 2. Evidence based information, where it exists, about how to address these issues is covered in later chapters.

A person with cancer experiences a range of emotional, psychological, physical and practical challenges. These may include: coping with the shock of their diagnosis and fears over their health and future; physical symptoms and adverse effects of treatment such as nausea, fatigue and physical changes in body appearance and functioning; financial costs, altered occupational, employment and financial status; and psychological difficulties ranging from concerns about body image and sexuality to severe disorders such as anxiety and or depression. Some will also have to face progressive illness and approaching death.

Some challenges will be experienced by all patients, regardless of cancer site. Other issues may be cancer site-specific or may be relevant to only a few cancers. The level of distress experienced may vary depending on the cancer site, prognosis and patient burden.³

The emotional adjustment to the diagnosis and treatment of cancer is influenced by several factors. For example, family, friends and religious beliefs have been reported to be important in providing hope,^{43,44} but clinical uncertainty has been found to reduce hope significantly.⁴⁵ High levels of social support clearly assist in coping (**Level III-2**).⁴⁶ The ability to identify with others for whom things are going well, and to contrast oneself with those for whom things are not going well has been identified by patients as a useful strategy for coping.⁴⁷

A review of studies examining age and adjustment to cancer indicates that younger patients may be particularly vulnerable to emotional distress.⁴⁸ This may be due to concerns about the impact of cancer on their partner and children, including practical issues such as income and childcare, the untimely nature of the diagnosis, and a sense of isolation. Older patients may face a different set of issues; difficulties due to co-morbid conditions such as heart disease, arthritis or waning mental capacity may increase the impact of cancer and affect ability to cope.

Research into any links between emotional adjustment and cancer outcome has focused on breast cancer and has yielded mixed results. One prospective study demonstrated increased risk of death on relapse in those with high levels of helplessness and hopelessness.⁴⁹ Another study has failed to find a clear link between coping strategies and disease outcome.⁵⁰ To date there has been no clear link established between stressful life events and either the development or progression of breast cancer.^{51,52} In general, adopting an active, problem-solving style in which emotions are openly expressed appears to make coping easier.^{50,52} In contrast, avoiding discussing emotional and other issues has been associated with more distress.^{53,54} The capacity to be flexible appears important, as those with a strong desire for control are more likely to experience emotional distress.⁵⁵

Gender also appears to influence the way people react to cancer. There are gender differences in mortality for some cancers¹ and other diseases.⁵³ It has been suggested that these differences may relate to social attitudes of men to health and illness, including the need to be strong in

adversity.^{1,53-56} Differences have also been documented in men's response to illness, including lower utilisation of health care services.^{53,57,58}

Table 2: Summary of the major issues by cancer type and page references for major discussion of these issues

Issue	Cancer type	Page/s
Emotional and social issues	All cancers	14-16 68-73 103, 119
Psychological issues		
Body Image	All cancers, particularly breast, colorectal, gynaecological, head and neck, laryngeal, prostate, skin	16-18 87 103, 107
Sexuality	All cancers, particularly breast, colorectal, gynaecological, head and neck, laryngeal, prostate, skin	17-18 87 103, 107
Interpersonal problems	All cancers	18, 88 103, 107
New relationships post diagnosis	All cancers	19 88-89
Stress and adjustment reactions/Severe emotional distress	All cancers	19, 89 103
Anxiety, depression, PTSD	All cancers	19-22 89-91 103 107-109 107
Physical issues	All advanced cancer	22-30 92-93 104, 107
Nausea and vomiting	All cancers, in direct relation to the disease or treatment. Also in relation to other problems such as bowel obstructions, or liver or cerebral metastases	22, 93
Pain	All cancers	22, 93
Fatigue	All cancers	23, 93
Fertility	All cancers, directly in relation to surgery, or where treatment includes radiation or chemotherapy	23-25 93-94 104
Lymphoedema	All cancers where disease or treatment involves lymph nodes	26, 94

Disfigurement	Breast, head and neck, skin, colorectal, gynaecological especially vulvar	26, 94
Odour	Gynaecological, colorectal, skin, head and neck	26-27 94-95
Incontinence	Especially increased risk for prostate, gynaecological, colorectal, all advanced cancer	27, 95
Bowel dysfunction	Especially increased risk for colorectal, prostate, ovarian, all advanced cancer	27, 95
Cognitive problems	Brain, possibly all cancers	27-28
Communication difficulties	Head and neck, laryngeal, brain	28, 95
Malnutrition due to factors such as: Lack of appetite, oral symptoms or swallowing difficulties	All cancers Head and neck Head and neck, laryngeal	28-29 96
Respiratory symptoms	Lung, laryngeal, head and neck, Hodgkin's Disease, any metastatic disease involving lungs and pleura	29-30 96
Practical issues		
Costs- diagnosis and treatment	All cancers	30-31
- supportive treatments/therapies	All cancers	74
- prostheses/aids	Breast, colorectal, laryngeal, all cancers where the disease/treatment result in removal or loss of body parts, problems with incontinence, erectile dysfunction, speech	30-31 74-76
Reconstructive surgery	Breast, skin, head and neck, colorectal, gynaecological – vulva, recurrent disease	31, 76
Lymphoedema	All cancers where disease or treatment involves lymph nodes	31, 76
Travel and accommodation costs	All cancers	31, 76
Other support needs, eg child care etc	All cancers	31, 76
Loss of income	All cancers	31-32 77
Difficulties with business dealings	All cancers	32, 77
Legal issues related to advanced disease	All cancers	32, 77

Towards-the-end-of-life issues	All cancers	32-34 80-83
Survival issues	All cancers	34-36 91

2.1 EMOTIONAL AND SOCIAL ISSUES

People with cancer experience a range of emotional and social difficulties. They often report feelings like 'being in a state of shock', 'feeling out of control' or being angry, fearful or helpless. Grief and loss are often key issues (see also Section 3.6), and there may be powerful feelings of distress and fear that the cancer could be fatal. People treated for cancer may also find their life has changed in other ways such as curtailment of activities they enjoy.

Emotional responses

People vary in their emotional responses to the circumstances surrounding the diagnosis and treatment of cancer. An individual's level of distress may also change over time. For example, among people with head and neck cancer, stress levels have been shown to be highest at the point of confirmed diagnosis, and recede during the treatment.⁵⁹ Psychological functioning and global quality of life gradually improves over three years after the treatment.⁵⁹ In women with cervical cancer, distress and disruption is reported to be high at diagnosis and treatment, yet the majority return to a level of functioning similar to pre-diagnosis.⁶⁰

Episodes of intense, unpleasant and distressing emotions such as tearfulness, fear and anger are part of the normal range of responses to a stressful event. These reactions are very common, are usually occasional, rarely last more than a day or two, and are not indicative of disorder.

There are a number of potential barriers to patients discussing emotional concerns, including not having the words to describe how they feel, not wanting to be a burden, fearing breaking down, being ashamed of admitting problems with coping, or perceiving that the doctor is too busy or disinterested. Health professionals may avoid discussion because of fear of causing distress, harm or worry for patients, feeling out of their depth or that the existential domain is not an appropriate part of medicine.

Psychological vulnerability and, emotional and social support

The extent to which a person with cancer has support and feels supported has been identified as an important factor in their adjustment to the disease.⁴⁶

Key points

People who perceive they have poor support are more likely to experience greater psychological distress.^{43,46,61,62}

Partners⁶³⁻⁶⁵ and children^{66,67} of patients with cancer are also vulnerable to psychological distress and in need of support.

Many patients are faced with significant restrictions to social activities as a result of the disease⁶⁸⁻⁷¹ and experience psychological distress in relation to this.⁷¹

Lack of support from family and friends

Perceived lack of support from family and friends may be associated with greater psychological distress.^{43,46,62} Further, patients' adjustment to living with cancer can be shaped by the reactions of their family and intimate others. Descriptive data suggest that adjustment by patients with cancer is enhanced by family and partner support,^{72,73} while criticism and overprotection by a spouse leads to negative mood and stress.^{73,74} Not only the type of support offered by the partner, but also qualities of the relationship and the couple as a unit, appear to be important.⁷⁵⁻⁷⁷

Discussion of cancer-related issues between men with cancer and their partners has been reported to be limited^{78,79} and constraints in talking to their spouses about cancer may be a negative factor in men's adjustment.⁸⁰ For instance, studies of men with prostate cancer and their spouses have reported poor communication between men and their spouses about emotions, worries, fears and responses to changes in physical and sexual functioning.⁸¹⁻⁸³ Further research is needed to ascertain ways to optimise intimate support between men with prostate cancer and their partners, as this may facilitate long-term adjustment.

Stress experienced by partners

The level of stress experienced by partners of patients with cancer is reported to be comparable to, or higher than, that of patients themselves.⁶⁵ Recent studies measuring stress levels of patients with colon and prostate cancer and their partners, indicate that partners experience significantly more distress than patients^{63,64,84} and receive less support.⁸⁴ Patients themselves often report family needs and issues as their biggest concern.⁸⁵ Data from descriptive^{65,76,86} and correlational studies^{87,88} also suggest that the adjustment of partners is closely related to the emotional and physical functioning of the patient.

Although there is evidence that support from a partner improves patients' adjustment, this appears to come at a cost for the supportive partner. For instance, descriptive studies indicate that those spouses who are most supportive of their partners have higher measured levels of distress⁸⁹ and higher levels of depression when they perceive that they receive little benefit from the relationship,⁹⁰ or when they have reported low levels of emotional support.⁹¹ Partners also have different information needs, which are not always met by the patient.⁹²

Women express more stress in adjustment to cancer, regardless of whether they are the patient or the partner,⁸⁴ but evidence data suggest that women are better at understanding their partner's experience with cancer than men.⁹³ A diagnosis of cancer may place additional anxiety and stress on same-sex couples, with fears that revealing their sexual orientation will result in stigmatisation and compromised care.^{94,95}

Stress experienced by children

Several studies of patients with various types of cancers report that children of parents with cancer are susceptible to levels of stress and in need of support,^{66,67,96} The following key issues have been identified:

- distress varies depending on age, sex of the child, and sex of the parent⁶⁶
- the child's usual support sources are often disrupted. For example:
 - findings from a breast cancer study reports that children perceive that their families offer them little support⁹⁷

- mothers with early breast cancer do not always check children’s understanding of the disease, nor to elicit children’s concerns⁹⁸
- parents coping with cancer may fail to recognise emotional distress in their children⁶⁷
- inability to discuss the illness with parents and spending less time with friends or on sport and leisure activities have been found to correlate with mal-adjustment.⁹⁶

Social impairment

Social support has been identified as an important factor in a person’s adjustment to cancer,⁴⁶ yet many people are faced with restrictions to social activities as a result of the disease. For instance, available studies of patients with laryngeal, lung, gynaecological or colorectal cancer show that these patients report significant restrictions to social activities.⁶⁸⁻⁷¹ Many experience psychological distress⁷¹ and lack of social support correlates with levels of depression.⁹⁹

2.2 PSYCHOLOGICAL ISSUES

In addition to general detrimental effects on emotional well-being, living with cancer can pose specific problems that have a strong psychological impact, including body image and sexuality problems, interpersonal difficulties, and anxiety, fear or concerns related to survival and recurrence.

Most people with cancer will experience minor or transient symptoms of anxiety and depression. Some will develop more severe problems, such as clinical anxiety, depression or post-traumatic stress disorder (PTSD), and will require specialised treatment. This section describes the nature, severity and prevalence of the psychological problems experienced by people with cancer.

Self concept, body image and sexuality

Self concept

A diagnosis of cancer and subsequent treatment can have a significant impact on self concept, the way in which people perceive or react to themselves. Living with cancer may affect *personal* self concept (facts about the self or a person’s self-opinion); *social* self concept (perceptions of how one is regarded by others); and self-ideals (perceptions of oneself with respect to how one would like to be).¹⁰⁰

Body image

Body image is a component of self-concept and involves the perception and evaluation of one’s body, appearance and functioning.¹⁰¹ Body image refers to the person’s conception of, and feelings about his/her body – its form, size, shape and the way it fits society’s norms.²⁸ People with cancer face complex issues of body image, beyond those directly related to missing body parts.¹⁰² This is consistent with reports by Australian women with breast cancer that sexuality entails “more than having breasts”.¹⁰³ In considering body image it is important to conceptualise the person as a whole and social being.

Body image is an area of concern for patients with many different types of cancers, including breast,¹⁰⁴⁻¹⁰⁶ prostate,¹⁰⁷ gynaecological,¹⁰⁸ head and neck,¹⁰⁹ laryngeal¹¹⁰ and skin¹¹¹ cancers.

Much of the literature about body image relates to women with breast cancer. There is clear evidence that women who have undergone breast conserving surgery have a significantly more positive body image than those who have undergone mastectomy.^{104,106} A recent study in women who had undergone prophylactic mastectomy demonstrated that one-third felt less 'feminine' to a minimal degree, and a smaller minority experienced more serious body image concerns.¹⁰⁵

Emerging evidence also suggests body image is an area of concern for patients with other cancers. Studies show that body image, masculinity, and cancer-related self-image are affected in men with prostate cancer,¹⁰⁷ and that body image is significantly affected in women treated for gynaecological cancer.¹⁰⁸ In addition to erectile dysfunction and fertility concerns, anecdotal evidence suggests that men with prostate cancer may also be concerned about the prospect of developing breasts as a result of hormone therapy. A study in patients surgically treated for head and neck cancer reported that 25% overall, and 57% of those with major disfigurement, experienced a change in self image.¹⁰⁹ The results of other studies suggest that many people who have had a laryngectomy experience psychological distress⁷¹ especially those with a stoma.¹¹² Surgery for skin cancer has also been shown to impact on body image.¹¹¹

The effect of gender on the impact of cancer on body image is unclear. In young adults with cancer, males appear to have a more secure body image.¹¹³ However, a review of 16 studies found that both men and women find hair loss related to cancer treatment a source of distress, depression and loss of confidence.¹¹⁴

Sexuality

Sexuality is properly understood to encompass body image, self-esteem, mood, support and sense of emotional connection and intimacy. That body image plays a key role in sexuality is evidenced by the fact that sexual problems are reported by patients with cancers that do not directly effect sexual organs, such as head and neck cancers,¹⁰⁹ laryngeal cancer,¹¹⁵ lung cancer¹¹⁶ and Hodgkin's Disease.¹¹⁷ This finding also suggests the need to address patients' issues of sexuality, regardless of the cancer site.

Estimates of the proportion of patients experiencing sexual problems following the diagnosis and treatment of cancer vary from 10% to 88%, depending on the cancer site and the type of problem.^{109,118-126} Concerns about current or potential sexuality problems are reported to be a major stressor¹²⁷ and are associated with anxiety.¹²²

Sexual problems may persist for many years after surgery. Several studies of men with testicular cancer indicate sexual dysfunction is a major persisting side effect even years after diagnosis.^{121,128,129} Sexual dysfunction persists up to 12 months after bone marrow transplantation in people with Hodgkin's Disease, and up to two years after surgery in women who have undergone mastectomy.^{118,119,125}

Factors affecting sexual adjustment in individuals with cancer include the following:

- age¹²⁵
- pre-existing problems in relationships or sexuality¹¹⁹
- pre-treatment menopausal status for women,^{121,130} and treatment-induced change in hormonal status,^{120,130,131} chemical menopause may produce atrophic vaginitis and dyspareunia, while changes in androgens alter libido and orgasm¹³²
- adjuvant chemotherapy, which affects sexual response,^{130,132} and desire,¹³³ by interfering with the production of oestrogen and testosterone¹³⁴

- alterations in body image due to alopecia, weight loss or weight gain,^{109,118,126,130,135} or disfigurement resulting from surgery^{109,118,126}
- treatments that directly impair sexual function or pelvic organs.^{121,123,126} Radiation therapy in the pelvic, lower abdominal or prostate areas may significantly affect sexual activity, satisfaction and desire.^{123,135-137} For women, effects may include dyspareunia due to lack of lubrication or fibrosis of vaginal tissue.

Table 2.2: Type and prevalence of sexual problems reported by patients with different types of cancer

Sexual problem	Cancer type	Prevalence %	Reference
Loss of libido, change in sexual activity, decreased satisfaction/orgasm	Breast cancer	10-50% ^a	118,119,124,125,138
	Head and neck	39-74% ^b	109
	Laryngeal	60% ^c	115
	Prostate	43-51%	139
	Lung	48% ^d	116
	Gynaecological	No % given	68,120,122
Sexual dysfunction (vaginal dryness, vaginal bleeding, stenosis, dyspareunia, atrophic vaginitis, pain)	Gynaecological	66% No % given	122 60,68,120,140
	Colorectal	20% ^e	*126
Erectile dysfunction and ejaculation dysfunction (premature, retrograde or dry ejaculation)	Colorectal (with stoma)	62-88%	*126
	Prostate	41-91%	123 ^f 141 ^g 139 ^h
	Testicular	25-70% ⁱ	121,128,129,131
	Hodgkin's Disease		117

Notes:

Studies marked * are reviews of several studies, all others are single studies.

- Women who have mastectomy are particularly vulnerable and those under 50 yrs of age are twice as likely as those over 50 yrs
- 39% with minor disfigurement; 74% with major disfigurement
- Significant decrease in sexual activity
- Severe in 27%
- Women whose sphincter muscle has been sacrificed suffer from dyspareunia
- h 71-91% who had radical prostatectomy and 41-62% who had radiation therapy
- i Highest if primary retroperitoneal lymph node dissection or chemotherapy plus secondary resection of retroperitoneal tumour mass

Interpersonal problems

Cancer and cancer treatments can place considerable strain on relationships, particularly in cases where difficulties existed before the diagnosis. Several studies of women with breast cancer¹⁴²⁻¹⁴⁴ and various other cancers types⁷⁵ suggest that problems in marital or family relationships may place a person with cancer at increased risk of psychological problems and affect their adjustment. A study of patients with head and neck cancer found that, generally, relationships with partners were unchanged after the diagnosis, but 27% of patients with major disfigurement resulting from the treatment report a worsened relationship with a partner.¹⁰⁹

New relationships post diagnosis

The establishment of a new relationship after the diagnosis and treatment of cancer poses complex issues, including the impact of self-esteem and bodily changes on the initiation of relationships, the timing and extent of disclosure about cancer and treatments, and concerns about sexuality, fertility and longevity. In addition, the experience of cancer challenges the beliefs and values of the individual, with attendant changes in expectations and hopes for relationships.

Many single men and women in whom cancer has been diagnosed may feel that their illness or the effects of treatment limit their chances of developing new sexual relationships. While research in this area is limited, one study reported pessimism regarding future relationships as a principal stressor among survivors of breast cancer.¹⁴⁵

Stress and adjustment reactions

The experience of the diagnosis and treatment of cancer is for most people a stressful life event that is followed by a range of distressing symptoms such as anxiety and depression. While these symptoms are likely to be transient, it is important to be aware that the experience of cancer is not a single, undifferentiated event. Rather, people with cancer encounter a series of stressful events or challenges over time, which may pose different demands and difficulties.¹⁴⁶⁻¹⁴⁸ As a consequence, a person's distress may become heightened at particular times, such as at diagnosis or disease recurrence, time of surgery, commencement of adjuvant therapy, at advanced disease stage, or presenting for medical surveillance.^{10,59,118,124,149-155}

Severe emotional distress

Although emotional distress in people with cancer is normally occasional and time-limited, some people experience more severe emotional reactions. Stress and adjustment problems may include stronger negative feelings that can last for a week or more, and these can be difficult and disruptive to a person's life. If such problems are left undetected and unacknowledged, some can develop into more serious emotional states.

Major psychological disorders include a major depressive episode, anxiety disorder, post-traumatic stress disorder (PTSD), or an emotional, behavioural or cognitive state that is overwhelming, lasts longer than a couple of weeks, causes significant impairment in functioning and over which the person feels they have little or no control.

Anxiety

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

Some people experience severe anxiety problems, including panic attacks, pervasive and generalised worry, treatment phobias, eg needle phobias, social anxiety and post-traumatic stress reactions.

Prevalence estimates for anxiety in patients with cancer range from 15% to 23%.^{156,157}

Moderate-to-severe anxiety has been reported in numerous studies of patients with different types of cancer, including gynaecological, lung, breast, haematological/ lymphatic, gastrointestinal, and urological cancers.^{4,110,120,122,156,158-163}

Factors affecting anxiety disorders in people with cancer include:

- reaction to the stress of diagnosis and treatment
- response to cancer-related medical problems such as uncontrolled pain
- response to drug treatment, such as steroids
- response to investigations such as computed tomography (CT) scans and magnetic resonance imaging (MRI)
- exacerbation of pre-existing anxiety or specific fears and phobias, eg needle phobias.¹⁶⁴

For instance, predictors of anxiety among survivors of Hodgkin's Disease are low educational status, the length of the observational period, combined chemotherapy and radiation treatments and pre-treatment psychiatric symptoms.¹⁶¹ Psychological distress does not consistently improve over time.^{161,165} Anxiety may also be a symptom of other medical conditions, such as thyroid disease, and is commonly associated with alcohol or benzodiazepine withdrawal.

Levels of psychological distress are likely to be higher when disease burden or complications are more severe. For example, in patients who have had a bone marrow transplant, the level of anxiety was found to be significantly higher in those patients who went on to develop grade II-IV graft-versus-host disease (GVHD) compared to those who developed grade 0-I GVHD.¹⁶² Mortality at one year post bone marrow transplant is also influenced by psychological distress and attitude towards treatment.¹¹⁰

Depression

In addition to the personal suffering it causes, depression is probably the most important risk factor for suicide.¹⁶⁶ Depression undermines the capacity of the individual to cope with illness, and is associated with increased severity of medical symptoms, and additive impairment in social and vocational functioning.¹⁶⁷ It is therefore not surprising that depression is also associated with increased health care costs in those with medical illness.¹⁶⁸ Depression may also compromise the physical care of the person with cancer – in general medical settings the odds are three times greater that depressed patient will be non-compliant with medical treatment recommendations,¹⁶⁹ and depressed patients with breast cancer have been found to be less likely to accept adjuvant chemotherapy.¹⁷⁰

The prevalence of emotional distress is high in patients with cancer, most studies finding prevalence rates for depression ranging from 20%-35%.^{3,149,156}

The prevalence of depression is increased in all chronic physical illnesses, and cancer is no exception. Prevalence rates may vary depending on the cancer site.³ Patients who are diagnosed with cancers with poor prognosis, such as pancreatic cancer, and high disease

burden are especially vulnerable to psychological distress, and high depression rates have been reported in these populations.^{3,171} Significant psychological distress has been reported in 43% of patients with lung cancer.³

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

A diagnosis of a major depressive episode in patients is best evaluated by the severity of depressed mood, loss of interest and pleasure, the degree of feelings of hopelessness, guilt and worthlessness, and the presence of suicidal thoughts.¹⁷² Recurrent tearfulness is often accompanied by social withdrawal and loss of motivation. The patient may feel they are unable to control the negative feelings and these feelings begin to dominate the day, on most days for two weeks or more.

Suicide

Accurate figures on the incidence of suicide in patients with cancer are difficult to obtain. Studies undertaken in Sweden suggest that the incidence of suicide is higher in people with cancer than in the general population, and that suicide is more likely to occur in the first year after diagnosis.^{173,174} Risk factors for suicide include severely depressed mood, a family history of completed suicide, past history of self-harm and a history of alcohol or other substance abuse, and poor social support. Lack of hope for the future has also been identified as a powerful predictor of suicide risk, particularly in those with advanced cancer.¹⁷⁵ Assessment, and exploration of suicidal thoughts, is crucial to the early recognition and treatment of psychological distress for the patient (See Section 3.7).

Post-traumatic stress disorder

Diagnostic classifications of mental disease have been revised to include diagnosis of a potentially life-threatening illness as sufficient stressor for the precipitation of PTSD, and there is a small but increasing research into traumatic symptomatology in patients with cancer. The bulk of the research to date has focused on patients with breast cancer.

Estimates of the prevalence PTSD among people with cancer vary from 3% to 12%, depending on the cancer and treatment.¹⁷⁶⁻¹⁸⁰

Many who do not meet the strict criteria for PTSD still report a high level of intrusive symptoms such as recurrent thoughts about the cancer diagnosis, or aspects of treatment. For example, in one study of women with breast cancer, 44% reported a high level of intrusive symptoms.¹⁸¹

A number of risk factors for PTSD have been identified in cancer patient. For instance, risk factors for PTSD in women with breast cancer include less social support and greater pre-cancer trauma.¹⁸² Among women with colorectal cancer, PTSD is associated with perceived intensity of cancer treatment and problems with health care professionals.¹⁸³ In patients treated with high-dose chemotherapy or bone marrow transplant, lower levels of

education and poorer health status are associated with increased risk for PTSD.^{178,180} Among patients with colorectal cancer, the reported rate of PTSD is twice as high in women as in men.¹⁸³

Traumatic symptomatology may persist long-term. In women with breast cancer, traumatic symptomatology does not appear to diminish with time.¹⁸⁴ While the duration of traumatic symptoms following bone marrow transplant is unclear, one large study of patients with various cancer types found that, at mean four-year follow-up post transplant, patients with PTSD continued to show significantly lower physical, social and role functioning.¹⁸⁵

2.3 PHYSICAL ISSUES

People with cancer experience a number of illness and treatment-related physical symptoms/side effects that may significantly affect their quality of life and increase the risk of developing more serious levels of anxiety and depression.¹⁸⁶ These include nausea and vomiting,¹⁸⁷ acute and chronic pain,¹⁸⁸⁻¹⁹⁰ fatigue,^{191,192} lymphoedema,¹⁹³⁻¹⁹⁷ disfigurement,^{109,111,198} odour,^{199,200} incontinence,²⁰¹ cognitive problems,²⁰²⁻²⁰⁴ difficulties in communication,²⁰⁵ swallowing difficulties,²⁰⁵ respiratory symptoms,^{203,206} loss of appetite and nutritional deficiencies,^{207,208} and fertility problems,²⁰⁹⁻²¹¹ as well as a decline in general health.

Chemotherapy-induced nausea and vomiting

Chemotherapy-induced nausea and vomiting cause significant suffering in some patients, despite recent improvements in anti-emetic treatment and medication. In some cases, patients may develop habitual nausea and vomiting occurring prior to a scheduled administration of chemotherapy (anticipatory nausea and vomiting) or in response to stimuli, such as tastes, smells and locations that have become associated with the chemotherapy (conditioned nausea and vomiting).

Recent data indicate that up to 24% of patients undergoing chemotherapy experience moderate to severe anticipatory and conditioned nausea and vomiting.¹⁸⁷

Pain

Patients with cancer may experience pain due to various causes, including the illness itself and the treatment procedures. Studies show that pain is one of the most frequently identified problems for people with lung cancer¹⁸⁹ or prostate cancer.¹⁸⁸ There is emerging evidence that pain arising from head and neck cancer can be severe and chronic, persisting beyond completion of treatment. One study found that 6% of patients report pain at 24 months and 4% of those have severe pain.¹⁹⁰

Pain may vary depending on the stage of the disease or treatment, and is common among people with advanced cancer. Pain has an adverse effect on general well-being and compounds psychological distress in patients with cancer. For instance, it has been reported as one of the greatest sources of suffering for people with lung cancer.¹⁶³

Pain also has an emotional dimension. In addition to social, family, personality and cultural factors, the individual's interpretation of the meaning of the pain may influence coping in patients with serious illness.^{212,213}

Fatigue

Fatigue is a common complaint of patients with cancer, and 91% of those who experience fatigue report that it prevents a 'normal life'.^{192,203} Emerging evidence suggests that fatigue persists even after acute treatment is completed,²¹⁴ and correlates with the use of chemotherapy, irrespective of the time since treatment.²¹⁵

Female fertility and pregnancy issues

Fertility and pregnancy issues are an under-recognised source of distress for women with cancer. Issues that may arise during the treatment of cancer at any site may include contraception, the effect of pregnancy on prognosis, the effect of treatment on the foetus, the effect of treatment on future fertility, and the availability of any reproductive technologies that might enhance the possibility of motherhood at a future, safe time. Women report they are concerned about these issues, and they have been identified as a source of significant levels of anxiety.^{209,211}

Avoiding pregnancy

Women who are not pregnant at the time of diagnosis may experience fears and concerns about becoming pregnant during treatment. Selection and choice of appropriate contraceptive methods may also cause concern. Women may be concerned about the hormonal adverse effects of cancer therapy and require specific specialist advice and reassurance on this issue.

The effect of pregnancy on prognosis or recurrences

Clinical experience and research do not substantiate the common belief that pregnancy shortly before, during or soon after the diagnosis of cancer worsens the prognosis, or increases the chance of recurrence,^{216,217} with the exception of trophoblastic disease. Despite the lack of scientific evidence, the fear that pregnancy could cause a recurrence is common among women with cancer, regardless of the cancer type.^{209,211} Treatment for cancer during pregnancy is more complicated, and must take into account potential risk to the foetus through surgery, chemotherapy or radiation therapy.

The effect of treatment on pregnancy

Women in whom cancer is diagnosed during pregnancy or after childbirth, may have concerns about the effects of cancer or treatment on the child,²¹¹ even after treatment is completed.²⁰⁹ The effect of treatment on the pregnancy may vary depending on the cancer site and the trimester of pregnancy.

Women with cervical cancer diagnosed during the first trimester will usually be treated by radical hysterectomy, with the concomitant loss of both the current pregnancy and any future pregnancies, because a delay in definitive surgery may worsen the prognosis. When the diagnosis is made during the mid or third trimester, delaying definitive treatment until after delivery may be a realistic and safe option for both mother and baby.

Women with ovarian cancer may undergo oophorectomy in the mid trimester, leaving the pregnancy intact. For all cancers, chemotherapy during the first trimester may affect dividing cells and organogenesis,²¹⁸ but there is increasing evidence that platinum-based chemotherapy during the second and third trimester is well tolerated by the mother and has no deleterious effects on the foetus.²¹⁹

Any radiation therapy to the pelvis and abdomen will result in the death of the foetus. Radiation therapy may be considered in the pregnant woman with breast cancer, each case being considered by its merits. Cancer diagnosed during pregnancy will always generate high levels of anxiety and distress. Those who terminate a pregnancy or experience a spontaneous pregnancy loss during cancer treatment may be particularly vulnerable.²⁰⁹

Lactation difficulties may result from some cancer treatments, such as surgery or radiation therapy to the chest or breast wall.²²⁰

Cancer treatment and loss of fertility

Loss of fertility occurs in patients with gynaecological or other malignancies for which definitive treatment involves surgical or radiation therapy to the pelvic organs, or chemotherapy that might induce a premature menopause. The potential loss of fertility, as a result of either surgical procedures or adjuvant therapy,²¹⁰ may be a source of concern and psychological distress.²⁰⁹

Whether or not early menopause results from chemotherapy or radiation therapy may be influenced by age, dose and radiation field. For example, the dosage typically used in lymphoma does not induce amenorrhoea in women under 40 years, but may produce early menopause in older women.²²¹ A radiation dose of 6 Gray to the ovary is very likely to induce menopause in a woman over the age of 40, but recovery is usually expected in a 20-to 30-year-old woman.²¹⁰

Gynaecological implications of systemic cancers

Women with cancers that are associated with a strong expectation of long-term survival, such as leukaemia, lymphoma and germ cell tumours, may have concerns that the treatment received may affect their chance of future pregnancies.

Fertility after cancer therapy

Many women may wish to retain the option of further childbearing after the successful treatment of their cancer. The preservation of oocytes or ovarian tissue is still at the experimental stage, and there have been no recorded pregnancies to date.²²²⁻²²⁴ Embryo storage is available. Concerns may arise about whether she is able to use her own uterus or requires a surrogate.

Key points

Despite the absence of good scientific evidence, many women still fear that pregnancy could cause a tumour recurrence.^{209,211}

Cancer diagnosed during pregnancy generates high levels of anxiety and distress. Women who terminate a pregnancy or experience a spontaneous pregnancy loss during treatment may be particularly vulnerable.²⁰⁹

The potential loss of fertility as a result of either surgical procedures or adjuvant therapy²¹⁰ may be a source of psychological distress.²⁰⁹

Male fertility issues

Fertility, properly understood as the overall result of sexual function, is an under-recognised issue for men with cancer. The literature in this area predominantly relates to testicular cancer, with few studies about other cancer types or heterogeneous cancer populations.

Infertility may occur as a result of impaired spermatogenesis, but fertility also declines when erectile function and libido are affected. According to one cancer study, only 57% of men receive information from their health care provider about infertility after cancer, despite it being a common concern.²¹¹ For some, infertility is irreversible. Approximately 20% of survivors of testicular cancer who are treated by retroperitoneal surgery and systemic chemotherapy are affected.²²⁵ Gonadal damage invariably results from high-dose chemotherapy used for allogeneic or autologous bone marrow transplantation.²²⁶

Infertility distress substantially alters the patient's quality of life. For men with testicular cancer, this is compounded because they are commonly at the peak of their physical, sexual and reproductive function.²²⁷ While the connection between sexual dysfunction and infertility is often not made for older men, re-partnering and delayed reproduction can make it an important issue for this population also.

Predictors of infertility distress include younger age, childlessness,²²⁸⁻²³⁰ and lower education level.^{228,229} Cancer stage and treatment modality may also be a factor. One randomised controlled study found that men with advanced testicular cancer who received chemotherapy and standard retroperitoneal lymph node dissection had significantly more infertility distress than those who did not undergo these.²²⁸

Treatment effects on fertility

Surgery, radiation therapy, chemotherapy and hormone therapy all cause varying degrees of erectile or ejaculation dysfunction, impaired spermatogenesis or loss of libido, which in turn affect fertility. Whether infertility is impaired irreversibly appears to be dependent on the type of treatment received. According to one review, the risk of azoospermia increases with the size of the radiation dose and the time taken for recovery, and the risk of permanent azoospermia increases with each dose.²³¹ According to comparative data, the risk of irreversible impairment of spermatogenesis by chemotherapy is determined by cumulative doses.²³²

Preservation of sperm for future use

Sperm banking becomes an important issue when treatment is likely to result in infertility due to impaired spermatogenesis or sexual dysfunction such as impotence, loss of libido or retrograde ejaculation. However, deciding whether to preserve sperm for later use may be a source of distress, due to the involved medical, legal, religious, social and financial issues.²³³ According to one study, only 24% of childless men banked sperm before treatment.²¹¹ Many patients may require information about cryopreservation and reproductive technology. Some may have ethical or religious concerns about using stored semen.²³³

Key points

Only 57% of men receive information from their health care provider about infertility after cancer, despite it being a common concern.²¹¹

Surgery, radiation therapy, chemotherapy and hormone therapy all cause varying degrees of erectile or ejaculation dysfunction, impaired spermatogenesis, or loss of libido.

Predictors of infertility distress include younger age, childlessness,²²⁸⁻²³⁰ cancer stage and treatment,²²⁸ and lower education levels.^{228,229}

Lymphoedema

The precise incidence of lymphoedema is unclear, reflecting uncertainties about its diagnosis and measurement (see the NBCC report about lymphoedema). It is reported to be of considerable concern to women who have been treated for breast cancer,^{234,235} the population in which the majority of cases of cancer-related lymphoedema occur.

Lower limb lymphoedema is also common in people with gynaecological cancers or lower rectal and anal disease who undergo pelvic and/or inguinal lymph node dissection, radiation therapy,^{194,195,197} or combined vein ligation and inguinal lymphadenectomy.²³⁶ Major long-term lymphoedema also affects patients who have undergone groin dissection for melanoma.¹⁹⁶ Less commonly, lymphoedema can occur in patients treated for other cancers such as head and neck cancers.¹⁹⁷ There is a paucity of literature relating to cancer types other than breast cancer.

Women with breast cancer who have lymphoedema report that the condition is debilitating, impairing ability to perform ordinary tasks,²³⁷ and resulting in increased psychological distress.²³⁸ Symptoms in the other arm, which may include weakness, limitation in range of movement, stiffness and pain, also have a negative impact on quality of life for patients with cancer.¹⁹³ Lower limb lymphoedema may impair mobility, especially when both legs are affected, leading to other problems such as obesity, heart disease or arthritis. Where only one leg is affected, loss of balance is also a problem.

A recent study suggests that a person's ability to cope with lymphoedema is affected by pain, the availability of social support, and the severity of physical symptoms.²³⁹ For some patients, in addition to the physical limitations it poses, lymphoedema may be highly visible of one's status as a 'cancer patient' and a constant reminder of the diagnosis.

The risk of cellulitis in the affected limb is increased in people with lymphoedema, because lymphatic fluid provided a perfect medium for infection.²⁴⁰ Repeated episodes of cellulitis increase the severity of the lymphoedema as infection promotes scarring²⁴¹ and increase blood flow and capillary permeability, thereby increasing the amount of fluid in the interstitial spaces.²⁴²

Disfigurement

Despite improvements in cosmetic results, disfigurement is still an issue for many people with cancer. Altered appearance results from surgery for many cancer types, including head and neck, breast, skin, and vulvar cancers and for patients requiring exenterative procedures, usually for persistent or recurrent pelvic disease. Thickened or keloid scars may also be disfiguring, regardless of where they are located on the body. Disfigurement can affect body image^{109,111,189,243} and sexuality.¹⁹⁸

Factors that may be associated with higher distress levels include the extent of the disfigurement and the preparedness of the patient for such outcomes. In a study of patients treated for melanoma, the greatest distress about appearance was reported by those with deeply indented scars, such as occur with skin grafting following removal of skin, subcutaneous and deep fascia, as well as those whose scars were longer than they anticipated.¹¹¹

Odour

Offensive bodily odours resulting from disease may have a devastating psychological impact on people with cancer, and compound depressive symptoms, social isolation and disinclination

to seek professional support.²⁰⁰ Odours may result from stomas, faecal or urinary fistulae or tumour necrosis, which may occur either within body cavities or at ulcerated and infected sites on the surface. Other potential sources of offensive odours are halitosis, uraemia, hepatic failure, fungal or bacterial infections.¹⁹⁹ Debilitated patients are more prone to fungal infections, especially in skin folds and groins, as well as the genital region. Vaginal odours may result from necrotic tumours, such as primary tumours of cervix, vagina or vulva, or may be secondary to direct extension of an intra-abdominal tumour through the vaginal vault, bladder or rectum, in the absence of fistulation.²⁰⁰

Odours may easily affect interpersonal relationships for patients with cancer, at a time when they are particularly vulnerable. The effects of odours may even compromise the ability of professional carers to provide good care.¹⁹⁹

Incontinence

Incontinence is one of the most frequently reported problems for men with prostate cancer,^{188,201} and is commonly moderate to severe.¹²³ Urinary incontinence is considered to be a major physical and emotional stressor for this population.^{127,135} Urinary incontinence may also occur with infection in debilitated patients of both sexes.

Bowel problems

In colorectal cancer, one third of patients report more than five bowel movements per day and 50% have problems with either diarrhoea or constipation.^{244,245} Impaired bowel function is reported following ultralow (coloanal) anastomosis,⁶⁹ and limited data suggest that this procedure is associated with greater morbidity than anterior resection.²⁴⁶ Other cancer studies reveal that 44% of patients with ovarian cancer report bowel problems²⁴⁷ and 13% to 38% of men with prostate cancer have moderate to severe bowel problems.¹²³ Bowel problems can also be associated with treatments such as pelvic radiation therapy,²⁴⁸ some chemotherapy regimens²⁴⁸ and medications such as analgesics.²⁴⁹

Cognitive problems

Impaired thinking, described as poor concentration, confusion or memory problems, is a common symptom reported anecdotally by people with cancer, and can be especially distressing. Few detailed studies have been conducted to confirm these experiences using valid and reliable neuropsychological tests. The cause of cognitive symptoms may be difficult to determine, particularly for subtle impairment that may be a sign of treatment side effects, metastatic disease or symptomatic of an anxiety or depressive conditions or fatigue.²⁵⁰

Studies in women with breast cancer treated with chemotherapy have reported cognitive impairment in the domains of attention, mental flexibility, speed of information processing, and visual processing.²⁵¹⁻²⁵³ All of these studies reported that the cognitive impairment was independent of mood disturbance. Cognitive impairment has also been found in women treated with chemotherapy for gynaecological cancer,²⁰⁴ patients treated for Hodgkin's Disease²⁰³ and patients treated with chemotherapy and radiation therapy for lung cancer.²⁵⁴ It is not known whether cognitive problems associated with bone marrow transplants improve over time. Patients who experience difficulty in concentration report that this causes moderate to severe distress.¹⁸⁹

According to data from randomised controlled studies, high-dose chemotherapy is more likely to be associated with cognitive impairment than standard-dose chemotherapy.²⁵⁵

Immunochemotherapy also appears to be associated with increased risk of cognitive impairment.²⁵⁶ Patients treated with stem cell transplantation for lymphoma and leukaemia report cognitive impairment to be a major component of quality-of-life impairment, even one year after the procedure.²⁵⁷

Research about cognitive function in patients treated for primary brain cancers has tended to focus on relatively insensitive measures of outcome such as IQ scores and performance status, and neurological examination.²⁵⁸ Mental speed and attention may be directly affected by the tumour,²⁰² while radiation for skull base tumours has also been associated with impairment of memory, visual-motor speed, frontal lobe executive function and fine motor co-ordination.²⁵⁹ Other studies of radiation and chemotherapy for cerebral cancer have failed to identify a clear trend towards worsening of cognitive functioning. Older patients with poorer performance status and subclinical tumour progression appear to be more vulnerable to cognitive effects.²⁶⁰ Patients who experience confusion or motor deficits related to their cerebral disease show diminished role and emotional functioning.²⁶¹

Communication difficulties

Many people who have undergone laryngectomy experience persistent communication difficulties.^{71,205,262,265} According to one study, a high percentage of patients treated with laryngectomy report severe psychological distress between two and six years after the treatment, apparently as a result of problems in effective communication with others.²⁶⁶ Emerging evidence suggests that 33%-40% of patients are totally or partly unsatisfied with their speech rehabilitation program,^{208,267} but over 50% achieve successful communication by oesophageal speech. Those who successfully accomplish oesophageal speech usually report minimal problems in other areas.²⁰⁸ A survey of patients treated for head and neck cancer, which assessed quality of life according to five domains (speech, eating, aesthetics, pain and social role functioning), the domains of speech and eating best predicted quality of life. The domain of speech had the most impact on well-being.²⁶⁸ Communication difficulties are also common for people who have brain cancers. One study reported speech difficulties in 37% of patients and another reported over 50%.^{269,270}

Nutritional deficiencies

Malnutrition, a common problem in patients with cancer, adversely affects survival and quality of life.^{70,207,271,272} Patients with head and neck cancer commonly have nutritional deficiencies before the diagnosis, either due to the disease itself or to pre-existing alcohol problems or tobacco use. Treatment can further impair nutritional status and increase morbidity.²⁰⁸

Enteral nutrition/tube feeding is physically well accepted, and has been shown to improve nutritional status and overall quality of life in several studies of patients with various types of cancers.^{272,274} However, a study of patients with head and neck cancer showed that a substantial proportion of patients experienced psychological distress as a result of the tube.²⁷⁵ Further, although enteral nutrition improves the quality of life of severely malnourished patients with head and neck cancer in the pre-operative period, no benefit is seen six months after surgery (**Level II**).²⁷⁶

Malnutrition results from several factors that alter nutritional intake, such as lack of appetite, problems related to oral cavity or swallowing difficulties.

Lack of appetite

Lack of appetite or poor appetite, especially in the terminal phase of illness, is a distressing problem that affects not only physical symptoms but also functional, social, and psychological aspects of a patient's quality of life.^{277,278} Lack of appetite can be due to cancer itself or its treatment.²⁷¹ Depression can also depress appetite.

Lack of energy or weakness resulting from poor food intake, overall disease burden or poor systemic health, may impair a patient's ability to perform basic daily activities. A poor appetite may also contribute to poor social interactions. There is evidence that family members' distress due to the person's poor appetite may compromise enjoyment of mealtimes. These problems have a negative impact on the patient's psychological well-being.^{277,278}

Oral symptoms

Many cancer treatments commonly result in oral complications such as infections, gingival bleeding, mouth ulcers, stomatitis/mucositis, dry mouth, change in taste, difficulty chewing, difficulty with dentures and increased tooth decay.^{190,279-281}

Dry mouth, change in taste, difficulty chewing, difficulty with dentures and increased tooth decay are common following treatment for head and neck cancer, especially radiation therapy.^{190,281} Oral complications also occur in approximately 40% of patients with non-head and neck cancer treated with chemotherapy and radiation therapy.²⁸² Mucositis, which is often severe and extremely painful, develops in over 75% of bone marrow transplant recipients²⁸³ and is common in patients receiving systemic cancer therapy, bone marrow transplantation and irradiation for tumours of head and neck.²⁸⁴ Oral complications also occur in patients with advanced disease.²⁸⁰

Swallowing difficulties

Available evidence suggests that swallowing difficulties are common in patients with cancer of the head and neck region and oesophagus.^{205,285} It can be due to the tumour, or treatment such as surgery or radiation therapy. Following laryngectomy, swallowing difficulties commonly persist for up to six months and require further investigation.²⁰⁵

Dysphagia also occurs in patients with other types of cancer, as a result of radiation therapy.²⁸⁶ This problem is common among patients with lung cancer.²⁸⁷ In a large multi-centred Australian study, dysphagia was reported by 12% of patients who were treated with radiotherapy alone, and 21% of patients who were treated with combined radiotherapy/chemotherapy.²⁸⁸ Figures were higher in an overseas study, with 64% of patients reporting difficulties²⁸⁹ although in the majority of cases this was mild. Difficulty swallowing is also a common problem in patients with advanced cancer.²⁹⁰⁻²⁹²

Respiratory symptoms

Breathlessness is a frequent and devastating symptom in patients with advanced cancer. It is common, and a source of anxiety, among people with primary lung cancer,²⁹³ people who have had bone marrow transplantation²⁵⁷ and survivors of Hodgkin's Disease.²⁰³ Alongside coughing, breathlessness is the most commonly reported symptom in lung cancer. Malignant pleural effusions are common complications of advanced lung cancer, resulting in dry cough, dyspnoea, fatigue, and localised and pleuritic chest pain.

Dyspnoea may be profoundly distressing, and is reported by patients to restrict many activities, both inside and outside the home. It has an impact on social life and generates considerable

anxiety.²⁹⁴ Dyspnoea is frequently under-diagnosed and inadequately treated.^{295,296} One large study in patients with lung cancer identified dyspnoea as the only respiratory symptom significantly associated with general symptoms, physical and psychosocial functioning and quality of life.²⁹⁷

Radiation therapy offers palliation of respiratory symptoms and improves quality of life in a substantial proportion of patients with non-small cell lung cancer. A recent prospective study in 164 patients reported response rates of 83% for hemoptysis, 68% for chest pain, 37% for dyspnoea, 31% for cough, 36% for global quality of life, 35% for physical and role functioning and 55% for social and cognitive functioning.²⁹⁸ In patients with lung cancer, home oxygen therapy improves dyspnoea in 76% of patients, quality of life in 78%, sleep in 60%, physical activity in 48%, tiredness in 49% and cognitive function in 40%.²⁹⁹

Respiratory symptoms after laryngectomy are both frequent and troublesome. Patients' common complaints include daily sputum production (98%), coughing (64%), forced expectoration in order to clear the airway (57%) and requirement for frequent stoma cleaning (37%).²⁰⁶ Respiratory symptoms correlate significantly with voice rehabilitation and several aspects of daily living.

General health condition

Many patients, although not experiencing severe difficulties with any one specific physical symptom or loss of function, may experience minor difficulties across a number of areas. While each problem in itself may not be severe, the cumulative effect of these minor problems may significantly affect their general health, quality of life and psychological well-being.

2.4 PRACTICAL NEEDS AND FINANCIAL ISSUES

During the period following diagnosis and treatment, people will have many concerns and information needs about practical issues. These include costs for screening, medical procedures, support services such as physiotherapy and counselling, prostheses, travel and accommodation and other practical issues such as child care, home help, etc. In addition, many may be faced with the financial burden resulting from loss of income. Concerns about these issues and how to access relevant information may influence their treatment and well-being.

Costs

People with cancer may incur considerable costs as a result of a cancer diagnosis. These include costs for:

- diagnosis and treatment
- supportive treatments and/or therapies required as a result of the illness. These may include speech therapists/pathologists, physiotherapists, occupational therapists, nutritionists, reconstructive surgeons, fertility clinics and counsellors, psychologists, or psychiatrists
- prostheses or aids necessary to maintain or improve their quality of life. These include:
 - breast prostheses
 - wigs

- continence aids, eg pads, indwelling catheters, garments
- erectile dysfunction aids, eg drugs that assist erectile dysfunction, injections, mechanical aides such as vacuum devices, penile prostheses
- laryngectomy aids, eg speech aids, voice prostheses, batteries, stoma maintenance and protection devices.

Costs may vary, depending upon a number of factors including eligibility for health care concession, financial assistance scheme entitlement, private health insurance cover, the decision to be treated as a public or private patient, state of residence, and accessibility to facilities.

Reconstructive surgery

Patients who have undergone surgical procedures resulting in disfigurement or altered appearance may wish to consider reconstruction or plastic surgery. This will result in additional costs and the extent attributable to the patient will depend on the same factors affecting costs of diagnosis and treatment as outlined above. They will require information about the procedures, local availability, likely costs and sources for financial assistance, as well as information about and referrals to experienced surgeons, eg breast, gynaecological or plastic surgeons.

Lymphoedema

Patients who develop lymphoedema will require physiotherapy, access to compression garments and additional support services. They will need information about trained therapists, treatment locations, compression garment costs and fitting, and assistance with costs. (See also Section 3.7).

Travel and accommodation

Many people in rural and remote areas may need to travel to the city for treatment. For instance, a survey of residents of temporary accommodation provided by the Queensland Leukaemia Foundation identified a substantial financial burden due to relocation for treatment for haematological malignancies.³⁰⁰

Many patients may not be aware of available financial assistance for treatment-related travel. Australian women travelling for breast cancer treatment spend over six weeks away from home on average, and many do not receive the financial assistance to which they are entitled.³⁰¹ For both local and rural patients, ambulance travel may also be necessary sometimes.

Other support needs

Some patients experience difficulties with domestic chores or self care,^{68,302} and may require support for child care, meals and home help while they are recovering from surgery, and during radiation therapy and/or chemotherapy. They will require information about available services and how to access them.

Loss of income

Some people may experience extensive periods off work while recovering from surgery, during radiation and/or chemotherapy,^{68,116,163} and may not qualify for sickness allowances. Others may have to cope with permanent loss of employment as a result of their cancer.

For example, some studies have shown that 50% of people who have had a laryngectomy do not return to full employment, and more than half report financial problems.^{71,267} According to a large national health survey, one in five people who have, or have had cancer report employment problems.³⁰³ Many experience psychological distress due to the financial effects of their illness.⁷¹

Difficulties with business dealings

In some cases, declaration of health status may be a legal requirement of business dealings or transactions. People who have, or have had cancer may be confronted with a range of difficulties including the right to sign contracts, access to loans, or eligibility for travel insurance or life insurance. For instance, a study of survivors of Hodgkin's Disease showed that they experienced difficulties borrowing from banks,²⁰³ and the results of a large national health survey showed that 9% of people who have, or have had, cancer were denied health insurance.³⁰³

Practical aspects of advanced disease

Patients in the palliative phase may have concerns and information needs relating to legal issues such as naming a Power of Attorney or preparing a Living Will or Advanced Care Directive. They may also be concerned over issues such as where they wish to die and funeral arrangements.

2.5 TOWARDS THE END OF LIFE ISSUES

Advanced cancer impacts on the quality of life of the patient and their family or caregivers in many ways. They will need to cope with ongoing physical symptoms and deterioration of physical functioning, increasing psychological distress and increasing disruption to social activities. They will also be faced with existential and spiritual issues as they come to terms with impending death. Clinicians working with people with advanced cancer also experience psychosocial effects (Section 1.4). Bereavement issues are discussed in Section 3.6.

Physical issues towards the end of life

Quality of life in people with advanced cancer is affected by symptoms, loss of function and curtailment of activity and physical effects of treatment.³⁰⁴ Symptoms affecting quality of life may be related to the cancer and/or treatment, and include nausea, pain, dyspnoea, fatigue, anorexia, vomiting, constipation, abdominal bloating and lymphoedema.

Towards the end of life, people with cancer are commonly unable to perform activities of daily living, including self-care activities (feeding, dressing, bathing), mobility (ability to move indoors/outdoors), physical activities (walking, lifting, bending) and role activities (work, school, household activities). Women with advanced breast cancer rank self-care, mobility, physical activity, appetite and sleep quality high among their quality-of-life concerns.³⁰⁵

Poorly controlled pain or inadequately assessed fatigue contribute to psychological distress and impairment of physical and social functioning.^{158,306,309} Patients with metastatic disease have a significantly greater unmet need for assistance with physical aspects of daily living compared with the needs of patients in remission.³¹⁰

Psychological issues towards the end of life

The diagnosis of recurrence challenges people to confront their mortality more than at any other stage of the cancer illness.³¹¹ Coping with grief and concerns associated with disease progression may be very difficult for patients and their families. Many report that distress increases as the cancer progresses.³¹² Studies of patients with breast cancer have shown that 25%-50% of women experience clinically significant anxiety and depression on receiving the diagnosis of recurrence,^{13,14,158,306} 50%-75% of women rating the diagnosis of recurrence as more devastating than the original diagnosis,^{13,14} and studies of patients with various types of cancer show that recurrence is associated with greater adjustment problems and more pessimism than the original diagnosis.^{313,314}

Physical burden of disease in patients with cancer exerts a major influence on the emotional coping ability. An Australian study of 110 melanoma patients with Stage IV disease revealed that the inability to minimise the impact of cancer on everyday life resulted in a deterioration in mood.³¹⁵ In a study of mostly elderly, seriously ill men with cancer, the expectation of a negative effect from the disease was associated with decreased quality of life.³¹⁶ Pain also exerts a powerful influence on adjustment, perceived self-efficacy being inversely correlated with pain, (i.e. people who believe in their ability to perform pain coping behaviours report lower pain scores).³¹⁷ Age and gender also affect cognitive appraisal of one's situation.³¹⁸

Patients' ability to cope with advanced cancer appears to be influenced by the quality of relationships and social support. Women with metastatic breast cancer report less distress when their relationship with their partner is more cohesive.³¹⁹ Better adjustment appears related to emotional expression³²⁰ and less avoidance.³²¹

Social issues towards the end of life

Cancer and cancer treatment can disrupt social relationships as a result of impaired ability to pursue normal activities (see Sections 2.1 and 2.3). Maintenance of social contacts may be seriously limited by the demands of treatment regimens, and by others' psychological reactions and concerns. Friends and family may fear that the person will be unable to manage the demands of social contact.

Existential and spiritual issues towards the end of life

Existential distress is defined as the worry and concern that arises from confrontation with mortality, the meaning of life, isolation and worth as a person. Existential issues such as concerns about death, freedom, isolation and the question of meaning may become increasingly important to people with advanced cancer. According to one study, existential issues were reported to be at least as important as the physical, psychological and social support domains in determining quality of life.³²²

Studies utilising structured interviews provide evidence that spiritual issues gain importance as determinants of quality of life as the physical condition deteriorates.³²³ In the spiritual domain, the basic human need for transcendence, 'to step back and move beyond what is', may manifest as a search for meaning in the illness. Spiritual considerations may also assist the individual to endure present discomforts and, if need be, to face death with courage and dignity.³²³⁻³²⁵

Impact of towards-the-end-of-life issues on the family

When a family member has cancer and is approaching the end of life, the family's distress appears to be heightened when there are unclear role and power structures.³²⁶ The needs of patients and family members may differ, as evidenced by a study of 38 families of patients of men with prostate cancer.³²⁷

A study comparing levels of distress among patients with advanced cancer with those of family members found that family and caregivers feel more distressed by the diagnosis than the patient,³²⁸ and that some family members may avoid discussing disease recurrence or dying because they are uncertain about what to say. An Australian study of 102 families of palliative care patients found that one-half of patients, one-third of spouses and one-quarter of offspring were depressed.³²⁹ Another study of families with a member receiving palliative care found that offspring of the patient were more likely to experience anger, and that anger levels were higher among family members with higher level of education, and those not living with the patient acting as primary caregiver.³³⁰

The needs of children who have a parent with advanced cancer are complex (See Section 2.1). Major factors affecting adjustment appear to be the developmental stage of the child, the extent of parental disease,³³¹ and the inability of parents to recognise and respond to the child's emotional needs.^{67,97} Findings from review studies and survey data assessing adjustment in children of patients with advanced cancer include the following:

- younger children are often concerned with the disintegration of the family, and are worried about the vulnerability of the well parent³³²
- children may experience guilt about their own possible contribution to parental illness³³³
- for adolescents who have a parent with breast cancer, disruption to social networks and leisure activities and increased domestic responsibilities are prominent issues³³⁴
- adolescent daughters of mothers with cancer report high levels of anxiety and depressive symptoms,^{67,335} which may reflect identification with their mother and changes in role expectation.⁶⁷ There appear to be gender differences in patterns of communication with children, fathers generally being less likely to discuss issues relating to cancer and death than mothers.³³⁶

Impact of towards-the-end-of-life issues on caregivers

Those who care for patients with cancer report high levels of role and personal strain, and overall burden.³³⁷ Those who offer informal care also appear vulnerable. Forty-one per cent of 39 informal carers of palliative care patients reported high levels of strain in one study, with younger age and female gender correlating with higher stress.³³⁸ An Australian study has identified, a greater number of adverse life events, past bereavement, and separation experiences as risk factors for adverse short-term bereavement outcome in carers. The major predictor was severity of distress at the time of referral to the palliative care service.³³⁹

2.6 SURVIVAL ISSUES

Medicine has traditionally focused on the diagnosis and management of illness, or its prevention. Earlier detection and improved treatments are now leading to increasing proportions of patients surviving cancer. The chance of survival is high for many patients,

such as those with locally confined prostate cancer. The precise emotional needs of patients who are cured have been less clearly defined.

A review of studies of patients with cancer who had survived for five or more years reported that many continued to experience negative effects of cancer and/or treatment on their daily lives well beyond the completion of therapy.³⁴⁰ Themes described by cancer survivors include the struggle between independence and dependence, balance, a sense of wholeness, life purpose, reclaiming life, dealing with multiple losses, having control, the altered meaning of health, and surviving cancer from a family perspective.³⁴¹ This research highlights the need to be aware of the physical, emotional and social impact of cancer even in the longer-term, incorporating an understanding of the unique meaning of the cancer experience to the individual.

Physical issues for cancer survivors

Physical symptoms may exert a powerful impact on psychological adjustment (see Section 2.3). It is important to recognise that, in many cases, the cancer survivor has not returned to their pre-cancer level of physical functioning. Fatigue is reported to be a severe problem for cancer survivors³⁴² and a major symptom interfering with daily life.³⁴³ Despite this, fatigue is consistently under-reported and under-recognised.¹⁹²

Some studies of survivors of head and neck cancers show that symptoms such as dysphagia, heartburn, altered taste and smell, and problems with saliva may persist, and are associated with greater functional impairment.^{281,344} Physical sequelae of cancer such as stoma, scars and disfigurement, or Electrolarynx implantation may lead to social isolation and disruption of work, social life and intimacy.^{345,346} Lymphoedema is also associated with substantial functional impairment and psychological morbidity.^{194,347} There is some evidence that cancer survivors of lower socio-economic status have worse outcomes for pain, ambulation and social and emotional well-being.³⁴⁸

In addition to these physical issues, according to one large national health survey, nearly one-fifth of the cancer survivors who worked before or after their cancer was diagnosed experienced employment problems because of their cancer (see Section 2.4).³⁰³ Unemployment and financial strain impose an additional psychological burden on cancer survivors.³⁴⁹

Sexual issues for cancer survivors

Disease or treatment that affects sexual function can have profound effects on quality of life and relationships (See Section 2.2). Survivors of gynaecological cancers report ongoing sexual difficulties.^{120,122} Cervical cancer, especially with radiation therapy, may result in vaginal dryness, stenosis, and lack of lubrication. These problems, and concerns that sexual activity is an aetiological factor, may adversely affect the woman's sex life and quality of life.³⁵⁰ For survivors of prostate cancer, sexual dysfunction is one of the most frequently identified problems¹⁸⁸ and a major stressor.¹²⁷ Sexual symptoms are also commonly reported by patients who have undergone bone marrow transplantation. In one study, 80% of women and 29% of men reported at least one sexual problem by three years post transplant,³⁵¹ another study of long-term survivors of Hodgkin's Disease reporting transient or permanent sexual problems in up to 16% of patients.³⁵² Even five years after initial treatment, women who have been treated for breast cancer report reduced quality of life in emotional, social and sexual functioning.³⁵³ As described in Section 2.2 the negotiation of new relationships post cancer treatment poses a complex series of concerns for many patients.

Specific emotional issues related to survival

The nature of the emotional concerns of those who have survived cancer is an emerging area of research, and there are limited data about issues specific to different clinical groups. It appears that psychological problems are commonly experienced by women who have survived endometrial cancer, with younger women experiencing higher emotional morbidity.³⁵⁴ Emotional well-being appears to improve over time for patients who have been treated for colon cancer.³⁴⁸ However, cancer is not universally a negative experience³⁵⁵ about 25% of patients who have survived leukaemia reporting a positive impact of the experience on their lives.³⁵⁶

The experience of cancer necessitates reflection on values, and challenges assumptions about life, relationships and mortality³⁴⁵ and sense of personal identity.³²⁴ However, there is potential for tension within relationship if others fail to recognise these changes. Partners and families may themselves feel emotionally exhausted and wish for painful reminders of the experience to be left behind. Urging the person to be 'grateful to be alive' may compound a sense of isolation and being poorly understood. In this context, cancer survivors may seek the company of other survivors who they feel will better understand their experiences and needs.³⁴⁵ Spouse relationships that were unsatisfactory before the illness may not survive as the survivor makes a new start in life.

Some authors also describe a sense of guilt about having survived, and a sense of personal or social debt among cancer survivors. Anecdotal evidence suggests that this may particularly apply in cases when the person has survived as a result of a bone marrow donation.

Concerns about recurrence

Survivors are vulnerable to fears of recurrence, and must confront this each time they feel unwell or present for follow-up testing or screening. For example, many women who have survived breast cancer report a psychological burden related to fear of recurrence.³⁵⁷ Strategies survivors use for coping with this fear of recurrence include adoption of a healthy diet and lifestyle, emotional sharing of concerns (often felt to be easier with other survivors), and use of humour.

Concerns for people with familial cancers

Between 5%-10% of common cancers in Australians are attributable to an inherited cancer disposition.³⁵⁸ People with familial cancer and their families, may face a range of issues.

These include:

- psychological distress (eg fear, anxiety, guilt) associated with having and passing on gene mutations to their children
- anxiety about developing cancer
- psychological distress (eg guilt, a sense of isolation) associated with not having a mutation when other family members do
- concerns and information needs about screening and genetic testing.

People with familial cancers should be referred to familial cancer clinics. The *NHMRC Familial aspects of cancer: a guide to clinical practice*, provides comprehensive details about the issues and management recommendation relating to familial cancers.

CHAPTER 3 CARE TO BE PROVIDED BY THE TREATMENT TEAM TO ALL PATIENTS WITH CANCER

The psychosocial care of a person with cancer begins from the time of initial diagnosis, through treatment, recovery and survival, or through the move from curative to non-curative aims of treatment, initiation of palliative care, death and bereavement. It involves all members of the treatment team, the person's general practitioner and family, friends and carers. These people may have psychosocial needs of their own that must be addressed if they are to function in support of the person with cancer (see Sections 1.4 and 2.1). In specific cases, eg for patients with pre-existing mental illness or medical condition, communication with the patients care provider is essential. Attention to these issues is likely to lead to increased patient satisfaction with care, reduction in distress and lead to enhanced professional satisfaction.

There is a need for social and cultural sensitivity in assessment of need, establishment of the setting for care, and the delivery of services. Successful strategies for meeting psychosocial support needs may differ with gender, although gender issues have often been ignored in clinical trials and lost in research syntheses supplying Level I evidence for psychological interventions **(Level I)**,³⁵⁹ **(Level II)**,³⁶⁰ **(Level III-2)**,³⁶¹ **(Level IV)**.⁵⁴ Where the delivery method is inappropriate or insensitive, people with cancer may simply not participate or may not gain a benefit **(Level II)**,³⁶² **(Level III-3)**.³⁶³

Effective communication is central to the identification of individuals' specific needs and the provision of appropriate information and psychosocial support. Sensitivity to the particular needs of each patient is required, with an awareness of issues of gender, age, culture, education and socio-economic status. Good communication involves more than a mere facility with words; it requires both a willingness to engage with others emotionally, and appropriate and sensitive use of physical touch. The ability of healthcare professionals to communicate with patients, the patients' families and friends, and each other, lies at the core of optimal patient care and professional satisfaction.

The development of clinic based protocols can be beneficial in ensuring effective communication between members of the treatment team and the patient, and the delivery of quality supportive care. Recommended protocols are summarised in Table 3. While these may not always be possible to implement in small or rural settings, they provide a useful benchmark against which to assess current services.

Table 3: Protocols to support psychosocial care in the treatment unit and evidence to support their implementation

Clinic-based protocols should be developed to ensure the following goals	Evidence to support implementation
<p>Information</p> <ul style="list-style-type: none"> Copies of evidence based information about treatment options are provided to all patients Listings of other information resources which may be of value are provided to all patients <p>Continuity of care and referral networks</p> <ul style="list-style-type: none"> All patients are able to identify a key health professional responsible for continuity of care Referral pathways for liaison psychiatry, psychologists, support groups and relevant allied health professionals are established and known to the team <p>Screening for special problems</p> <ul style="list-style-type: none"> All patients are screened for clinically significant anxiety and depression <p>Communication skills</p> <ul style="list-style-type: none"> All staff working with patients with cancer have participated in relevant communication skills training 	<p>A³⁶⁴ B³⁶⁵ C³⁶⁶ Level III-3³⁶⁷</p> <p>C³⁶⁸ Level II³⁶⁹ Level III-2³⁷⁰ Level III-3³⁶⁷ Level IV³⁷¹</p> <p>A³⁷² B³⁷³</p> <p>A³⁷² B³⁷³</p> <p>B³⁷⁴ B³⁷⁵ Level III-3^{376,377,378}</p> <p>Level III-1³⁷⁹ Level III-2³⁵ Level III-3³⁸⁰ Level IV^{115,381,382}</p>

A denotes Guideline

B denotes Review article

C denotes Report

3.1 GENERAL INTERACTIONAL SKILLS

Communication skills

Potential benefits of effective communication between treatment team members and people with cancer include improvements in the patient's psychosocial adjustment, decision-making, treatment compliance and satisfaction with care (**Level I**).¹⁵

People with cancer repeatedly report a desire to be well informed. The clinician is often the key source of information, especially around issues of diagnosis, treatment and prognosis. Research indicates that up to 66% of patients with cancer prefer key information to come from a hospital specialist.³⁸³

Beyond the provision of information, effective communication requires a process of individually-tailored explanation, problem-solving and acknowledgement of the person's feelings. The way clinicians present information significantly affects people's recall of that information (**Level III-2**).³⁸⁴ Survey data indicates that people prefer communication styles which provide information in a 'sensitive and reassuring' way and to be treated as individuals.^{385,386}

The benefits of communication skills training

The quality of medical care is as dependent on competence in interactional skills as it is on technical competence.³⁸⁷ Survey data suggest that many clinicians are uncomfortable with their level of communication skills.³⁸⁸ Their failure to communicate well often seems to result from a lack of confidence or perceived lack of knowledge.³⁸⁹ Training in communication skills can assist clinicians to improve (**Level III-I**),³⁷⁹ (**Level IV**)^{115,381,382} and continuing training in the appropriate clinical setting may be beneficial, given evidence that skills need to be reinforced and consolidated over time (**Level IV**).^{115,381,390,391}

The following interactional skills (summarised in Table 3.1) are relevant to any clinical situation, and should be considered in any consultation with a person with cancer.

Skills to convey support

Patients' psychological adjustment improves when clinicians express empathy and listen actively (**Level III-3**),³⁹² (**Level IV**).³⁷¹ A randomised control trial conducted to assess the effect of physician compassion on patients' anxiety revealed that women who saw a 40-second 'enhanced compassion' videotape in which the physician acknowledged the psychological concerns of the patient, expressed partnership and support, validated her emotional state, touched her hand and tried to reassure her, were significantly less anxious than women who saw a tape without these components of compassion (**Level II**).³⁹³ The enhanced compassion components took just 40 seconds, and yet had these significant effects.

Expressing empathy means acknowledging the person's feelings through phrases like 'This must be very hard for you to hear'. *Listening actively* includes verbally acknowledging what the person has said and/or asking questions to clarify what they mean. Active listening can help the clinician understand the patient and encourage the patient to explore their feelings and beliefs.

A patient's potential range of responses is encouraged by asking open questions, eg 'How are things?' or 'Can you tell me how you are feeling?' Asking only closed questions, eg 'Are you coping OK?' or 'Is everything alright?' elicits specific discrete responses that may be limited in their information value and can inhibit effective communication.

Appropriate non-verbal communication suited to the patient's style of communication can increase the effectiveness of the interaction. Friendliness and openness can be conveyed by sitting facing the person in a relaxed manner, leaning towards the person when they are speaking, and making regular eye contact.³⁹¹ Physical touch is occasionally helpful, for both the clinician and the patient, and may be experienced as therapeutic.³⁹⁴

Ensuring medical information is understood and retained

It is important to deliver information in such a way that is easily understood and retained by people who are not familiar with medical terms. A review of relevant studies indicates that people forget a significant amount of information heard and understood during a consultation.³⁸⁹

Evidence suggests that understanding and recall can be boosted by:

- giving clear, specific information (**Level III-3**)³⁶⁷
- explaining medical terms and avoiding medical jargon (**Level III-3**)³⁶⁷
- presenting the information in terms of the specifics for each patient, rather than in a general format (**Level III-3**)³⁸⁹
- giving the most important information first (**Level IV**)³⁹⁵
- repeating and summarising important pieces of information (**Level III-3**)³⁶⁷
- actively encouraging questions (**Level II**)³⁹⁶
- actively checking understanding, eg 'Just so I can be sure I've explained everything clearly, could you summarise what you think your options are?' (**Level III-3**).³⁶⁷

Clinicians need to be sensitive to issues of gender, social class, ethnic background and religious belief and aware of possible hearing impediments in older patients. Clinicians who use open ended questions at the beginning of a consultation, display empathy and clarify verbal clues given by the patient have been found to be more likely to recognise psychological distress.³⁹⁷

Patients should be fully involved in the communication process, and not passive recipients. Simple diagrams, models or pamphlets can be used to complement verbal advice.

Additional strategies shown to increase satisfaction, recall and understanding include:

- providing written information (**Level III-3**)³⁶⁷
- providing general information tapes (**Level II**)³⁶⁹
- taping of the consultation (**Level II**)^{398,399}
- sending a summary letter as a follow-up to the consultation (**Level II**)⁴⁰⁰
- encouraging the presence of a support person (healthcare professional, family or friend) (**Level II**),⁴⁰¹ (**Level IV**).³⁹¹

Communicating in a quiet and private environment

Information about cancer and treatment often has considerable emotional impact on people. People may forget a large proportion of information, feel unsatisfied and become distressed if confronted with information about diagnosis and treatment in a distracting environment such as an open ward, or by professionals who they perceive to be rushed and unsupportive, as may occur during a ward round.

Role of the clinician

Clinicians have a key role in ensuring and facilitating effective communication between all members of a patient's treatment team, their carers and family. It is important for clinicians to appreciate the distinction between patient-centred and doctor-centred communication behaviours. A patient-centred style consists of more affective behaviours (empathy, openness, reassurance) and involves the patient in the decision-making process. In a doctor-centred style, the clinician is task focused, exhibits controlling behaviours and tends to be less empathic.⁴⁰²

In general, both patients and their relatives prefer a patient-centred consulting style. There is some evidence that patients are less satisfied when a clinician verbally or emotionally dominates the interaction (**Level III-3**),⁴⁰³ and that patients expect clinicians to broach the subject of psychosocial issues (**Level III-3**).⁴⁰³ However, as a substantial minority of patients prefer a doctor-centred style, at least at some times, clinicians need to be alert and to regularly assess patients' wishes in this regard (**Level II**).⁴⁰²

Clinicians should keep an open mind as to the patient's possible response to their diagnosis or treatment plan, particularly in the first consultation. Not everyone will be shattered or compliant at the news. It may be necessary to ride out the patient's anger, negativism or even rudeness. These patients may grieve later, in private, and not admit this to the clinician.

Responding to patterns of behaviour that may compromise treatment and cure

Treating patients whose outcome is potentially affected by delayed presentation or continued risk-taking behaviour such as heavy smoking can engender feelings of frustration and despair in health professionals, who may struggle to comprehend the circumstances that have led to the clinical situation. There is a potential for clinicians' reactions and concerns to adversely affect interactions with such patients, many of whom will be isolated and poorly educated and thus at increased risk of adverse psychological outcome, particularly if their disease is advanced.

Asking about the reasons for delay may provide useful information that will inform the way information is structured and how the discussion of clinical treatment is approached. It is best to phrase questions in a way that will avoid communicating frustration or criticism. For instance:

'You were saying that you first noticed [the symptom] six months ago. Can you tell me what thoughts you had then about what it might be?'

'I guess you have thought about it a bit... Did you feel worried about what [this symptom] might mean?'

'You've said that you were aware of [this symptom] a while back, but you didn't feel too concerned. Can you tell me what made you concerned now, and if anything in particular prompted you to seek attention now?'

It is important in this context to consider the benefit of a multidisciplinary approach to the clinical care of such patients, including attention to needs for appropriate support, and early identification and treatment of psychological disorders. It is often beneficial for the treatment team to discuss patients whose behaviour confronts or distresses team members.⁴⁰⁴

A variety of factors other than symptoms may result in a late presentation for assessment, leading to delays in diagnosis and initiation of treatment, with adverse implications for prognosis. In the case of melanoma, the rate of self-detection tends to be lower, delays before seeking medical treatment longer, and tumour thickness higher in males, those with lower levels of education, those living in rural areas, and in people with lower levels of awareness of melanocytic cancers.⁴⁰⁵

Clinicians may also find it difficult to deal with patients who continue to smoke and consume alcohol following treatment for head and neck cancer. It appears that different factors are relevant for these behaviours. Higher education, living with a partner, later stage, laryngeal site and having surgery or combined therapy are associated with decreased odds for

smoking. In contrast, male gender, Stage I disease and longer time since treatment are associated with increased odds of drinking alcohol.⁴⁰⁶ It is important that clinicians actively encourage patients in healthy behaviour, given the poor levels of public awareness of the risk factors for oral cancers, the high receptivity of cancer survivors for health promotion campaigns and the evidence that many cancer survivors successfully cease smoking.⁴⁰⁷⁻⁴⁰⁹ People who attribute the cause of their cancer to past substance use, and feel that their future cancer-related health is contingent on their own behaviour are more likely to cease smoking.⁴¹⁰

Table 3.1: General interactional skills

GENERAL INTERACTIONAL SKILLS

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

Supportive communication

- Ask the person if they would like someone to be with them during the consultation
- Show regard and concern for the person by using appropriate verbal and non-verbal behaviour, including sitting attentively and facilitating the person's responses
- Use verbal and non-verbal behaviours which are appropriate to the person's age and cultural background
- Express empathy and listen actively
- Allow and encourage the person to express their feelings, eg crying, talking about concerns, fears, anger, anxieties, etc.
- Handle embarrassing or disturbing topics directly and sensitively

Delivering medical information in plain English (see also Section 5.1)

- Assess the person's understanding before providing additional information
- Explain difficult terms and avoid medical jargon
- Use explicit categorisation (provide information clearly grouped into specific topics)

Strategies to aid recall and understanding

- Actively encourage questions and seek understanding
- Make use of simple diagrams and pictures where appropriate
- Repeat and summarise important information
- Reinforce important information by using one or more of the following aids:
 - writing down relevant information
 - taping the consultation as needed and if wanted
 - sending a summary letter as follow-up

Ongoing support

- Assess the person's level of family or social support
- Provide the names and contact details of relevant persons or organisations to obtain more information
- Refer to a specialist oncology nurse or other professional for support as required

Adapted from *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer*²⁸

3.2 PROVIDING INFORMATION

3.2.1 Telling a person they have cancer, a recurrence or metastases

The way in which a diagnosis of cancer is delivered affects not only the person's understanding of the illness, but can also impact on their longer term psychological adjustment.^{62,371} For example, reaction to the diagnosis of a life-threatening illness has recently been accepted in criteria for post-traumatic stress disorder.⁴¹¹

Most existing guidelines, and the relatively small amount of research in this area, have focused on how the initial diagnosis of cancer is given and received. Evidence indicates that the psychological impact of news of a recurrence may be more devastating for the patient than the initial diagnosis (**Level III-3**)³⁹² and may prove more difficult to communicate for the clinician. (See also Section 2.5)

Much of the information and subsequent recommendations presented in this section have been adapted from reports commissioned by the Cancer Council NSW,³⁹¹ from guidelines,³⁶⁴ and from surveys commissioned by the National Breast Cancer Centre.³⁶⁸

Setting

People may receive the news of diagnosis of cancer in hospital clinics, wards, doctors' offices or screening facilities. It is essential for a diagnosis of cancer to be given in a place that is quiet and private and for a support person, such as a specialist oncology nurse, counsellor, family member or friend, to be invited to be present.³⁶⁴ Special measures may be necessary to ensure privacy if an individual is presented with test results in a hospital ward setting. People usually need uninterrupted time to discuss issues arising from this news.

Consideration should be given to the appropriateness of giving a diagnosis of cancer over the phone. Where the diagnosis is likely to be cancer, clinicians should ensure that early appointments are made so that patients are not subjected to unnecessary additional stress while waiting for their test results or diagnosis.

Type of information

Research suggests that most people prefer to be told all of the information about their disease, even if it is bad news. The most appropriate approach is to tailor the information to the individual's needs (**Level IV**).³⁷¹

Most people appear to be satisfied with the way that they are told their diagnosis, but would like more information, particularly about their test results and their prognosis (**Level IV**).³⁷¹ There is also a duty of care for clinicians to disclose any information that may impact on the person's treatment outcomes and/or quality of life.

At the time of a diagnosis of cancer, many people will be concerned about the possibility of death and dying. However, it may not be until the person has been diagnosed with a recurrence or distant metastasis that clinically, they need to face the issue of dying from cancer. The clinician has a central role in supporting patients so as to enable them to address these issues in a manner appropriate for each individual. This entails acknowledging fears people express and providing them with the relevant information.

Increasing understanding

A person's ability to recall medical information is an important factor in their ability to take a role in making treatment decisions. Effective methods of communication ensure the person is best able to absorb, understand and recall information (see Section 3.1 and Table 3.1).

Key supportive interactional strategies include:

- repeating information, especially information given initially about prognosis and treatment
- taking into consideration any other health concerns that are not related to cancer
- maintaining supportive, non-verbal communication, such as good eye contact
- acknowledging gender, age and cultural differences affecting emotional support.

Discussing difficult issues

In general it is important to encourage all individuals to talk about the illness and its impact and to offer appropriate support. Directly confronting the reality of the illness and openly expressing emotions appears to be associated with enhanced adjustment whereas avoidance of issues is associated with higher levels of distress.⁴¹²⁻⁴¹⁴ Therefore it is important to encourage the individual to talk about the illness and its impact and to offer appropriate support whilst recognising individual preferences.

Each person's response to the news of a diagnosis, recurrence or metastasis will be influenced by their personality, past experience, social situation, responsibilities and disease burden. An individual may employ one of many coping strategies, and particular coping strategies used may vary over time⁴¹⁵ or with disease stage.⁴¹²

Patients' preferences

Data from a large survey of patients with different types of cancers, that investigated how important various aspects of being given a cancer diagnosis were to patients, suggests that patients rate the message content as most important, although the supportive and facilitative dimensions are also rated highly. Female patients rated content and support more highly than male patients, and patients with more education wanted more detail.⁴¹⁶

An Australian survey of women with breast cancer³⁶⁸ found that the majority of patients reported that they wanted members of the treatment team to:

- encourage them to bring a relative or friend
- give an opportunity to ask questions and listen to their fears and concerns

- ask if they would like a second opinion
- write down and summarise what they have been told
- explain any medical terms and check understanding
- give them published information about their situation
- keep checking whether they want to be told the prognosis
- emphasise the good aspects of the prognosis
- talk about complementary therapies, eg relaxation
- provide information about support services.

However studies show variations in patient preferences. For example, it is generally recommended that another person is present at the time of diagnosis.³⁹¹ In one survey, most women with breast cancer said they would take this opportunity if it was offered.⁸⁵ In contrast, in a study of people with head and neck cancers, 81% did not want anyone else present at the time of diagnosis,⁴¹⁷ and another study found few melanoma patients had a preference for having another healthcare professional present at the time of diagnosis.⁴¹⁸ Therefore, the primary recommendation is to always check with each patient at each visit about their preferences.

Recommended steps for discussing diagnoses are detailed in Table 3.2.1.

Table 3.2.1: Recommended steps for telling a person they have cancer, a recurrence or metastases

These steps are recommended in conjunction with the general interactional skills in Table 3.1.

Prior to discussing diagnosis, recurrence or metastases

- Ensure the news is given in person, in a quiet, private place and allow enough uninterrupted time
- Encourage a second person to be present if appropriate
- Arrange to provide other methods to convey the information, eg written materials, video tapes, tapes of consultations

When providing the information

- Assess the person's understanding of their condition and their personal preference for information
- Briefly explain the process by which the diagnosis was reached
- Provide information simply and honestly, using lay terms without using euphemisms
- Avoid giving the message that 'nothing can be done'
- Clearly indicate that the individual will have the final decision regarding their care

Emotional and supportive role

- Encourage the person to express their feelings, eg crying freely, talking about concerns, fears, anger or anxieties, and respond to their feelings with empathy
- Address disturbing or embarrassing topics directly, and with sensitivity
- Assess the type and level of assistance that may be required, such as financial, transport or child care assistance
- Provide information about support services

Concluding the discussion

- Summarise main points of the consultation and assess the person's understanding
- Ask if there is anything further the individual would like to discuss
- Offer assistance to tell others difficult news
- Indicate your availability for contact to address any questions or concerns and arrange a further appointment to review situation within a stated time period, eg within 24 hours to two weeks

After discussing a diagnosis, recurrence or metastases

- Document information given to the person and family members
- Let others, particularly the individual's general practitioner, know the extent of information given and your perception of the person's understanding

Adapted from Girgis *et al.*³⁹¹ *How to Break bad News*. NSW Cancer Council and NHMRC *Clinical Guidelines for the Management of Early Breast Cancer*.³⁶⁴

3.2.2 Discussing prognosis

After receiving the diagnosis of cancer, patients' decisions about treatment will be governed by the information they receive about prognosis, and their response to that information.

The National Health and Medical Research Council (NHMRC) recommends that patients should be given "adequate information about all pertinent matters, including even low probability or risk in a form which promotes understanding".⁴¹⁹ It is important to consider which information patients find most useful. Depending on the patient, this might be information that is:

- specific, eg median survival
- general, eg 'I think your chances are good'
- statistical, eg average time gained, risk reduction or survival curves
- about exceptional cases.

As many patients and clinicians wish to preserve hope, negotiating when and how to discuss each of these aspects is a critical clinical skill.

Recommended steps for discussing prognosis are presented in Table 3.2.2.

Influence on psychological adjustment

While few studies have assessed how the way in which prognosis is communicated influences subsequent psychological adjustment, available data suggest that prognostic information that is tailored to the patient's preferences, can contribute significantly to the person's well-being.⁴¹⁸ According to a study of patients with melanoma, patients who reported that their doctor had talked about the severity of their cancer, life expectancy and how the cancer would affect other aspects of their life expressed higher satisfaction with their medical care, especially if their preference was to discuss these aspects. Lower levels of anxiety and depression were also observed amongst those patients who reported having their need for life expectancy discussions satisfied and having been able to discuss their questions on the same day as the diagnosis.⁴¹⁸

However, information about a major change in a patient's prognosis may be destabilising and should be communicated with special care, according to one qualitative study.⁴²⁰ Care is also needed when discussing prognosis and treatment options with patients who have cancers with poor prognosis, such as pancreatic cancer, as these patients are especially vulnerable to psychological distress, and high levels of depression have been reported in this population.¹⁷¹

Influence of risk communication on treatment decisions

A balanced presentation of the facts will assist patients in making treatment decisions. The clinician's opinions or recommendations should be distinguished from the facts of the patient's case.

In some studies, patients have reported that their choices among treatment options are influenced by the way in which clinicians communicate the risk of recurrence and relative risk reduction of treatments.⁴²¹ A study of patients with metastatic colon cancer or advanced non-small cell lung cancer found that patients who had optimistic misperceptions of their prognosis often requested medical therapies that decreased their quality of life and did not result in any increase in longevity.⁴²²

Current practice

Most Australian patients are now routinely told their diagnosis,⁴²¹ although current practice regarding the communication of prognostic information is likely to differ according to the stage of the cancer.

An Australian study of patients with early or late stage breast cancer or melanoma, interviewed six to 12 months after their diagnosis, found that only 27% said they had been told their prognosis, whereas 57% said they wanted prognostic information.⁴²¹

There have been few studies documenting how people with cancer seek or receive prognostic information. One study reported that patients with incurable disease who received more prognostic information were no more anxious after the consultation than those who were not given this information (**Level III-2**).⁴²³

An Australian study that analysed audio-tapes of consultations between 118 patients with incurable cancer and their oncologists for prognostic content found that at the initial consultation, most patients were informed that their disease was incurable (75%) and just over half (58%) received information about life expectancy (**Level III-2**).⁴²³ In the adjuvant setting, a similar audio-tape analysis of consultations with 101 patients with cancer found a much higher rate of disclosure; all but one of the patients were informed of the treatment prognosis, and the prognosis with no further treatment was discussed with 88%. Prognosis was expressed in both words and numbers in 66% of the consultations (**Level IV**).⁴²⁴

An American survey of hospice clinicians, found that only 37% indicated they would communicate a correct prognosis, 23% would not communicate survival estimates, and 40% would communicate a different estimate from the one they had formulated (mostly more optimistic). Older, more experienced clinicians and those least confident about their prognostic abilities were least likely to favour disclosure. The clinicians' own estimates of prognosis were optimistic, compared to actual survival ascertained from death registries.⁴²⁵

Patient preferences for content

Research findings suggest that patients desire to know both positive and negative aspects of their prognosis, but that specific information preferences are diverse. One approach

consistent with the data is to tell patients what type of prognostic information is available, then ask how much of this information they want to hear.³⁶⁸ It appears best to discuss prognosis in relation to the outcomes for each different treatment option, and to emphasise the hope-giving aspects of each option. Focusing on what can be achieved, rather than what cannot be achieved, is a useful strategy.⁴²⁶

A survey among women with breast cancer identified considerable variation in preferences for specific types of prognostic information.³⁶⁸ Over 90% of the women wanted to know about the probability of a cure, the chances that the recommended treatment would work and the staging details. Almost half the women wanted survival data.

In another study, Australian women with cancer expressed a desire for 'good news' stories, but felt that honest, straight-forward disclosure of information was helpful in decision-making, in allaying unrealistic fears and in ensuring a trusting, equal relationship with the clinician. Participants in this study also emphasised the importance of negotiating the content and timing of prognostic information.⁴²⁶

Providing support and emphasising hopefulness

The way information is given may be as important, or more important, to people with cancer than the content of that information. One study of patients with breast cancer found that patients whose surgeons used counselling techniques during the cancer diagnostic interview showed improved psychological adjustment to their cancer (**Level III-3**).³⁹²

Information should be presented in a way that emphasises the reasons for hope. A study of women with metastatic breast cancer that used in-depth interviews identified a desire for information about prognosis, but also an opinion that the duration of life should not be expressed solely in terms of probability. Interviewees unanimously indicated the importance of sustaining hope.^{426,427}

Certain communication skills may enhance people's perceptions of hopefulness. For example, one study concluded that patients want physicians to adopt an 'attitude of confident openness and to act as supportive and encouraging coaches rather than acting as detached clinicians or consoling caretakers' (**Level IV**).³⁷¹

Timing of prognostic information

Although there are limited data about the optimal time to talk about prognosis, available evidence suggests this should be introduced at the first visit. In a survey of women with breast cancer, 91% indicated a preference for prognosis to be discussed at the first visit with their cancer specialist, before treatment has commenced. Nevertheless, 64% of respondents wanted their doctor to check with them first before telling them their prognosis.³⁶⁸

It has been suggested that people be given information in a staged manner, which gives them the opportunity to confirm their diagnosis and prognosis, formulate questions, and have these questions addressed prior to commencing treatment.⁴²⁸ Given that information preferences change over time,²³ it is important to keep checking how much information the person wants.

To help people make fully informed treatment choices, information about prognosis can be offered to people who wish to receive it during the discussion of the outcomes of their different treatment options.⁴²⁸

Framing of prognostic information

The treatment decisions made may depend on how clinical information is framed. Several studies presenting hypothetical medical situations have shown that both patients with an illness and healthy volunteers were more willing to select risky medical options when the same probabilistic information was worded positively (expressed as the chances of survival), rather than negatively (expressed as the chances of dying) (**Level II**),^{429,430} (**Level III-1**).⁴³¹

Forty three per cent of women with breast cancer surveyed preferred positively framed statements and only 33% preferred negatively framed statements.³⁶⁸ However, descriptive reports of consultation behaviour suggest that negative framing is the style of communication most frequently employed by oncologists.⁴³²

Effective communication style has been shown to be as important as the framing of information (**Level III-2**).^{384,433,434}

Numerical versus verbal estimates of risk

Discussion of prognostic information will often include communication of risk probabilities. However, most people have difficulty understanding information expressed as probabilities (**Level III-3**).⁴³⁵⁻⁴³⁷ When discussing prognosis or the outcomes of treatments, a clinician needs to check an individual's understanding of numerical and non-numerical estimates of risk in order to establish that the person has correctly interpreted this complex information. The clinician may need to correct a person's estimation of their prognosis or the expected benefits of treatment. As this adjustment of expectations can be distressing for patients and their families, the person must be offered the time and resources to consider the benefits and limitations of treatment options properly.

Individual preferences for the presentation of numerical or non-numerical estimates of risk vary.⁴²⁸ The way in which people translate non-numerical probability terms, eg 'certain', 'almost certain', 'very likely', 'probable', and 'frequent', into numerical estimates also varies. Thus, the use of these terms can lead to misunderstanding among clinicians, and between clinicians and lay people (**Level III-2**),^{438,439} (**Level III-3**).⁴⁴⁰

A study of women with breast cancer confirmed that there is no consistency in the interpretation of the verbal description 'good' for the chances of survival. This same study demonstrated that there was no agreement concerning the non-numerical interpretation of the risk statistic '30%', with 48% of women perceiving this statistic indicative of a low risk, 34% a medium and 15% a high risk.³⁶⁸

Taking time to explain information

Providing verbal explanations of graphs and figures has been found to influence the treatment decision (**Level II**).⁴⁴¹ Treatments offering long-term benefits were more likely to be chosen when a longer discussion had taken place. Patients' treatment choices appear to be more influenced by the perceived comprehensiveness of explanations about prognosis, than the facts themselves.

In another study examining the impact of survival information on treatment decisions, patients aged over 65, were more likely to choose the treatment option giving better short-term survival than the option with poorer short-term outcome and improved long-term survival. However, patients with higher levels of education more likely to prefer the option with better long-term survival, even if there was a risk of poorer short-term survival (**Level II**).⁴⁴²

Mode of presentation

No published data are available comparing the effects on patients' perceptions and decision-making of different communication modes, such as visual versus verbal information, or the use of different statistics, such as five year versus 10-year survival rates.

In an Australian survey of women with breast cancer, one-third of respondents did not understand risk at all, and thought that their doctor could predict whether or not they would relapse.³⁶⁸ While most women could interpret survival graphs, very few understood statistical terms. Less than half of the women could do the mathematical calculations necessary to interpret relative risk reduction. However, the degree to which these findings are generally applicable is not clear, given anecdotal evidence for gender differences in these skills. Patients' understanding may be improved if clinicians demonstrate several example calculations in their explanations.

Table 3.2.2: Recommended steps for discussing prognosis with individuals with cancer

These steps are recommended in conjunction with the general interactional skills in Table 3.1.

Offering prognostic information

- Offer prognostic information prior to commencing treatment as part of treatment decision-making
- Ask first if the person wants to be given information about prognosis, (eg 'I can tell you what happens to most people in your situation. Would you like me to do that?') and what they currently understand and expect

Aspects of prognosis to discuss

- Adhere to the person's stated preference for information about prognosis. If/when desired, the following can be provided:
 - staging details and their implications for prognosis
 - chances of being cured or that cancer will never return
 - likely benefits and risks of treatment
 - chance of the cancer shortening the individual's life compared to other life events, eg heart disease
 - average and longest survival times, emphasising a range rather than a single time point

How to discuss prognosis

- Preface any prognostic estimate with its limitations
 - explain that you can't predict how the person as an individual will respond to the illness and its treatment
 - provide an initial estimate of prognosis based on available information, and explain how this may be revised by additional information. Suggest a time frame for when additional prognostic information is likely to be available
- Use mixed framing: give chances of cure first, and then chances of relapse
- Present information in a variety of media: words, statistics, graphs
 - combine verbal estimates, eg 'small chance' with numerical estimates
 - provide verbal explanations of survival graphs

- When explaining relative risk reduction, provide several examples of the calculations
 - only use statistical terminology, eg median, hazard risk ratio, if a person is familiar with these concepts

Concluding the discussion

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

Adapted from Lobb et al.³⁶⁸ *Talking about prognosis with women who have early breast cancer.*
National Breast Cancer Centre.

3.2.3 Discussing treatment options: Providing information and choice

People with cancer consider access to accurate and reliable information about treatment options to be of major importance, as confirmed by a review of over 200 research articles relating to communication dimensions of the cancer experience.³⁶⁵ Detailed evidence-based information and treatment recommendations are documented in a series of clinical practice guidelines (see Appendix E), many of which are also available as a consumer version.

The way in which the information is communicated to the patient with cancer needs to be carefully considered. The decision-making process that follows a diagnosis of cancer requires the patient to consider an enormous amount of information, learn a new set of technical and disease-specific terms, and make profoundly life-affecting decisions (**Level III-2**).⁴³² Decisions about treatment are made at a time when stress can affect the recall of information that is provided (**Level III-3**).³⁶⁷

The ability to listen to the patient and evaluate individual needs is crucial to patient satisfaction and an ethical decision-making process (see Sections 3.2.1 and 3.2.2). Communication skills are underpinned by an empathetic and supportive approach.

The following issues are relevant when providing treatment information and choice to people with cancer, and are summarised in Table 3.2.3.

Variations in patients' needs for information

Clinicians should recognise and respond to the fact that patients will vary in their needs for information, and that the needs of individual patients will change as their treatment proceeds.

Satisfaction with communication in medical settings is not a simple function of communication skills and the provision of adequately structured information. The patient's coping strategies – either seeking out or avoiding information – need to be taken into account (**Level III-2**),⁴⁴³ (**Level III-3**).⁴⁴⁴ Some people cope with cancer by avoiding information or making no active efforts to find out about issues.⁴⁴³ It has been argued that for these people, satisfaction with communication is not associated with higher levels of factual knowledge concerning the causes and treatments of cancer.⁴⁴⁴ They may simply feel confident that their clinician will make the right decision for them.⁴²⁰ At the other extreme, the desire for information may be so intense that no amount of factual data will be sufficient (**Level III-3**),⁴⁴⁴ (**Level IV**).⁴²⁰ and such a person may find it difficult to gain satisfaction from a medical encounter, no matter how skilled the clinician is in communicating.

Clinician's interpersonal style

Available evidence indicates patients' preferences for communication styles vary according to individual needs (**Level III-3**),³⁹² (**Level IV**).^{385,386} Accordingly, it is suggested that clinicians tailor the format of information to the patient's requirements and avoid using a standard format. It is also recommended that clinicians involve the patient in decision-making. Data from a randomised controlled study indicate that most patients generally prefer such a 'patient-centred' approach, especially if the prognosis is poor. However, one-third of patients preferred a more authoritative, doctor-centred style when discussing treatment options (**Level II**).⁴⁰²

The way clinicians' present information significantly affects a person's recall of that information (**Level III-2**),³⁸⁴ (**Level III-3**).³⁶⁷ The amount of information recalled can be increased by simplifying the language, dividing the information into key issues, and repeating key messages (**Level III-3**).³⁶⁷

Timing

Information about treatment is usually given immediately after information about diagnosis. Despite suggestions that the patient's anxiety and distress at the time of diagnosis makes it an inappropriate time to provide other information, findings from one study indicate that people with cancer feel capable of taking and using information at this time to form treatment-related decisions.⁴⁴⁵ However, a review of the literature about the psychology of people in crisis suggests that some patients may experience difficulties with organisation, problem-solving, and planning.⁴⁴⁶ Clinicians are advised to check on a patient's preference regarding the timing of treatment information and decision-making.

The NHMRC⁴⁴⁵ offers the following recommendations for the timing of information delivery:

- provide information in stages
- employing a nurse or counsellor with experience in caring for people with cancer, to reinforce information provided by other health professionals
- pay attention to how messages are framed
- consistently encourage patients to ask questions relevant to their particular circumstances.

There is usually no need to rush patients into making decisions about their treatment. However, a survey of women with early breast cancer found that 41% reported having been told they had to make a treatment decision immediately.⁸⁵ Many patients will need reassurance that taking a few days to make a decision will not prejudice their outcome.

Requirement for informed consent

In Australia no medical services can be provided without the consent of the individual concerned. For consent to be valid, it must be a voluntary choice, free of coercion and given after receiving adequate and appropriate information at the individual's level of comprehension. In some states, eg New South Wales, requirements for informed consent are specified in State law. The only exception to this general rule is patients whose capacity to give consent is impaired by serious mental illness, in which case the relevant State Mental Health Act may be invoked in rare cases.

The key issues in informed consent are:

- ensuring that the person has truly understood the nature, benefits and risks of the procedure or treatment⁴⁴⁷
- giving the person adequate opportunity to ask questions and to read and understand any written information provided⁴⁴⁷
- providing information in a manner that ensures ease of comprehension and enables the person to assess the overall effects of the medical condition and its treatments prior to making a treatment decision.⁴⁴⁸

Patients' priorities for duration of life versus quality of life need to be considered on an individual basis, taking into account that patients' opinions regarding treatment differ from those of health professionals and also differ between patients.⁴⁴⁹

Care should be taken that all steps are followed and documented. In one study of patients undergoing radiation therapy for cancer, 22% could not recall signing a consent form, and one quarter were unable to list common side-effects of radiation therapy.⁴⁵⁰ Despite problems with achieving genuinely informed consent, improved communications will reduce the frequency of ill-informed consent (**Level III-3**).³⁸⁹

Amount of information

Clinicians and other members of the treatment team should regularly assess whether each patient has received adequate information, given that the psychological well-being of people with cancer is improved by the provision of appropriate detailed information well-being (**Level I**).¹⁵

Research indicates that helping patients become well informed assists in sustaining hopeful attitudes and does not promote depression (**Level III-3**).³⁷⁰ A further study showed that women with breast cancer who believed they had been poorly informed were twice as likely to be depressed and/or anxious 12 months after diagnosis as those who thought they had been adequately informed (**Level III-2**).⁷

The results of two studies, one of which was a large multicentred study, suggest that people often want more information than they are given about their cancer and its treatment.⁴⁵¹ Clinicians may underestimate the amount of information that patients require and patients may fail to raise questions and issues that are important to them during a consultation.⁴⁵¹

Studies report varying levels of satisfaction with information among patients with cancer. Differences in findings may reflect the survey design, the availability of detailed information in the geographical region at the time of the survey, and the sample demographics surveyed, eg more educated patients tend to express higher levels of dissatisfaction with information.⁴¹⁶ International research may not be relevant in the Australian context, since strategies to provide information and patient characteristics of will be different.

Studies with some patients with cancer have shown considerable dissatisfaction with the information provided. For example, a 1995 Australian review of studies in women with breast cancer found that six of eight studies indicated high levels of dissatisfaction with the amount of information received.³⁷³ Available research also indicates that approximately one-third of men with prostate cancer are dissatisfied with the informational support provided to them by their treatment team.^{80,452,453}

The provision of detailed information can result in improved satisfaction. For example, following the release of the *NHMRC Clinical practice guidelines for the management of early breast cancer*,³⁶⁴ an evidence-based consumer guide for women with breast cancer was produced. By 1998, 61% of women with early breast cancer reported receiving the consumer guide; by 2001, this had risen to 83%.⁴⁵⁴ A 1998 survey of 544 women with early breast cancer found that overall, most women (81%) reported receiving the right amount of information about different aspects of treatment and support.⁸⁵ However, only 22% received information about their own diagnosis suggesting that the provision of personalised information appears to be inadequate; and only 12% received information about clinical trials (see below, this section).

Content of information

In order to make an informed choice about their treatment, patients require information about surgical, radiation therapy or chemotherapy options that are to be tailored to the individual's disease and information needs.

Available research data show that people want information about their specific cancer, treatment options, the likelihood that treatment will be a success, possible adverse effects of treatment and practical issues.⁴⁵⁵⁻⁴⁵⁸ Studies of women with breast cancer show that receiving information about chances of cure and spread of disease is important to them (**Level III-2**),⁴⁵⁹ as is accurate information about side effects that are likely to delay a return to normal activities.⁸⁵ Men with prostate cancer express the desire for information about their disease and its treatment,⁴⁶⁰ but their preferences for specific information content appear to vary widely.^{461,462}

Tailoring and presenting information

Current research findings do not offer clear guidance about the most appropriate information format. A multi-faceted approach, in which information is provided by healthcare professionals using a variety of media, may best satisfy most people. Treatment team members are advised to elicit and respond to the individual's own concerns.

Information from clinicians and other healthcare professionals

Emerging evidence shows that men with prostate cancer report a high reliance on their clinician for information and support in making treatment choices (**Level IV**).^{460,463-465} In women with breast cancer, there is strong evidence that understanding is improved and psychological morbidity reduced by the opportunity for further discussions with a specialist breast nurse who is present during consultation (**Level II**).^{243,401,466,467}

Question prompt sheets

A question prompt sheet – a structured list of questions designed to provide a framework for questions – can assist patients in acquiring information suited to their needs. The questions are usually suggested by experienced patients and health professionals in developmental qualitative studies. The prompt sheet is provided to patients before their first consultation, and can be taken home for future reference and to share with family and friends. Answers to questions are not provided on the document (and therefore do not need updating). Rather the prompt sheet is designed to facilitate discussion with health professionals, who endorse the prompt sheet and the importance of asking questions.

Provision of a question prompt sheet to patients with cancer during an initial medical oncology consultation has been found to promote patient questions, reduce anxiety, improve recall and shorten the consultation (**Level II**).³⁵⁰

Written information

To be noticed and used, written information needs to be provided in a format that is readable and easily understood. To be viewed as credible, it should cite sources and use sources relevant to the target audience.³⁶⁷

Provision of consumer guidelines, where available (see Appendix E), will assist patients in considering their treatment options. Some consumer guidelines are also available on the Internet (see Section 3.2.6). The consumer guidelines provide examples of questions that people might find useful in clarifying the sort of information they need. Willingness of clinicians to answer such questions conveys an interest in promoting the patient's understanding of their situation and their treatment options.

Patients do not appear to have clear preferences for either verbal or written information, based on the available data, which are derived from breast cancer studies. One review indicated that women with breast cancer have no clear preference for verbal or printed information, as both media were seen as complementary.⁴⁴⁵ In another study, women receiving chemotherapy for breast cancer expressed preferences (in some cases more than one) for the following information sources: verbal information from the oncologist in the consulting room (53%), or written materials including newspapers (31%), magazine articles (29%) and popular books about cancer and various treatments (21%).⁴⁶⁸

Information on CD and the Internet

The use of CD programs and the Internet to obtain cancer information is increasing. These media are flexible and enable people to select the information they are most interested in, and can provide video clips and testimonials.

As yet, there have been few evaluations of the effectiveness of such products. In one randomised controlled trial, these informational products did not affect the treatment decisions of women with breast cancer, although women tended to learn more about breast cancer from multimedia packages than from reading a brochure (**Level II**).⁴⁶⁹

Increasingly, patients and their families are turning to the Internet for information about cancer and treatment. This can be at once a convenient way to gather information in private, and a source of great confusion and anxiety for both patient and doctor. It is recommended that health care professionals offer patients guidance in using the Internet for cancer information (see section 3.2.6).

Patient-specific information

Several methods of providing patients with specific information about their own diagnosis and management have been trialled.

A personalised follow-up letter after the consultation has been shown to improve patients' understanding (**Level II**).⁴⁰⁰

Tape recordings of consultations have also been shown to improve patients' understanding (**Level II**),³⁹⁹ but are rarely provided.⁸⁵ There is evidence that providing a general

information cassette may impair the patient's recall of specific information provided in a consultation (**Level II**).⁴⁷⁰

The use of *decision aids* has shown benefits for both clinicians and patients in assisting with understanding and decision-making (**Level I**),⁴⁷¹ (**Level III-2**),⁴⁷² (**Level IV**),⁴⁷³⁻⁴⁷⁵ Decision aids provide patients with information about the medical treatment options available to them, and may include descriptions of how treatments work, the potential benefits and costs of each treatment, and suggestions about how to decide between them, eg listing the options and weighting individual preferences. The formats of decision aids include audiovisual and written material, charts, illustrations, decision trees and computer programs. Decision aids improve knowledge, reduce decisional conflict, and stimulate patients to be more involved in decision-making. The simpler aids appear to be as effective as the more intensive aids, although the latter help with the extent to which choices are based on realistic expectations and personal values (**Level I**),⁴⁷¹ (**Level III-2**).⁴⁷² There has been little research about the effect of aids on the outcomes of decisions such as persistence with choice, regret and quality of life.⁴⁷²

The effectiveness of a *personalised health record* has not been assessed in people with cancer, but has been shown to be effective in improving understanding in relation to other health issues (**Level II**).⁴⁷⁶

Psycho-educational programs

Psycho-educational programs have both psychological/supportive and skills/knowledge-building components. These programs may be provided on an individual or group basis over a number of weeks, and may include information about cancer, treatment, coping strategies and complementary therapies.

Several studies have found that psycho-educational programs decrease anxiety (**Level II**)^{477,478} and depression (**Level II**),⁴⁷⁷ and increase knowledge (**Level II**),^{478,479} (**Level III-2**).⁴⁸⁰ However, differences in effectiveness between the various types of psycho-educational programs have not been established (**Level I**).¹⁵

Factors that influence patients' treatment decisions

Clinicians should ask patients about the factors that are important to them in making treatment decisions and discuss alternatives for expanding treatment options. Improved understanding of factors that influence a person's treatment decisions can facilitate the provision of information, and promote better-informed decision-making. For example, a person from a rural or remote area may be concerned about choosing treatment that would require travel to the city as this may raise difficulties for them and their the family. Discussion of this and the provision of information about travel, accommodation and childcare assistance will enable the patient to make a more informed decision. Refer to Section 3.4 for a full discussion of practical and financial support.

It appears that choice of treatment is influenced by a number of factors, including:

- demographic variables, such as age, sex, financial status, education and geography (**Level III-3**),⁴⁸¹ (**Level III-2**),⁴⁸² (**Level IV**)^{468,483}
- external factors, such as media, family and friends (**Level IV**)⁴⁸⁴
- psychological factors, such as body image concerns (**Level III-2**)⁴⁸⁵ (**Level IV**)^{486,487}

- the physician's preferences for treatment (**Level III-2**),⁴⁸² (**Level IV**)^{465,488}
- lay beliefs about treatment (**Level IV**)⁴⁶⁵
- amount and specificity of information provided (**Level IV**)^{424,489}
- the patient's level of hopefulness (**Level III-3**)³⁷⁰
- treatment duration and side effects (**Level IV**)^{489,490}
- quality of life and outcome statistics (**Level IV**)⁴⁹⁰
- faith in doctors' expertise (**Level IV**)⁴²⁰
- whether decision is made during initial consultation (**Level IV**).⁴²⁴

The NHMRC⁴⁴⁵ has identified a number of barriers to the provision of treatment choices to people with cancer. Some of these can be overcome or mitigated by the following principles:

- ensuring an appropriate period of time between diagnosis and treatment
- providing consistent information across the treatment team
- recognising that the patient may be inhibited if discussion about treatment options are undertaken while they are undressed, lying down or in the presence of medical students
- making sufficient consultation time available to the patient.

Alternative and complementary therapies

The term 'alternative therapies' is used loosely to describe any treatment options outside the orthodox range of surgery, radiation and chemotherapy.⁴⁹¹ It includes many different approaches ranging from visualisation to diet and prayer, often with the promotion of a body-mind connection.⁴⁹² Those therapies that do not replace or preclude concurrent conventional medical therapies are termed 'complementary therapies'.

Some techniques, such as relaxation and guided imagery, have been subject to scientific evaluation and shown to be effective (**Level I**),¹⁵ and can be considered as integral components of psychological care. Prayer is being tested in controlled clinical trials and has so far been shown to be effective⁴⁹³ and laughter has also been shown to be effective for some individuals.⁴⁹³

The majority of alternative therapies have not been assessed for efficacy and safety in randomised clinical trials. Whereas complementary therapies can work alongside conventional therapies, alternative therapies may involve some tension or interference with conventional therapies. Their use can sometimes interfere with chemotherapy (**Level IV**)⁴⁹⁴ or have other harmful or toxic effects.³⁷²

The cost of alternative therapies is variable. Many appear to be inexpensive and considered good value for money while some are remarkably expensive⁴⁹⁵ and not subsidised by health insurance or government health programs.

Use of alternative therapies

A study conducted in three major Australian oncology clinics found that 22% of patients reported using alternative therapies.⁴⁹⁵ Other studies (both overseas and Australian) have found that 9%-54% of adults with cancer use alternative therapies.^{496,497} The use of such remedies may be more prevalent in certain ethnic groups.

Reasons given for using alternative therapies include the need for a new source of hope, a preference for 'natural' therapies, a desire to try something different and achieving a sense of greater personal involvement.⁴⁹⁵ For many patients, feeling they can assume some control of the treatment of their disease is psychologically empowering. According to one large study, there is a significant association between the use of alternative/complementary therapies and unmet needs, helplessness, and lower scores on emotional and social functioning scales.⁴⁹⁸ Clinicians need to be aware that decisions to use alternative therapies may not be based on the same philosophical approach as that used by doctors.

Why alternative therapies should be discussed

It is to the advantage of all concerned if patients are able to discuss alternative therapies openly, secure in the knowledge that they will continue to receive support and understanding from their treatment team, whether or not the clinicians agree with the therapy being used.

The issues of effectiveness, safety and cost need to be explored with all patients who use alternative therapies. However, they can only be explored if the clinician is aware of the patient's use of such therapies. In the study conducted in Australian oncology clinics 40% of patients with cancer using alternative therapies did not tell their clinician about this,⁴⁹⁵ either because they were not asked or did not choose to disclose. Patients' concerns about negative attitudes from the treatment team may inhibit frank discussion of alternative therapies, resulting in lost opportunities for clinicians to express their support or give information about the potential effects of such therapies.

Clinical trials

It is appropriate for clinicians to discuss participation in clinical trials with all eligible patients, given indirect evidence that people who participate in clinical trials have better outcomes than similar patients given similar treatment outside trials (**Level III-2**).^{499,500} Informed discussion of potential trial involvement will depend on all treatment team members keeping informed of all current and relevant trials and their enrolment criteria.

It has been argued that, when a randomised clinical trial is recruiting, it should be presented as one of the standard treatment options to all eligible patients treated at the relevant centres.^{501,502} Particular attention needs to be given to ensure that older, less educated, and rural patients are offered inclusion, as evidence suggests these patients are less likely to receive information about clinical trials.⁸⁵

It is recommended that communications between the clinician, other members of the treatment team, and the patient follow the general interactional skills outlined in Table 3.1. The NHMRC⁴⁴⁵ also suggests the following:

- reassure patients that specialists participating in clinical trials are in touch with the best and most up-to-date treatments available, and are seeking to improve them
- explain that the control group in a randomised clinical trial receives the best available standard therapy which would be offered outside the trial
- allow time for the patient to decide
- inform the patient that they can withdraw from the trial at any time without explanation or compromising their medical care.

The decision to participate in a clinical trial appears to entail a complex interaction between the clinician and the patient. Specialist oncology nurses also have an important role to play here, with survey data showing that patients who see a breast nurse or other specialist nurse are more likely to be informed about clinical trials.⁸⁵

People's attitudes to clinical trials appear to depend upon whether they are asked to consider the issue when healthy or as a cancer patient, and whether the person with cancer is asked to consider clinical trials in general or a particular trial that is discussed in detail.⁵⁰²

Helping people make a decision about participation in a clinical trial

Taking the time to elicit and address patients' concerns and understanding about a clinical trial is important. In making a decision about participation in a clinical trial, considerations that confront the patient include:⁵⁰²⁻⁵⁰⁵

- the effect of participation or non-participation on treatment – altruistic or humanistic issues and the desire to obtain the best treatment for themselves
- discomfort and misunderstandings about the procedural aspects, in particular the randomisation to the various arms of the study
- the different roles of the doctor as clinician and as researcher
- the process of informed consent
- the timing of the request for participation, especially if this follows the stress of a cancer diagnosis
- the benefits and costs of participation.

The clinician must be scrupulously ethical in providing patients with all relevant information, whilst taking care not overly influence their decision. There are conflicting data about the effect of the patient's active or passive role in the decision-making process. For example, some studies have indicated that those who adopt a more passive role in the clinician-patient interaction are more willing to participate in clinical trials.⁵⁰⁶ However, a study of women with breast cancer found that the decision to enter a clinical trial is an active decision.⁵⁰² Some research suggests that patients are more likely to participate in a clinical trial if the clinician verbally presents material normally included in a consent form, and is patient-centred, supportive and responsive in manner (**Level IV**).⁵⁰⁷

While few people with cancer are currently offered the opportunity to take part in clinical trials, many would do so if given the opportunity.⁸⁵ The decision not to participate may reflect concerns about the uncertainty and experimental nature of a clinical trial, added to the uncertainty patients are already experiencing about their diagnosis and treatment.⁵⁰² These concerns highlight the need for patient support at this time.

In order to assist people to become better informed and have a better understanding of clinical trials, the NHMRC Clinical Trials Centre has developed information for consumers (available at www.ctc.usyd.edu.au).

Participation in decision-making

Changes in consumer expectations and medical ethics, government interest in improving health outcomes, and legal examination of patient rights have increased the focus on patients' involvement in decisions about their care. In cancer, where the benefits of treatment

are commonly uncertain and may be offset by adverse effects on quality of life, an optimal treatment choice should be sensitive to the values patients ascribe to both positive and negative outcomes of treatment.

There is considerable uncertainty about what constitutes an ideal level of patient participation. It has been demonstrated that as a person moves along the continuum from wellness to illness, preferences for involvement shift. People who are well typically express a preference for a dominant or collaborative role in decision-making, but this preference is less strong in those diagnosed with a potentially fatal disease such as cancer and some patients prefer to entrust decisions to doctors (**Level III-2**).^{508,509}

Models for shared decision-making

A variety of models of clinician-patient relationships have been proposed. These include the 'physician-as-agent', 'informed decision-making', and 'shared decision-making' models.⁵¹⁰⁻⁵¹²

In the physician-as-agent model, the doctor takes patient values into account when making treatment recommendations, and patient participation is limited. In these circumstances, there is a risk that either the amount of information given or how this information is conveyed may bias the opinion of the patient.^{429,513}

In the informed decision-making model, the clinician neither advocates nor advises, but is required to honestly disclose information to patients to enable them to arrive at decisions consistent with their values.

In the shared decision-making model, clinicians and patients are seen as partners and are required to exchange information and share their preferences for treatment in order to negotiate a mutually acceptable decision.^{514,515} This model may have the greatest potential for meeting clinical and ethical demands.

In practice, the situation is rarely as clear-cut as the models. In many circumstances, especially for people with less common or very advanced cancers, the choices and the evidence to support the various options may be limited. However there are always choices to be made, if only between active treatment and passive care.

What people with cancer want

Available research suggests that, among people with cancer, there are wide variations in preferences for involvement in decision-making.^{370,420,445,488,516,517} Since these preferences may also change over time (**Level III-2**),²³ it is prudent for the clinician to review an individual's preference throughout the treatment process and at each phase of care.

While most patients may want as much information as possible, there may still be patients who prefer to relinquish control over treatment decisions, particularly if faced with increasingly distressing and unfamiliar situations.^{451,517} Those patients who are older, less educated or male, especially men with cancer of the reproductive system, may be less likely to seek involvement in their treatment decisions.⁵⁰⁸ Patients with advanced disease and with a poorer health status are least likely to want involvement (**Level III-2**).²³

Benefits of patient involvement in decision-making

Research findings underscore the pre-eminence of the shared decision-making model and suggest that encouraging patients' participation may be the safest approach to take routinely. Patients who begin by preferring non-involvement may gain confidence in the consultation, if

encouraged and carefully informed. Although the trend is to increasing patient involvement in decision-making, clinicians need to recognise that there are times when patients look to them for direction and guidance, and they should avoid taking this approach if it suits the patient best.

According to one study, patients whose preferred level of involvement in decision-making matched their actual level of involvement had lower anxiety levels post-consultation than patients whose preferred and actual levels differed. Further, patients who reported a shared role in decision-making were most satisfied with the consultation and with the information about treatment and emotional support received. Those who reported that either they or their doctor made the decision exclusively were the least satisfied.⁵¹⁸ Support for shared decision-making also comes from the results of a series of studies that followed 269 women with breast cancer from diagnosis to three years, which showed that patients who were offered a choice had lower levels of anxiety. The authors further suggested that being an equal participant in decision-making may be more critical than actually being given a choice **(Level III-2)**,^{7,519} **(Level III-3)**.⁵²⁰ However, it should be noted that offering choice with no guidance may result in increased levels of anxiety **(Level III-2)**.^{521,522}

Seventy three per cent of women with breast cancer surveyed stated that their current level of involvement in the decision-making process was as desired. Of these women, 58% viewed their treatment decisions as jointly made, 24% said that they made an independent decision, and 16% left the decision to their clinician.⁸⁵

Facilitating involvement in decision-making and choice

Ensuring that patients feel involved in decision-making may be more dependent on the communications skills of the clinician than on the provision of treatment choices. Skills in facilitating involvement are complex. For some patients, treatment choices may be limited or non-existent due to specific disease factors and overall health status. However, they can still be involved in reviewing the evidence that leads to that conclusion.

The responsibilities of the treatment team in this regard are highlighted by the results of a survey of women with early breast cancer. Women who underwent mastectomy were no more likely to report that they had no choice than women who had a lumpectomy (breast conserving surgery), although it is notable that 22% of women said they were given only one treatment option.⁸⁵ In another study in which initial medical oncology consultations with 101 patients with heterogenous cancers were audiotaped and coded, most were provided with essential information and more than one treatment option discussed in all but one case. However, only 59% of patients were explicitly offered a choice in decision-making and, in half the consultations, doctors did not check patients' understanding or elicit preferences for information detail.⁴²⁴

Table 3.2.3: Recommended steps for discussing treatment options and encouraging involvement in decision-making

These steps are recommended in conjunction with the general interactional skills in Table 3.1.

Information about treatment

- Explain to the person using language that they understand what treatment options are available (including no treatment) and ask how much detail they would like about each option
- Tailor the information to the person's needs and preferences for information content and detail, which may include a discussion of the expected outcomes and major side effects of each treatment option
- Acknowledge the uncertainty of any treatment achieving its aim; explain the pros and cons of each option and then summarise them
- Use a variety of media to provide information about treatment options, eg written information, video tapes, tapes of consultations, etc.
- Ask the person about any questions they may have regarding alternative and complementary therapies
- Ask the person to talk about the concerns they have regarding different options

Making decisions about treatment

- Explore at an early stage how the patient would like to be involved in decision-making and adhere to their wishes
- Be aware that the person's preferences may change over time and regularly check the level of involvement they would like
- Ask the patient about their values and life situation in relation to the treatment options
- Use inclusive language (*we, our*)
- Make it explicit that there is a choice to be made, and that the patient can be involved in the choice
- If the person is unaccompanied ask whether they would like to discuss treatment options with family or friends and tell the person that there is an opportunity for them to be involved in treatment decisions
- Assure the person that there is enough time to consider the treatment options and offer to arrange for them to come back with a decision

Emotional and supportive role

- Consider the specific needs related to gender, age and culture
- Give the person the opportunity to discuss and express their feelings, eg crying freely, talking about concerns, fears, anger, anxieties, etc. Acknowledge individual differences in emotional impact
- Address disturbing or embarrassing topics directly, and with sensitivity
- Provide information about support services
- Make your own recommendations clear, but offer your willingness to be involved in the ongoing care of the patients (if required) no matter what they decide in response to your recommendation

Concluding the discussion

- Summarise main points of the consultation and assess the person's understanding
- Ask if there is anything further the person would like to discuss; encourage questions
- Offer assistance to tell others difficult news
- Indicate your availability for contact to address any questions or concerns and arrange a further appointment to review situation within a stated time period, eg within 24 hours to two weeks

After discussing a diagnosis, recurrence or metastases

- Document information given to the person and family members
- Let others know the extent of information given and your perception of the person's understanding, particularly the person's general practitioner

Adapted from Cockburn J.³⁶⁶ *Effectively discussing treatment options with women with breast cancer*. National Breast Cancer Centre.

3.2.4 Preparing patients for potentially life-threatening procedures and treatment

Providing patients with information about the procedure they are about to undergo significantly reduces their emotional distress and improves their psychological and physical recovery (**Level I**).^{523,524} The majority of research also indicates that adequate preparation for threatening medical procedures can reduce the level of anxiety and lead to faster recovery, with fewer complications (**Level I**),^{523,524} (**Level II**).^{525,526} Patients' anxiety appears to be reduced most when provided with information both about the procedure, and about what they are likely to experience physically and psychologically (**Level I**).⁵²³

Procedural information

Procedural information includes practical details about what will happen before, during and after a procedure (see Table 3.2.4). A variety of formats for providing information about procedures have been shown to decrease anxiety and psychological distress. These include discussions with a clinician or other appropriately trained health professional such as a specialist nurse (**Level II**),^{401,527} written information in a booklet (**Level II**)⁵²⁸ or videotape information (**Level II**).⁵²⁹ Diagrams and illustrations are often useful.

Sensory information

Sensory information describes what the person is likely to experience before, during and after the procedure, including their feelings in response to the preoperative medication, and the amount and type of pain to be expected. The provision of comprehensive sensory information has produced significant reductions in anxiety in patients undergoing medical procedures (**Level I**),⁵²⁴ (**Level II**).⁵³⁰

Psychosocial support

Psychosocial support has been shown to be useful at this time (**Level I**).¹⁷ Psychosocial support strategies commenced prior to treatment procedures include providing people with an outlet to discuss concerns, fears, coping and relaxation strategies, offering education about exercises, information and available resources. This role might be performed by a specialist

oncology nurse, specialist breast nurse, social worker, occupational therapist or another appropriate member of the treatment team.

Some procedures present particular difficulties. For example, for those patients who undergo bone marrow transplantation, the fear of the unknown (what to expect either during the procedure or recovery) and death is balanced with hope for survival.⁵³¹ Patients who undergo laryngectomy face significant changes in their lifestyle and ability to interact with others. The opportunity to meet with others who have undergone the same procedures may be beneficial to these patients.^{71,531}

Table 3.2.4: Recommended steps involved in adequately preparing a patient for a potentially threatening medical procedure

These steps are recommended in conjunction with the general interactional skills in Table 3.1.

Before the procedure

- Explain why the procedure is needed and the expected outcome
- Ask how much detail the patient would like to know about the procedure before explaining it
- The information may include:
 - where the procedure might take place, and who will perform it
 - any tests needed before the procedure
 - what the patient will need to do before the procedure
 - what the patient is likely to experience during and after the procedure
- Give the patient the opportunity to talk about their concerns such as pain, fear, death, embarrassment
- Ask what they think they can do to cope
- Enquire about, and reinforce, previous coping strategies, eg relaxation and imagery
- Provide the opportunity to meet with someone who has undergone this procedure or a support group

During the procedure

- Provide information about what will be done and how it will feel
- Give the patient control, where possible, eg ask them to tell you when they are ready to begin
- Encourage the use of coping strategies

After the procedure

- Encourage the use of coping skills, eg relaxation methods and imagery
 - Encourage the patient to state their needs and reframe complaints into requests
 - Arrange follow-up and support
-

Adapted from Cockburn J.⁵³² *Preparing patients for potentially threatening clinical procedures*. National Breast Cancer Centre.

3.2.5 Preparing patients for progression from curative to palliative treatment.

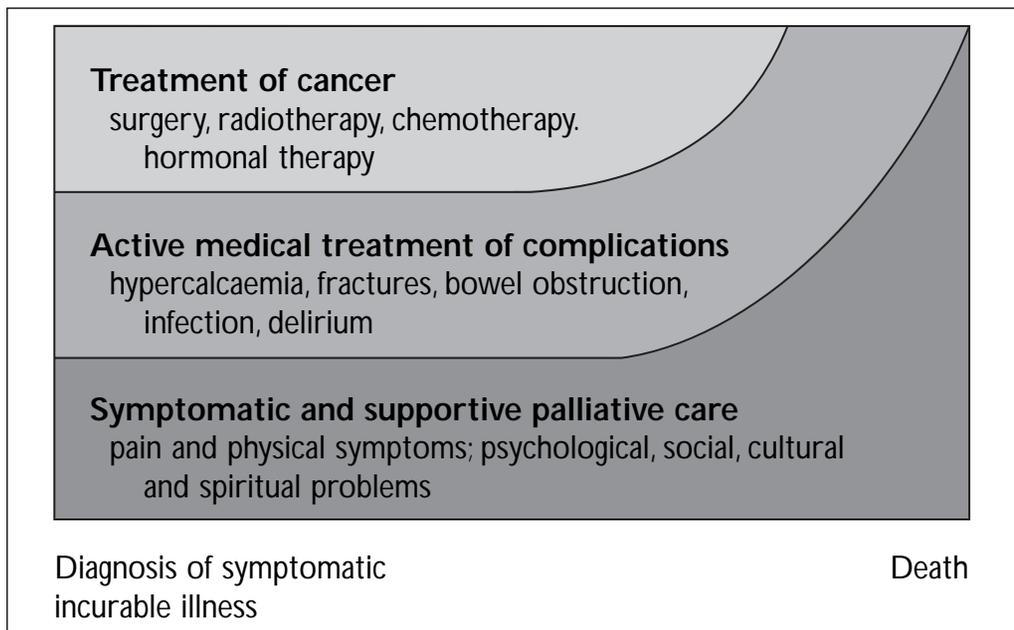


Figure 1: Diagram describing total care of the patient whose disease is not responsive to treatment. Adapted from Roger Woodruff 'Palliative Medicine' 3rd edition, Oxford University Press, 1999,⁵³³ with permission

The movement from curative to palliative treatment represents a crucial step for patients with cancer and their treatment team. In considering palliative care for patients with advanced cancer, it is important to distinguish between a palliative approach (where active treatments may still have an important role to play and focuses on both level of comfort and level of function), palliative care (that may include the involvement of specialised palliative service providers for patient and carer assessment, support and advice), and terminal care (when the patient is in the final stages of life). The distinction is important not only in care planning, but in establishing the goals for treatment. Discussion with the patient and family is crucial at this time.

A key aspect of the successful transition is ensuring that both the health care team and the patient recognise that palliative care does not preclude active treatments to improve symptom control and enhance quality of life. For many patients with cancer the transition from curative treatment to palliative care is gradual (Figure 1). Where active treatment continues to be offered, its goal changes from cure to control of disease and, subsequently, to the control of symptoms.

As unnecessary delays in referral to specialist palliative care services can lead to increased suffering for the patient, it is important for the palliative care team to be introduced as soon as required and that this team is seen as an integral component of the cancer services provided within an institution or region, that is, as part of the treating cancer team and not a separate entity.

Managing the transition to palliative care can be one of the most difficult communication tasks faced by cancer health professionals. It is important to make clear to the patient that

this transition does not imply discontinuation of active care or abandonment from their treating cancer team.

Evidence about the best way to prepare patients for this transition is primarily based on expert and consensus opinion. Guidelines about breaking bad news recommend open and honest provision of relevant information, such as changes in the cancer, treatment efficacy and prognosis, and making sure enough time is provided to allow discussion of the implications of this information and the patient's emotional response and support needs. It has been suggested that open-ended questions and empathic responses be used to elicit the patient's concerns, goals and values before discussing specific clinical decisions.⁵³⁴ Physicians should also screen for unaddressed spiritual and existential concerns. At this time, the best possible 'treatment' may be listening to patients' concerns with compassion – in its original sense of 'to feel or suffer with'.

The point where treatment goals become focussed on improving quality of life is usually clear. However, the appropriate time to introduce a formal palliative care service is often less clear.⁵³⁵ The World Health Organization defines palliative care as "the total active care of patients whose disease is not responsive to curative treatment," and emphasises that "Control of pain, of other symptoms, and of psychological, social and spiritual problems are paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families."⁵³⁶

A study examining the perceptions of health care professionals relating to aspects of palliative care indicated that most health professionals felt patients should be involved in decisions about commencing palliative care, and introduced the concept as involving experts or specialists who could help with symptoms or provide support.⁵³⁵ Opinions about the appropriate time to introduce palliative care varied widely, with most recommending when advanced disease is diagnosed, or when symptoms warrant. Nurses and hospital doctors, in particular, felt that early referral was helpful, to ensure that patients receive optimal care throughout their illness and to correct misperceptions that palliative care heralds imminent death.⁵³⁵ When making a palliative care referral, careful exploration of the meanings patients ascribe to palliative care, and correction of misunderstanding is recommended.

Table 3.2.5: Recommended steps for preparing patients for transition to palliative care

These steps are recommended in conjunction with the general interactional skills in Table 3.1.

- Provide a private environment, with adequate time for a full discussion A³⁶⁴ B⁵³⁷ (Level IV)³⁹¹
- Provide information openly and honestly about changes in the cancer, treatment efficacy and where requested, prognosis (Level IV)^{371,391,538}
- Elicit the patient's concerns and goals before discussing specific clinical decisions
- Ask open questions, such as C⁵³⁴ B⁵³⁹
 - *What concerns you most about your illness?*
 - *What has been most difficult about this illness for you?*
 - *What are your hopes and expectations and fears about the future?*
 - *As you think about the future, what is the most important to you?*
 - *Is faith (religion, spirituality) important to you in this illness?*
 - *Would you like to explore religious matters with someone?*
- When concerns have been discussed, provide reassurance where possible. For example about symptom management, and the availability of expert palliative care
- Introduce palliative care workers early
- Incorporate all health professionals involved in the patient's care as a team
- Explore the patient's understanding of palliative care and emphasise its role throughout illness
- Explicitly state to the patient that they will receive optimal care and will not be abandoned (Level IV)³⁷¹

A denotes Guideline

B denotes Review article

C denotes Consensus opinion

3.2.6 Issue for special consideration: Directing people to quality cancer information on the Internet

It is helpful if clinicians and members of the treatment team are aware of, and can recommend, several quality Internet sites in the relevant therapeutic (see Appendix J for list of recommended sites). The Cancer Helpline (13 11 20) can also provide assistance with information on Internet sites and with assessing the value of the information found.

People with cancer and their families and friends are increasingly using the Internet to access information about cancer and how it is treated, and for support from others who have had similar experiences.^{276,540} The Internet offers quick and private access to information about cancer as well as introductions to support groups. However, there are now thousands

of sites offering cancer-related information of variable quality and veracity. Some information about acceptable practice or available treatments may not be applicable in Australia, even if sourced from reputable sites. In some instances, clinicians may be overwhelmed by the informational and support needs of people who have accessed information from the Internet but lack the skills to evaluate its usefulness for their specific case.

Accessing quality information on the Internet

The following advice is useful for people with cancer and their clinicians:

- look for quality sites with credible information. Websites of State and Territory Cancer Councils, government health agencies and recognised support groups provide links to recommended sites. Cancer treatment centres are increasingly able to provide guidance to people with cancer on appropriate sites to access
- to assess the credibility of information on an Internet site, check who set up the site, when it was last updated, that there are references to authoritative journals and institutions, and whether the site complies with the Health on the Net (HON) or similarly recognised code of conduct
- encourage people to talk with health care professionals about information found on the Internet. Some patients may wish to change their treatment or adopt a new treatment based on information they find on the Internet without recognising the specific factors that may apply. Some Internet sites promote alternative treatments with unproven safety and efficacy
- support groups available on the Internet may be a source of help for many people, especially those who are geographically or socially isolated, but there are no standards for assessing their quality.

3.3 EMOTIONAL AND SOCIAL SUPPORT

Guideline

The extent to which a person with cancer has support and feels supported has been identified as a major factor in their adjustment to the disease (**Level III-2**).⁴⁶ It is essential to check the extent of support available to the patient, to recommend additional support as required and to provide information about where this is available.

Health professionals involved in the care of people with cancer are encouraged to organise their practice and develop their professional skills to ensure they can provide optimal patient support (refer to Table 3 at the beginning of Chapter 3).

A patient's need for support will vary depending on individual strategies, and to what extent emotional concerns impair their daily living. Understanding and utilising patients' existing coping mechanisms is a useful strategy and can help ensure the most appropriate information, reassurance, and support are provided. People with cancer (and their families and carers) may not voice their concerns or even recognise them; often these must be carefully and thoughtfully elicited.

Support can be provided by health care professionals, family and friends, or special cancer support services. Different types of support sources can make specific contributions to minimising psychosocial distress and physical dysfunctions, and it is difficult to differentiate the effectiveness of the various types (Level I).¹⁵

Table 3.3A summarises the recommended process for ensuring that people with cancer have adequate social and emotional support. Table 3.3B identifies the different types of support sources available.

Gender and psychosocial support

Guideline

Clinicians and the treatment team need to consider that the psychosocial needs of men and women may vary both in extent and how they are expressed. Successful strategies for meeting psychosocial support needs may therefore differ for men and women. Where the delivery method is inappropriate or insensitive, men may simply not participate or not gain a benefit (Level II),³⁶² (Level III-3).³⁶³

Some studies suggest that men tend to value different quality-of-life dimensions compared with women, emphasising activity rather than relationship.⁵⁴¹ Despite gender stereotypes, several studies have found men with cancer show high levels of psychological distress³⁸³ and unmet needs.^{453,542}

There is evidence that the nature of psychosocial support sought by men is different from that of women, with a lower expressed preference for emotional support and reluctance to share emotional concerns.^{543,545} and a greater demand for information and instrumental support.⁵⁴⁶ A study of Internet cancer support groups found differences in the way men and women give each other support: men were twice as likely to give information, and women twice as likely to give encouragement and social support.⁵⁴⁶ Available research also shows there are also marked gender differences in the utilisation of social support at times of crisis such as a cancer diagnosis, with men utilising support less.⁵⁴³

Recognising unmet needs

A high proportion of people with cancer may have unmet needs,³¹⁰ despite expressed satisfaction with their care. For example, a survey of Australian women with breast cancer found that 82% were highly satisfied with their care, but 15% would have liked more emotional support and counselling for themselves, and 9% wanted more for their families. About half of the younger women and 29% of older women needed additional services at some point.⁸⁵ Research has shown that many people will not raise their concerns unless this is explicitly invited.^{403,539}

Table 3.3A: Recommended steps involved in ensuring that all people with cancer have adequate emotional and social support

These steps are recommended in conjunction with the general interactional skills in Table 3.1.

Support from the treatment team

- Ask the patient how they are feeling emotionally at every visit
- Ask the patient how they are feeling about treatment
- Listen to fears and concerns about treatment and prognosis
- Provide access to an oncology nurse, or other allied health professional, eg social worker, at all phases of care, where appropriate and available
- Provide the patient with information about counselling and arrange a referral, if needed
- Do not under-estimate the emotional support that patients derive from clinicians who deliver their surgery, chemotherapy and radiation therapy

Assess support provided by family and friends

- Ask the patient about:
 - their support network and the level of support provided
 - how their family and partner are dealing with their cancer
 - others with whom they can openly discuss their thoughts and feelings about their situation
 - who they have to assist with practical issues, eg transport, work, childcare

Providing additional support services

- Provide the patient and their family and carers with information about support services and peer support programs and how these can be accessed

Adapted from *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer*²⁸

Support from the treatment team

Clinicians are responsible for the psychosocial care of their patients as well as their surgical and medical care. Provision of such care and support entails more than referral to psychosocial services, and may be as simple as a shared emotion, an encouraging personal word or a physical touch.

People with cancer who are provided with an opportunity to explore feelings with a member of the treatment team or a counsellor experience less psychosocial distress than people not provided with this opportunity (**Level I**).¹⁵

Australian women with breast cancer see clinicians as a considerable source of support for themselves and their families, looking particularly to the surgeon, the oncologist and their GP.⁸⁵ The integrated provision of medical and psychosocial services assists patients and their families adjust to the diagnosis of cancer, its treatment and consequences. For example, emerging findings from studies of patients with laryngeal cancer show that the integration of

a multidisciplinary team, including the surgeon, speech therapist, psychotherapist and social worker, at the outset of treatment planning, is crucial in helping the patient adjust to laryngectomy.²⁶⁷

Support from partner, family and friends

Members of the treatment team should ask people with cancer about their key support people and to define the level of involvement of these people. Special attention should be paid to the partners of people with cancer, recognising that this may be someone of the same sex (see also Section 5.4). Involvement of their general practitioner or an advisor from a relevant community health group can help ensure that appropriate supportive care is provided to gays, lesbians, and trans-sexuals. Assumptions should not be made about the ability or willingness of partners and family to be involved.

Family and friends can provide an integral part of a patient's cancer care^{43,62,72,73,267} (**Level III-2**).⁴⁶ However, they bring with them a range of emotional reactions, interpersonal dynamics and expectations for the care the patient receives. Findings from a multicentre project that analysed the contents of 19 focus group discussions show there is a need for explicit conversations between professional caregivers, patients and their loved ones in order to negotiate the expectations and needs of each.⁵⁴⁷

Once the level of support from a partner has been established, couple therapy may be considered. In relation to women with breast cancer, couple therapy has been shown to reduce emotional distress and increase sexual satisfaction in both partners, and reduce depression in the woman (**Level II**).⁵⁴⁸ In people with colon cancer, early interventions can help with emotional distress and family functioning and support (**Level III-3**).⁸⁴

Support for the family and friends of people with cancer

It is important to enquire about the psychosocial needs of the partner and family along with those of the patient, because partners and families are also vulnerable to distress (see Chapter 2).^{66,67,89-91,96}

Professional support can be pivotal to helping families of patients with advanced cancer cope with anticipatory grief as they observe their relative entering the terminal phase of their illness.⁵⁴⁹ However, research to date provides inconsistent findings about the application of family intervention, and uncertainty remains about which families will require help and the optimal type of treatment.⁵⁴⁹

Psycho-educational programs

A psycho-education programme may be offered as a component of information about specific treatments. Patients may also find the supportive components of these programs valuable. Psycho-educational programs decrease anxiety (**Level II**)^{477,478} and depression (**Level II**),⁴⁷⁷ as well as increase knowledge (**Level II**),^{478,479} (**Level III**)⁴⁸⁰ (see Section 3.2.3).

Peer support programs and groups

It is recommended that clinicians have up-to-date knowledge of the peer support programs and groups available in their area, and ensure that patients are aware of their availability.

Peer support programs are based on the premise that shared experience is a valuable resource that assists individuals to adjust to and cope effectively with stressful events.

Information, patient education and access to needed services may also be provided. These programs may be professionally or peer supervised, and peer supervised programs often work in association with local health professionals. Peer support program formats include one-to-one visits, group settings and using technologies such as the Internet or teleconferencing.⁵⁵⁰

In Australia, peer support programs are well established for a number of cancers including breast, prostate, bowel, and head and neck cancer, as well as for specific groups such as children, teenagers, parents of children with cancer, young adults, and non-English speaking groups (see Appendix E). Some programs are professionally supervised, eg the Laryngectomy Association works in collaboration both with State Cancer Councils and treatment centres. Other programs are peer supervised, eg the Support and Advocacy Committee of the Prostate Cancer Foundation of Australia, which has chapters in each state. The Cancer Helpline (13 11 20 Toll Free) provides a central point from which to access details about locally available peer support programs.

Men and women join support groups to seek information and emotional support and to enhance coping by comparing their progress with that of others.⁵⁵¹ Results of a descriptive study suggest that peer support programs may be a preferred style of psychosocial intervention for sections of the community in which the incidence of cancer is low, or for specific groups for whom social stigma or isolation is a particular problem (**Level IV**).⁵⁵² As well, being community based, these programs are usually easily accessed and free of charge.

Peer support provided through teleconferencing has shown high levels of satisfaction for both professionally and peer supervised programs, according to the findings of two small post-test studies (**Level IV**).^{95,553} Participants regarded teleconferencing as an intimate setting for safe disclosure. Few studies have assessed Internet support programs, but descriptive studies describe them as helpful in enabling participants to share concerns and information.^{554,555}

Data from several non-randomised studies using case comparison (**Level III-2**),⁵⁵⁶ post-test (**Level IV**)^{552,557} and descriptive designs^{551,558} suggest that patients benefit from one-to-one programs, such as the Breast Cancer Support Service (BCSS), and group format programs such as prostate cancer support groups. In these studies, peer support programs rated highly for consumer satisfaction, and were seen to provide valuable information about coping from the perspective of shared experience, to reduce social isolation, to 'normalise' the cancer experience, and to assist participants with specific fears such as loss of femininity and body image concerns. Patients have also reported feeling less anxious and more optimistic about the future after involvement in peer support programs.

It has been suggested that peer support programs may not be universally helpful. A study of women in self-help groups found that participants reported more concerns than a control group who did not participate, but displayed less psychological distress (**Level IV**).⁵⁵⁷ One randomised control study of women with breast cancer compared a professionally facilitated peer support group with an educational program and a control group (**Level II**),⁵⁵⁹ (**Level III-1**).⁵⁶⁰ When women were assessed two weeks after the interventions, peer support appeared to be helpful for women with poor pre-existing social support, but had a negative effect on the vitality of women with good pre-existing social support. These effects were not significant six months after the intervention and were not evident at a longer term follow up. At three-year follow-up, only women in the educational program maintained a benefit (**Level II**).⁵⁶¹ More recently these authors have suggested that a one-to-one matched program, such as the BCSS where peer role models are trained and supervised, may be more effective.⁵⁶²

Table 3.3B: Support sources that can improve the emotional well-being of people with cancer*

Type of intervention	Description	Research
Treatment team	Provides opportunity to explore feelings with a member of the treatment team (clinician, counsellor or specialist nurse), which decreases psychosocial distress	Level I ¹⁵
Family and friends	Provide emotional and physical support and opportunity for discussion of illness	Level III-2 ⁴⁶ Level III-3 ⁴³ Level IV ⁶²
Assistance for family and friends	Provides emotional support, and opportunity to explore feelings. Can help decrease feelings of frustration and helplessness Can be provided by treatment team or peer support groups	Level IV ⁵⁶³
Peer support programs	Emotional support that is based on shared personal experience May be delivered on a one to one or group basis, and through face to face or remote technologies. Programs may be peer or professionally supervised Preliminary evidence that pre-existing social support may interact with the intervention in professionally supervised peer support group programs	Level II ^{559,564,565} Level III-2 ⁵⁵⁶ Level III-3 ⁵⁶⁰ Level IV ^{551,552,558}
Telephone support programs	Provide geographically and socially-isolated patients with an opportunity to be involved in support groups	Level II ⁵⁶⁶ Level IV ^{95,553} Level IV ⁵⁶⁷
Internet Groups	Computer-mediated support groups enable sharing of information and concerns Chat room formats have little quality control and may lead to promulgation of misinformation	Level IV ^{554,555}
Psycho-educational Groups	Enhance understanding and knowledge about cancer and associated issues such as treatment, diet, health behaviours, coping, adjustment and available services	Level I ¹⁵ Level II ^{477-479,568}

*Where major difficulties exist, specific therapy is required, see section 4.1

For more detailed information, see report by Kissane & Burke²⁴ available from National Breast Cancer Centre.

3.4 PRACTICAL AND FINANCIAL SUPPORT

Many patients and their families may have faced considerable financial strain before the diagnosis of cancer. Concerns about costs and availability of and access to services, and access to relevant information may add to the emotional burden of patients and their families and may influence treatment choices. Open discussion of these issues and the provision of relevant information and advice are important to the overall care of the patient.

Clinicians can explore whether patients are concerned about costs and ascertain the extent of assistance available for the issues outlined below by asking questions like:

'I know that this may result in considerable costs for you and your family. Sometimes people are worried about this. How do you feel about it – are you concerned about these costs?'

'Do you have any means through which you may be reimbursed, or be eligible for reductions, such as private health insurance cover or a health concession card?'

As private health insurance policies will differ in the services covered and levels of coverage, patients with private insurance will need to clarify what their insurance will and will not cover.

It is also important to find out whether the patient is able to access the services he/she may require.

'I hope that getting to (insert appropriate) will not cause you any difficulties. Do you have means of transportation or can you easily get there by public transport?'

Information about the availability and types of treatment, services, supportive therapies, prostheses, aids etc, or advice about how to obtain information or access support should be provided to all patients.

Cost of diagnosis and treatment

Patients will need to be given information about the costs of treatment, including medications, and the factors that may influence those costs. It is recommended that treatment team members provide written material about these matters to each patient. Patients with concerns about financial burdens resulting from these costs, and/or the impact of treatment on employment can discuss these concerns with a social worker or welfare worker. Patients can also obtain information and advice from State and Territory cancer organisations (see Appendix E).

Cost, availability and types of other supportive therapies

If patients require referral to additional supportive services (see Section 2.4), referring clinicians, need to discuss with patients and their families their ability to access and pay for them. Patients can obtain information and advice about costs, availability and types of therapies from local State and Territory cancer organisations (see Appendix E).

Cost, availability and types of prostheses

Breast prostheses

A wide range of breast prostheses are available. Breast prostheses are available from lingerie shops and department or specialty stores where staff members have been specially trained to fit women with the product most suited to their needs. When purchasing a breast prosthesis, women should consider the range of products available from the outlet and the level of training and experience of the staff. The woman's bra and prosthesis should be fitted at the same time.

Financial assistance programs are available through State health departments to help women with the purchase of a breast prosthesis, although these are usually means tested. In some States, these programs are administered through local public hospitals. The Department of Veterans Affairs and some private health funds provide cover for breast prostheses. Advice specific to each state can be obtained from the Cancer Helpline (13 11 20).

Continence Aids

The Continence Foundation of Australia runs a National Continence Help Line (1 800 330 066) which can help direct patients to the nearest continence advisor (see Appendix E). Continence advisors are generally nurses or physiotherapists, and they may operate from hospitals, community health centres or private practice. The continence advisor or the Help Line can advise on continence aids and their costs. There are some funding schemes available to assist with costs, although these are limited and criteria for access vary from state to state.

Erectile dysfunction aids

A wide range of erectile dysfunction aids are available (see Section 2.4), some of which are subsidised through the Pharmaceutical Benefits Scheme (PBS), eg direct penile injections. Others, eg penile prostheses, may be covered by the patient's private health insurer. Drugs to assist erectile function and mechanical aids are not covered by the PBS. The patient's urologist can provide information and advice about types of aids, availability, local access and costs. Patients can also be directed to their local cancer support group or the Cancer Helpline (see Appendix E).

Laryngectomy aids

Public hospitals lend speech aids at the time of surgery, and may extend this loan if patients are unable to purchase their own equipment. For patients treated in private hospitals, speech aid costs may be covered by some private health insurers. Patients will need to clarify this with their insurers.

The Laryngectomy Association can purchase speech aids, batteries, and accessories, as well as other necessary equipment such as stoma maintenance and protection devices, at reduced prices for their members. The speech pathologist and the Laryngectomy Association welfare officer in each state (see Appendix E) can assist with information and advice about all necessary aids.

Colostomy bags

Colostomy bags are provided free of charge through a Federal Government scheme operated by the Colostomy Association in each State (see Appendix E). The initial referral will be made

through the stoma therapist who visits the patient in hospital. Patients need to be made aware that, although colostomy bags are free, the Colostomy Association charges a small annual fee, and monthly postage costs apply, unless supplies can be personally collected.

Wigs

Support for patients with cancer for the purchase of wigs varies between states. Some state health departments provide a subsidy towards the purchase of a wig, and some public hospitals and State and Territory Cancer Councils provide a wig service where either pre-used or new wigs and turbans are provided free of charge. As well, some private health funds provide cover for wigs. For advice about local services patients can contact the Cancer Helpline (13 11 20).

The Look Good Feel Better program, sponsored by the Cosmetics, Toiletries and Fragrance Association of Australia, helps people who are experiencing changes with their appearance, such as hair loss, as a result of cancer treatments. Trained volunteers demonstrate techniques to assist women with make-up application, wigs, turbans and skin care. The Cancer Helpline can provide details of local programs.

Reconstructive surgery

Patients expressing a desire for reconstructive surgery will benefit from information about the procedures (see Section 3.7), local availability, likely costs and sources for financial assistance.

Lymphoedema

Patients who develop lymphoedema require appropriate assessment and management by qualified practitioners. This may include physiotherapists, occupational therapists and registered nurses who have completed post graduate training in lymphoedema management. They may also require access to compression garments and additional support services. Treatment of lymphoedema is available through major hospitals and in private practices throughout Australia. Information about trained therapists, treatment locations, compression garment costs and fitting, and assistance with costs can be obtained from State and Territory cancer organisations, lymphoedema associations and cancer-specific support services, eg BCSS. Contact details for these resources are listed in Appendix E. Health funds can also provide advice about coverage for private treatment costs.

Travel and accommodation

Patients in rural and remote areas may be unaware that they may be eligible for financial assistance for travel and accommodation expenses. Travel and accommodation schemes have a different name in each State and Territory (see Appendix F) and selection criteria may be means tested and vary from State to State. Social workers and welfare workers can offer advice and assistance with application forms (as soon as possible after diagnosis).

Patients need to be advised that ambulance travel may be necessary at certain times and that they should check their entitlements for ambulance travel since these may vary between states.

Other support needs

Patients in need of support for practical issues such as child care, meals or home help can be informed that assistance may be available and provided with information about how to access

support services, eg local councils, community health centres, hospital social workers or cancer organisations in each State and Territory.

Loss of income

Benefits to assist with financial concerns are provided by the Commonwealth Department of Family and Community Services. Information about Sickness allowance can be obtained by calling Centrelink on 13 27 17. For advice about Childcare Benefits, the Family Assistance Office should be contacted on 13 61 50. Some State and Territory Cancer Councils also provide limited financial assistance for patients with cancer. Discussions with a social worker or welfare worker may also be beneficial in providing information and advice about leave entitlements or other employment benefits, or other sources of financial support.

Difficulties with business dealings

Patients who are concerned about, or who have had difficulties with business dealings or transactions may benefit from referral to a social worker for advice.

Practical aspects of advanced cancer (wills, Power of Attorney etc)

It is important to provide patients with information about the practical issues of preparing for death and where they can obtain assistance and advice. All treatment team members should make available written information about the preparation of a living will or advanced care directive. Social workers may provide valuable assistance and emotional support at this time.

Also as legal considerations differ in each State, patients should be advised to obtain advice and assistance with the preparation of wills and Power of Attorney from their solicitor. For patients who do not have a solicitor, information about local legal services would be beneficial. Patients should communicate with their GP and families their wishes for care.

3.5 ENSURING CONTINUITY OF CARE

In Australia, healthcare services are delivered through both the public and private sectors, in urban and rural remote locations, and involve State and Federal funding. Patients move between a variety of treatment settings and service providers during the phases of diagnosis, treatment and follow-up, which may be provided over a considerable period of time. Attention to continuity of care for these patients may require active interventions. See Table 3.5 for recommendations for establishing continuity of care.

Identification of a coordinator of care

The identification of a coordinator of care, often a GP, can be useful in ensuring continuity of care.^{372,373} GPs often have knowledge of a patient's background, such as family and social history, usual responses to illness, and medical history, as well as awareness of local community agencies which would be helpful. The GP may also look after the family throughout the patient's illness and follow-up. In rural and remote areas in particular, the general practitioner may play a key role in ongoing care. It is important to note that patients who have been treated for cancer may have co-morbid conditions (medical or mental), and a GP is likely to be in the best position to coordinate overall care and facilitate appropriate specialist referral.

The coordinator of care could also be the treating surgeon or another member of the treatment team, and should be selected by the patient in consultation with the treatment team. It is important that the patient identifies who they wish to be their primary care professional. The coordinator of care needs to be informed of all consultations, treatment plans and treatment outcomes.

Patients in public hospitals are more likely than patients in private hospitals to report that they had seen too many healthcare professionals during their treatment and would prefer one person identified as their contact point with the system and their care.⁸⁵

Specialist oncology nurses

In the area of breast cancer, a new approach to achieving continuity of care has been developed. Specialist breast nurses are advanced practice nurses whose skills include: coordination of care; counselling; provision of information and support; clarifying or reinforcing information; providing continuity of care; and facilitating specialist referral (**Level II**).^{401,466,569} Specialist breast nurses are uniquely positioned to provide support and practical assistance to patients throughout the various stages of their treatment and have been found to be effective and beneficial in the ongoing care of the patient. In a recent demonstration project conducted by the NBCC among women with breast cancer, 80% of respondents believed specialist breast nurses made a significant contribution to their care and 99% reported they would recommend seeking treatment at a centre that provides a breast nurse (**Level III-3**).⁵⁷⁰

Because of the success in the area of breast cancer there is a growing interest in specialist nurses and the potential for developing this role with other cancer groups, such as individuals with prostate and gynaecological cancers. These roles are not yet as developed as that of the breast care nurse, and further research is required in this area although emerging evidence suggests that prostate care nurses are seen as very acceptable sources of information and support for men with prostate cancer.⁵⁷¹

Specialist oncology nurses, in both inpatient and outpatient settings, play a major role in ensuring continuity of care by coordinating the patient's path through treatment. These nurses are often best placed to liaise with different members of the treatment team, assess and monitor the patient and provide support. Stomal therapy nurses have an educative, clinical and supportive care role for individuals requiring stomas.

The role of tumour-specific specialist oncology nurses has been developed primarily in metropolitan settings. The specialist breast nurse role has been evaluated in a rural setting with benefits to women identified to in both settings (**Level III-3**).⁵⁷⁰ Maintaining this degree of specialty will depend on the caseload, and in many rural areas this is not sustainable or feasible. Consequently, the role of a specialist oncology nurse for all patients with cancer is being currently explored and developed for rural settings. The focus of the role will be on improving continuity of care, and providing practical and supportive care.

Multidisciplinary care

It is increasingly recognised that the development of a treatment plan by a multidisciplinary team improves outcomes for patients with cancer,⁵⁷² and most clinical practice guidelines include a recommendation that care be provided in a multidisciplinary manner.^{364,372} Multidisciplinary teams may include a core set of disciplines such as surgery, medical oncology, pathology, radiology, radiation oncology, general practice and supportive care. The multidisciplinary team ideally has links to other disciplines that can provide advice and

treatment when required. These might include genetic services, liaison psychiatry, physiotherapy, occupational therapy, social work or orthopaedics. It is important that each individual therapist have appropriate skills in cancer management.

Effective multidisciplinary care requires excellent communication among team members, including discussion of individual patient issues at regularly scheduled dedicated case conferences. These meetings may be held in a variety of formats including face-to-face meetings, or linking separate sites through the use of e-health technologies such as teleconferences or video conferencing. Multidisciplinary treatment planning meetings, in which all key disciplines are represented, are increasingly used to facilitate effective communication. In order to ensure that each patient's psychosocial issues are considered, multidisciplinary meetings should include a core team member who represents the psychosocial areas of care, such as an oncology nurse, social worker or a designated clinician.

Effective written communication is also fundamental to successful multidisciplinary care. Teams should develop protocols that include an outline of the information required by treating clinicians to ensure continuity of care. Special attention should be paid to ensuring that the GP receives adequate information, including relevant psychosocial issues.⁵⁷³

Local protocols should include strategies to provide similar information about diagnosis and treatment to the patient. These might include the provision of copies of letters or pathology reports and/or specially developed written treatment and follow-up plans.

Patient-held records

The use of patient-held records is an emerging area of research, and appears to be a promising mechanism for improving continuity of care for people with cancer. Research has shown that patient-held records are beneficial for patients (**Level II**)⁴⁷⁶ and have considerable medico-legal benefits, such as documentation of doctor-patient communication, with no substantial practical drawbacks (**Level IV**).⁵⁷⁴

Table 3.5: Recommended steps for establishing continuity of care

Ensuring continuity of care

- Develop a communications framework for the multidisciplinary team and train team members in communications skills
- Schedule regular dedicated case conferences
- Ask the patient who they would like to coordinate their care, eg, GP, specialist nurse, etc.
- Document designation of coordinator of care in medical notes and/or patient-held record
- The coordinator of care should inform specialists and members of the treatment team of any known psychosocial or medical risk factors that may influence treatment
- Notify the coordinator of care promptly after each visit to a specialist or when there are any changes in treatment. Options include a phone call, a fax, or a letter carried by the patient
- Notify the coordinator of care of any inter-specialist referrals. A phone call or fax message may be sufficient (or even preferable), rather than sending the patient back and forth
- Provide letters of referral and letters of reply with relevant information to members of the treatment team

- Forward all relevant health information to the coordinator of care; however, the patient should be encouraged to contact the appropriate member of the treatment team for clarification and further information
- Ensure patient is aware of ongoing collaboration and communication between multidisciplinary team about their treatment

Adapted from the *Clinical Practice Guidelines for the Management of Advanced Breast Cancer*. National Breast Cancer Centre.³⁷² and *Multidisciplinary care for women with breast cancer: A national demonstration program*.⁵⁷²

3.6 SUPPORT TOWARDS THE END OF LIFE

Maintaining quality of life and minimising the physical and psychosocial impact of the cancer and its treatment should be a major focus of the management of people with cancer, as these have been shown to be a significant, independent prognostic predictors of survival in clinical trials.^{575,576} This is especially important for patients living with advanced cancer. Health professionals need to be aware of the potential impact of the disease on quality of life for patients and their families (see Chapter 2), and set up monitoring strategies so that appropriate interventions can be implemented (see Table 3.6). Valid and reliable quality-of-life assessment is also important as it may influence decision-making about the type of treatments used. For most individuals living with advanced cancer, remaining at home is the preferred option. However, care can be provided in a range of clinical settings, and is not limited to the acute hospital setting.

In some cases, particularly the more complex ones, palliative care can be provided by specialist palliative care teams. A systematic review of the evidence for palliative care found that specialist palliative care services improve patient outcomes in relation to patient satisfaction, the proportion of patients being cared for in their place of choice, family satisfaction, control of pain, symptoms and family anxiety **(Level I)**.⁵⁷⁷

Key points

If pain and other symptoms are not actively treated or controlled, psychological distress increases and physical and social functioning decreases **(Level IV)**.^{158,306-308}

Pain can be controlled by guided imagery, relaxation therapy, music **(Level I)**¹⁵ and educational programs aimed at enhancing pain control **(Level II)**.⁵⁷⁸

Education sessions can improve adjustment, knowledge, death awareness and increase positive self concept **(Level III-2)**.⁴⁸⁰

Psychological interventions are associated with improved outcomes in a number of domains of quality of life, including mood, self-esteem, coping, sense of personal control, physical and functional adjustment **(Level I)**,^{15,17} **(Level II)**.^{579,580}

Open communication and expression of feelings promotes adjustment **(Level II)**,⁴⁰¹ **(Level III-1)**.⁵⁷⁹

One of the features associated with a 'good death' (i.e. from the patients perspective) is the social life of the dying patient.⁵⁸¹

Families and carers benefit from support and counselling **(Level IV)**.^{549,563}

Specialist palliative care services improve patient outcomes in relation to patient satisfaction, the proportion of patients being cared for in their place of choice, family satisfaction, control of pain, symptoms and family anxiety,^{582,583} **(Level I)**.⁵⁷⁷

Responding to patients who are dying and their families, may engender considerable distress. It is helpful for health professionals to draw on the expertise of members of a multidisciplinary team, particularly in dealing with complex clinical problems **(Level IV)**.⁴⁰

Having the opportunity to express grief is important in promoting adjustment.⁵⁸⁴

See also *National Palliative Care Strategy: A National Framework for Palliative Care Service Development*. Commonwealth Department of Health and Ageing 2000⁵⁸³

Supporting patients coping with physical issues

In people with advanced cancer, quality of life is impaired by symptoms, loss of function and curtailment of activities (see Section 2.5).³⁰⁴ As patients enter the phase of palliative care, physical symptoms require active treatment. If pain and other symptoms are not actively treated or controlled, psychological distress increases and physical and social functioning decreases **(Level IV)**.^{158,306-308}

In addition to medical management, cancer pain can be significantly improved by relaxation therapy, either alone or with guided imagery and music **(Level I)**.¹⁵ Further, educational programs conducted by nurses and aimed at enhancing pain control result in better adherence to treatment and improved pain control **(Level II)**.⁵⁷⁸

Patients with metastatic disease and their carers also need to be provided with advice and information about how to access help for managing the physical aspects of daily living such as self care, mobility, physical activities, household activities, (see Section 2.5) as well as appetite/nutrition control.³⁰⁵

Supporting patients coping with psychological issues

For patients and their families, emotional distress, anxiety and depression may increase as the disease increasingly impacts on daily life and they are confronted with their own, or their loved one's, mortality. Recognition of grief, and the provision of psychological support and bereavement support are integral aspects of care.⁵⁸⁴⁻⁵⁸⁶ Education sessions can improve adjustment, knowledge, death awareness and increase positive self concept **(Level III-2)**.⁴⁸⁰ Psychological interventions are associated with improved outcomes in a number of domains of quality of life, including mood, self-esteem, coping, sense of personal control, physical and functional adjustment **(Level I)**,^{15,17} **(Level II)**.^{579,580} Refer to Chapter 4 for a detailed discussion of appropriate and effective psychological therapies. Bereavement support is discussed within this section.

Psychosocial interventions can be undertaken by members of the treatment team or by specialist providers of psychological care. Providing psychosocial support to patients with advanced cancer requires a multidisciplinary approach, as patients pass through many different phases of the disease and require varied treatment from a range of specialists.^{24,25} In addition to medical specialists and nursing staff, the team may variously include liaison psychiatrists, social workers, clinical psychologists and physiotherapists. It is also important to consider the contribution of community based health professionals such as general practitioners, occupational therapists and speech therapists.

Supporting patients coping with social issues

A study examining the experience of patients with cancer in their final year of life found that one of the features associated with a 'good death' (i.e. from the patients perspective) was the social life of the dying patient.⁵⁸¹ As social life may become increasingly disrupted as the disease progresses it is important for clinicians to monitor the level of social support/interaction the patient has, desires and is capable of, and to offer advice and assistance. Where no support is available, information about available services, such as visiting programmes by church or community groups, may be beneficial.

Supporting patients with 'putting their affairs in order' and coping with existential and spiritual issues

Other factors reported to be important to the dying patient are the creation of open awareness, the adjustment to, and personal preparation for, death, and the public preparation, such as arrangements relating to work and final farewells.⁵⁸¹ Given the opportunity, health professionals should ask their patient about their expectations of dying and death.

As existential and spiritual issues have been shown to be important, or gain importance, towards the end of life (see Section 2.5), health professionals have a role in providing the opportunity to discuss spiritual and existential issues and assessing the needs and support available to the patient and the family. Many patients will have their own spiritual advisor who should be consulted. Information about resources and available support sources should be provided to those in need.

Support the family can provide

Families play a major role in a patient's ability to cope with cancer. A study of patients with breast cancer found that open communication styles and expression of feelings generally facilitate adjustment (**Level III-1**).⁵⁷⁹ There is no evidence that being upset will worsen the prognosis, in fact, there is evidence from breast cancer studies that expression of feelings may improve adjustment (**Level II**).⁴⁰¹ Therefore, in general it is appropriate to encourage patients to express feelings and concerns, and to maintain open communication with their family and friends.

Supporting the family and caregivers

Families and carers may benefit from information about support services and groups that can provide practical assistance, support and counselling. A detailed discussion of appropriate and effective psychological therapies for families and carers is provided in Chapter 4. Information about local services for families can be obtained from the Cancer Helpline, and hospital social workers.

Anger is common in the offspring of patients with cancer and the ability of families to cope with this is further undermined if there are poorly defined roles and power structures within the family (see Section 2.5).³³⁰ Review articles and data from surveys also suggest that parents with cancer may fail to recognise the extent of distress, and emotional needs of their children, as they are preoccupied with coping with treatments and disease burden.^{67,97,326,330} For these reasons, access to specialised support may be beneficial.

In addition, external services that offer specialised support have a benefit.⁵⁸³ A study of 292 family members of dying nursing home patients, half of whom had cancer, showed that the perceived quality of care for the emotional needs of carers increased from 64% to 90% after the introduction of a hospice.⁵⁸²

Issues that arise for clinicians caring for patients and their families

Treating patients whose disease has progressed, or failed to respond to treatment poses a stress for health professionals. Responding to patients who are dying and their families, may engender considerable distress. In this setting it is helpful for health professionals to draw on the expertise of members of a multidisciplinary team, particularly in dealing with complex clinical problems (**Level IV**).⁴⁰ The capacity to reflect on professional and personal priorities is important,³⁸ as is the opportunity to discuss difficult issues with colleagues. Enhancement of skills in communication and management may be further strategies to reduce stress (**Level III-2**).³⁵

Support for the bereaved

Historically, grieving has been facilitated through families, church, funeral rituals and other social customs. However, the reduced emphasis on such formalities and rituals may make it more difficult for some people to deal with the thoughts and feelings of grief.

Factors that are associated with higher distress levels in the bereaved include a sense of blame or guilt about the circumstances of the death; if the death has been sudden or highly traumatic, the bereaved person is at high risk of ongoing distress.⁵⁸⁷ This risk is compounded by factors such as social isolation, unemployment, and a past history of depression or other major illness. Australian research has identified that having the opportunity to express grief is important in promoting adjustment,⁵⁸⁴ although more commonly, socially the expression of grief is inhibited by others rather than facilitated. It appears that men are at increased risk both physically and emotionally following bereavement, yet men may feel more uncomfortable with the direct expression of grief.⁵⁸⁸

It is important to recognise gender and cultural differences in response to grief. For example, in the aboriginal culture it is considered disrespectful to mention the name of the dead person.

Request for an autopsy

Autopsies may prove of considerable value in addressing unanswered questions that existed clinically. However, clinicians need to be aware that any request they make for an autopsy comes at a time of intense grief, distress and uncertainty for families. While some families may find that the results of an autopsy are helpful in understanding the course of the disease, it is important that families are given a realistic time frame for final results of an autopsy to become available.

Even though the distress of relatives is likely to make the request difficult, there is some evidence that this task is often delegated to junior staff⁵⁸⁹ who are offered little training.⁵⁹⁰ Such practices not only undervalue the traumatic impact of this work on junior staff, but are a failed opportunity for preventing psychological distress among the patient's family and among staff.⁵⁹¹

Clinicians should recognise that attitudes towards autopsy are shaped by personal and cultural attitudes toward death and medical science, and also by the context in which the request is made. Many of the techniques detailed in Table 3.2.1. *Telling a patient they have cancer, a recurrence or metastases*, may be adapted to requesting an autopsy.

It is essential that the request for autopsy be followed with clear communication of the results, as this feedback is crucial for families. The senior clinician should arrange a time – usually a few weeks after the death – to meet with surviving family members to explore any concerns that may persist or may have emerged since the patient's death.

Table 3.6: Recommended steps involved in providing end of life support

These steps are recommended in conjunction with the general interactional skills in Table 3.1.

Planning care

- Ask about the person's understanding of their disease status, including their current needs and priorities
- Discuss plan of future management and monitoring, including understanding of short and medium term outcome goals
- Check with the patient and their family members about the amount and type of information they desire
- Keep the person, their partner, children, and significant others continually informed about issues of most importance to them, such as the likely course of the disease, symptom management and service availability, tailoring this to the wishes of the individuals

Physical issues

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

Psychological issues

- Actively encourage the person to discuss how they and their family are coping with the disease and how others' reaction to the disease is impacting on the person's well-being
- Where appropriate, make specific arrangements for counselling/support/information to be available for the person and their family

Social issues

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

Bereavement issues

- Recognise gender and cultural differences in responses to grief
- Provide the family with an opportunity to talk about the deceased and their responses to his/her death
- Provide the family with information about counselling/self-help groups that are available if they wish to utilise them
- When requesting an autopsy, recognise that attitudes are shaped by personal and cultural differences. Provide the family with a clear communication of the results and arrange a suitable time for family members to explore any concerns they may have

Other issues

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

3.7 EXPLORING AND RESPONDING TO SPECIFIC CONCERNS

Maintaining quality of life and minimising the psychological and physical impact of both the cancer and treatment side effects should be a major focus of care. The majority of patients with cancer will negotiate their diagnosis and treatment and develop a new level of adjustment. However, a significant proportion of patients will experience a level of emotional distress that causes them significant personal suffering, which is often associated with disruptions in family and interpersonal relationships, and impaired capacity to engage in occupational or recreational activities. Depression may also directly impair clinical care, as there is evidence that patients who are depressed are less likely to accept adjuvant chemotherapy (**Level IV**).⁵⁹²

Although there is evidence about the efficacy of treatments in improving adjustment in patients who are depressed, there remains considerable stigma about psychological disorders and lack of awareness in the community about their nature and treatment.⁵⁹³ Patients may therefore be reluctant to request or accept assistance. One Australian study found that oncologists show low rates of detection of depression and anxiety in patients with cancer (**Level IV**),⁵⁹⁴ and another Australian survey found that only 25% of depressed patients with cancer had received any counselling or psychological treatment.⁵⁹⁵

For these reasons, it is prudent for all health professionals involved in the care of patients with cancer to be aware of the risks for adverse emotional outcome, and actively assess adjustment and mood during the course of treatment and follow-up. Although, in many instances, the emotional and psychological care of the patient may remain in the hands of their treating professional, it is important that clinicians recognise their own level of training and skill in this area, and refer patients whose problems are complex or beyond their training and expertise to specialised services. It is also recommended that people considered to be at risk for psychological problems are referred to specialised psychological services early in the course of treatment, as this may minimise the likelihood of their developing significant disorders (**Level I**).⁵⁹⁹

Guidelines are provided here to improve the care of patients with psychological and physical distress, the detection and appropriate referral of patients with significant psychological distress or disorder, and, where appropriate, assist in the monitoring of, and referral needs of physical symptoms that require specialised services. The types of specialised services available, the benefits of each and the referral process are discussed in Chapter 4.

The recommendations detailed herein are ideally incorporated into routine clinical practice. However, local circumstances and the availability of resources may limit the opportunity to implement some of the recommendations. For example, difficulties in obtaining access to specialist staff such as psychiatrists, clinical psychologists or specialist oncology nurses may limit the implementation of some recommendations.

Existential concerns

Uncertainty about the clinical course may compound existential distress. The patient who has existential concerns may find it difficult to express their fears in detail and present with agitation, poor sleep or nightmares or somatic symptoms of anxiety (see Section 2.2).

Encouraging the patient to talk about their fears and 'speak the unspeakable' provides an opportunity to give support. For example:

'How is your situation affecting your sense of self, of worth and your feeling of dignity as a person?'

In palliative care and in the terminal phases:

'It is enormously painful for any of us to contemplate our own death. Are there particular fears or issues concerning you about facing death and what that means?'

Psychological problems

Although psychological problems, including body image distress, depression and anxiety are common in people with cancer, they are frequently under-recognised and under-treated.⁵⁹⁶ This may be partly because many people are reluctant to mention their distress to their doctor, because they feel that depression or anxiety is a sign of personal weakness. Some clinicians are also reluctant to ask about psychological problems because of their belief that depression and anxiety are a 'normal' response to cancer.

It is imperative that members of the treatment team monitor the emotional and psychological impact of the cancer on patients. This process begins with asking broad, open-ended questions. This is important not only to elicit information, but to indicate to patients that attention to psychosocial issues is an integral aspect of clinical care. The prevailing social views about mental illness and emotional problems mean that it is likely that patients will find it more acceptable to complain of physical symptoms rather than emotional concerns. Furthermore, patients are likely to follow the cues given by their clinician and respond with physical concerns if they are questioned about physically orientated symptoms.⁵⁹⁷ The following questions are given as examples; prompts that may help clinicians frame questions which facilitate expression of emotional concerns

'How are things going overall?'

'How have you been feeling since your diagnosis?'

'How do you think the cancer has affected you emotionally?'

Depending upon the initial information given by the patient, the nature, severity and impact of their concerns can be further explored.

Key points

It is prudent for treatment team members to actively assess adjustment and mood during the course of treatment and follow-up.

Referral of people at risk for psychological problems, to specialised psychological services early in the course of treatment may minimise the likelihood of their developing significant disorders (**Level I**).³⁵⁹

Treatment team members can provide opportunity for discussion of concerns and the expression of thoughts and feelings and conduct/direct a range of techniques/strategies that are helpful for specific concerns (see below).

Referral to specialised services is recommended for people experiencing severe concerns or disorders.

Body image concerns

Clinicians need to be alert to patients' body image concerns throughout treatment. It is possible to explore whether the patient has significant concerns about the impact of treatments on their body or sense of self by asking questions like:

'We don't often talk about it, but cancer certainly changes how we feel about ourselves. Many people tell me that they do have concerns about how they will look, and how they will feel about themselves after treatment. Is this something that you feel you could discuss with me?'

This may then be followed with questions such as:

'Have you discussed any concerns with your partner?'

'Are there specific things that cause you particular concern?'

After treatment it is worthwhile to explore sensitively whether the patient is concerned about changes to their body and to assess the nature, severity and impact of these concerns on their functioning, including the impact on relationships. It can be helpful to ask about the degree of distress this is causing, and the extent to which the patient avoids situations such as catching sight of themselves, allowing their partner to see them naked or undressing, or undressing in public changing rooms or using public toilets.

Support and education may help with adjustment. For instance, women with breast cancer report that sharing intimate thoughts and feelings promotes sexual adjustment.⁵⁹⁸ In addition, exercise may be helpful. Emerging evidence indicates that women with breast cancer who exercise regularly have higher body image than those who do not (**Level III-3**).^{599,600}

In more severe cases, the patient may benefit from psychological interventions such as cognitive behavioural, supportive or crisis therapy (see Tables 4.1B and 4.1C). These can be provided by practitioners trained in these specialised techniques. Effective treatment of depressive or anxiety disorders will often have a positive impact on self-esteem and body image.

The clinician needs to be aware that a patient might also avoid sight of their altered appearance or be disturbed by images of it because of fear of recurrence and fear of cancer. In either case it is important that they are offered a referral to a trained specialist who is able to assess these difficulties thoroughly and provide treatment as needed.

Sexual difficulties

Given the relatively high incidence of sexual difficulties in patients with cancer (Refer to Chapter 2), questions about sexual adjustment should be part of routine clinical care and follow-up. Skilful communication can make it easier for people to disclose sexual concerns. However many people will feel reluctant to broach the subject of sexual difficulties but may be more willing to discuss issues of sexuality with certain members of the treatment team if they feel comfortable with them. Comments such as the following may help put people at ease whilst initiating assessment of sexual adjustment:

‘Cancer affects so many parts of people’s lives, yet we often don’t talk about things that are very important to us. When I ask them, many people admit that the cancer has affected their relationships and sex life – yet they usually don’t talk about it unless I ask them. It would be important for me to hear if there are any concerns that you have about issues like this, as there are quite a few ways of helping.’

This may need to be followed by more specific questions. The clinician should consider referring people who are experiencing sexual difficulties to specialised services such as women’s health nurses, family planning, personal and/or couple counselling and endocrine assessment if a hormonal basis for the problem appears likely (see Tables 4.1A, 4.1B and 4.1C). Some patients may benefit from attending peers support programs, however there is limited data to support advising this as a strategy. In addition, patients would benefit from information about resources on the topic of cancer and sexuality which may be available from organisations such as the NBCC (for patients with breast cancer) or State and Territory cancer organisations.

Interpersonal problems

People may feel reluctant to discuss their interpersonal problems because they feel embarrassed that they are not coping, or because they feel that nothing can be done. There is however evidence to indicate that appropriate psychological interventions are effective in the management of interpersonal problems (see Tables 4.1B and 4.1C).

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

‘The diagnosis and treatment of cancer affects everyone in the family’

This can then be followed by,

‘I was wondering how things have been going for your family...How do you feel your partner and family are handling things?’

‘Have they been able to offer you the emotional and practical support you need?’

People experiencing interpersonal problems may benefit from referral to couple or family counselling. In addition, it is worthwhile to offer family members the opportunity to discuss concerns and, if deemed appropriate, offer referral to an appropriate counsellor.

Concerns for new relationships (post diagnosis)

There is little research to guide health professionals in how to assist patients who are faced with concerns about negotiating new relationships. Available evidence highlighting the benefits of expression of emotional concerns following the diagnosis and treatment of cancer

(Level I)¹⁵ suggests that asking about concerns is appropriate, with consideration of referral for specialist counselling if there is severe or ongoing distress.

Severe emotional, stress and adjustment difficulties

Emotional, stress and adjustment problems compromise psychological health, functioning and quality of life. There are a range of interventions that may be of benefit. For instance, studies have shown that psycho-educational interventions and anxiety reduction strategies such as relaxation training and visual imagery (Level I)¹⁵ are often useful for patients with cancer experiencing distress, and the use of coping strategies reduces the level of emotional stress (Level III-3).⁶⁰¹ A review of the role of exercise in women with breast cancer has suggested that exercise as an adjunctive treatment may also have a favourable impact on psychological distress (Level III-3).⁶⁰⁰

Patients suffering from severe difficulties may benefit from specialised psychological interventions such as cognitive behavioural therapy or supportive psychotherapy, (see Tables 4.1B and 4.1C) conducted by practitioners trained and skilled in these techniques. Referral of these patients may prevent the development of more enduring or disabling emotional disorders, such as depression.

Anxiety

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

'Not surprisingly, many people with cancer experience some level of anxiety. Often it settles over time, but sometimes it can make things very hard for people. Do you feel that anxiety has been an issue for you?'

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

'Are there any particular things that make you feel anxious?'

'Are there any specific times when you feel more anxious?'

'How often do you feel this way?'

'Are there any times when the anxiety is almost overwhelming?'

'How would you say these feelings affect your life? Do these feelings affect your relationship?'

'Is there anything you're avoiding because of this anxiety?'

Cognitive behavioural techniques such as relaxation therapy, guided imagery, systematic desensitisation, problem solving, education and other supportive interventions have been demonstrated to be effective in reducing anxiety (see Tables 4.1B and 4.1C). In some cases however, anxiolytic medication is also required. (See Section 4.2 for a full discussion of the use of medication for the treatment of anxiety and depression).

When anxiety problems become severe, specialist treatment is required. Assessment by a clinical psychologist or psychiatrist is recommended for people reporting intrusive or difficult-to-manage anxiety. Prompt consultation is recommended when an acute anxiety state or panic threatens to impede or complicate treatment.¹⁶⁴ The treatment team also needs to be alert to signs of chronic anxiety disorders developing, and recommend consultation before enduring and disabling conditions develop.

Depression

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

'Apart from the physical effects of cancer, we're aware of the emotional toll it can take on you and your family. We know that coping with cancer isn't just about physical issues, and we now recognise that the emotional impact is also very important.'

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

'Could you tell me about what the cancer has meant emotionally?'

'How would you say you are feeling?'

'Would you say that you had ever felt really sad or depressed?'

This can be followed with clarifying questions about the depth of any mood disturbance which, in severe cases, the patient will often describe in terms such as 'hopeless' or 'helpless'. It is also important to inquire about whether these feelings are transient ('a bad day') or more frequent and lasting.

In assessing depression, clinicians also need to recognise the contribution of disease burden and pain to depression, as one study of patients with newly diagnosed pancreatic cancer found one-third to have inadequate pain relief.⁶⁰²

Cognitive behavioural techniques such as relaxation therapy, guided imagery, psycho-education, problem solving, and other supportive interventions have been demonstrated to be beneficial in reducing depressive symptoms (see Tables 4.1B and 4.1C). When concerned that a patient may be becoming clinically depressed the clinician can explain that depression is common and there are many effective treatments. Assessment, preferably conducted by a psychiatrist or clinical psychologist, is recommended.

Table 3.7A: Effective strategies/techniques that can be utilised by treatment team members to improve the psychological well-being of patients

Body image concerns	Support, education and exercise ⁵⁹⁸ (Level III-3) ^{599,600}
Stress and adjustment difficulties	Psycho-education, relaxation training visual imagery (Level I), ¹⁵ the use of coping strategies (Level III-3), ⁶⁰¹ and exercise (Level III-3) ⁶⁰⁰
Anxiety	Relaxation therapy, guided imagery, systematic desensitisation, problem solving, education and other supportive interventions (Level I) ^{15,16}
Depressive symptoms	Relaxation therapy, guided imagery, psycho-education, problem solving, and other supportive interventions (Level I) ^{15,16,603-605}

Note: Specialised interventions that can be conducted by appropriately qualified health professionals are outlined in Chapter 4.

Asking about suicidal thoughts

There is no evidence that asking about suicidal thoughts will prompt suicidal behaviour in someone who had not previously considered the possibility of suicide.⁶⁰⁶ Sensitive exploration of suicidal thoughts, plans and access to means is crucial.

Introductory questions might be along the lines of:

'Sometimes people feel so overwhelmed by things that they feel everything is "just too much". Would you say you have ever felt like that?'

'Have you ever felt that you can't keep going? Do you feel that things will get better?'

This can be followed by clarifying questions such as:

'Have you thought that you could end it all?'

'Have you wished you were dead? If yes, what have you thought about doing?'

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

Traumatic symptoms

In view of the emerging evidence about the frequency of ongoing traumatic symptomatology, it is worthwhile to ask patients directly about this. As with many other emotionally distressing symptoms, patients may be reluctant to mention them unless they are specifically asked:

'Can you tell me about the way the diagnosis of cancer has affected you?'

'How much do you feel that thoughts about the cancer intrude on your life?'

'Have you found that you are feeling jumpy and easily upset?'

If the person responds in the affirmative, it is worth checking in more detail the extent and type of intrusive thoughts, and offering referral for specialist assessment.

Supporting people who have survived cancer

Emotional responses, needs and expectations change depending on the stage of disease and treatment, and the characteristics and social circumstances of the individual. There is clear evidence of the value of providing support for patients with cancer, and their families, at the time of diagnosis, and during treatment for cancer. However, there has been less research regarding the nature of assistance that is likely to be of benefit to those who have survived cancer and insufficient evidence to make clear recommendations about specific strategies to assist patients who have survived cancer.

Given the potential for individual differences, and the emerging evidence about the nature and potential extent of physical and emotional issues for patients, it is prudent for health professionals to continue to assess emotional adjustment and explore specific concerns even in longer-term follow up of patients who have been treated for cancer. It is also important to be aware of the potential need for specialised treatment if patient concerns are persistent or severe, or associated with disruptions in relationships and functioning.

Table 3.7B: Example clinician questions to screen for psychological difficulties

General questions to assess emotional well-being

- 'In addition to looking at the medical/surgical issues, I am interested in hearing how things are going more generally for you'
- 'How have you been feeling emotionally?'
- 'Could you tell me how your mood is?'
- 'How would you say the diagnosis and treatment has affected you?'

Specific clinical issues

- 'Diagnosis and treatment for cancer is often stressful for the couple and members of the family. Can you tell me how things are at home? How are your partner and family handling it?'
 - 'Depression is pretty common during treatment, but once we pick it up, we can offer effective treatment. Would you say that depression has been an issue for you?'
 - 'Anxiety is pretty common when people are diagnosed with cancer, and coping with treatment can make it hard as well. Would you say that anxiety has been an issue for you?'
 - 'Many people who have been treated for cancer feel that their whole outlook on life has changed. Changes in your body and how it functions mean having to make a lot of adjustments too. Are you able to tell me about how you feel about these things? Are there any particular issues that concern you? Do things like this affect the way you think about treatment?'
 - 'Sometimes it can seem difficult to discuss, but self-image and intimate relationships are often affected by cancer, and this has a big impact on how people feel overall. Can you tell me if there are things like that that are worrying you?'
-

Physical symptoms and or difficulties

As previously discussed, a person with cancer may experience a number of illness and treatment-related physical symptoms (refer to Chapter 2). Treatment team members need to be alert to these difficulties and assess their impact on the psychological and physical well-being of the patient.

Inquiring about the presence of and adjustment to physical symptoms is part of routine clinical care and follow up. Support, and where necessary, appropriate referral to specialised services should be provided for physical symptoms.

In addition it is important to assess the degree of psychological distress resulting from physical symptoms. The following comments may be helpful:

'Having pain or other symptoms certainly makes a big difference to the way we feel emotionally as well. It is important for me to have a sense of how troublesome these symptoms are for you, and how much they are affecting your life.'

Any patient experiencing severe psychological distress may benefit from referral to psychological specialists for interventions, such as cognitive behavioural, supportive or crisis interventions, that may assist in reducing the distress and impairment associated with physical symptoms, and in some cases to reduce the severity of the symptom itself (see Tables 4.1B and 4.1C).

Chemotherapy induced nausea and vomiting

Patients suffering from persistent nausea and vomiting may benefit from psychological interventions, including cognitive behavioural techniques such as progressive muscle relaxation, guided imagery and systematic desensitisation, supportive interventions and education (**Level I**),¹⁵ (**Level II**).^{525,607-610} Therapies such as relaxation and meditation (**Level I**),¹⁵ (**Level III-2**),⁴⁵⁵ and exercise (**Level II**),⁶¹¹ (**Level III-3**)^{600,612} have also been found to be effective in reducing a patient's level of nausea and vomiting⁶¹³ (**Level I**).¹⁵

Pain

The potential causes of pain are complex and multifactorial. History taking, examination and appropriate investigation and treatment of pain are key aspects of clinical care and can effectively relieve pain in over 95% of cases.⁵³⁶ Pain also has an emotional dimension and for patients with serious illness, the interpretation of the meaning of pain may influence the way the individual deals with it, as may social, family, personality and cultural factors (**Level III-2**).^{212,213}

A number of psychological approaches have been shown to be effective in the management of acute and chronic pain in patients with cancer. These include progressive muscle relaxation, guided imagery, distraction, controlled breathing and other techniques.^{212,614,615} (**Level II**)⁶¹⁶ Therapies such as meditation and prayer⁴⁹³ (**Level I**),¹⁵ (**Level III-3**),⁶¹⁷ are also effective in reducing distress and in some instances reduction in pain. In addition antidepressant medication may be a useful adjunct when treatment with opioid analgesia is required.

Please refer to the discussion of psychological therapies and pharmacotherapy for the treatment of anxiety and depression in Chapter 4.

Fatigue

Many patients fail to discuss fatigue with the treating team because of the belief that nothing can be done to help.¹⁹² For those who do mention fatigue, bed rest or relaxation is commonly recommended. However, there is emerging evidence that exercise is valuable in promoting physical functioning in patients who have been treated with chemotherapy (**Level II**)⁶¹¹ and differences in physical performance have also been demonstrated following an exercise programme undertaken by those who have undergone high dose chemotherapy and autologous peripheral stem cell transplantation (**Level III-3**).⁶⁰⁰ Comprehensive assessment is required¹⁹¹ and it may be appropriate to consider referral to a therapist who can assist the patient develop strategies in coping, such as an occupational therapist.

Fertility/Pregnancy

Awareness of fertility issues by clinicians and providing an opportunity for sensitive discussion, may allow patients to consider the potential impact of treatment on their fertility (see Section 2.3). When sexual dysfunction (impotence, libido, retrograde ejaculation) is likely as a result of treatment, it is important to discuss this with the patient. The options of sperm banking or preservation of ovarian tissue, oocytes or embryos should be discussed. Patients wishing to explore these options may benefit from referral to a fertility clinic prior to treatment.

For pregnant women in whom a diagnosis of cancer has been made, it is important that a multidisciplinary approach to treatment be instituted to ensure optimal care of both mother and foetus. Referral to an endocrinologist for hormone assessment and therapy is recommended for all women at the completion of treatment. Women who desire specific

medical contraceptive methods or pregnancy termination can be treated by a gynaecologist. Despite the lack of good scientific evidence, many women still fear that pregnancy could cause a recurrence (see Section 2.3). For this reason the opportunity to discuss concerns and receive appropriate information is important.

Patients and their partners may also benefit from couples and/or personal counselling particularly if distressed or anxious about fertility loss, contraception, pregnancy effects on prognosis or recurrence, termination of pregnancy or treatment effects on pregnancy.

Lymphoedema

Inquiring about the presence of limb or other swelling, or other symptoms is important, with clinical assessment and referral as necessary. Recent studies have shown that complex decongestive physiotherapy, administered by a therapist trained and experienced in the procedure is an effective treatment for lymphoedema reduction. Initial reductions in volume are maintained in the majority of patients and these patients typically report a significant recovery from previous functional impairment and from the psychosocial limitations they experience (**Level III-3**).^{153,618}

Although intuitively early intervention seems ideal, there is no scientific evidence to support this. However, because patients are concerned, early discussion about the prompt treatment of lymphoedema and the availability of treatment may be beneficial. Contact details for lymphoedema associations and support groups are listed in Appendix E.

Disfigurement

Potential disfigurement needs to be considered in discussion with the patient prior to treatment. It is essential that patients are well informed about the nature of surgery or other treatments anticipated, including details such as the length and nature of the wound and subsequent scarring. This is so, particularly if an unsatisfactory cosmetic outcome is likely,¹¹¹ however it needs to be recognised that there is considerable variation in what a patient may consider a satisfactory cosmetic outcome. In addition, information about the appropriate time, advantages and disadvantages of the various types of reconstructive surgery should be provided to all patients who are undergoing procedures likely to cause disfigurement, regardless of age, family situation or location,⁶¹⁹ or site of surgery. Patients expressing a desire for reconstructive surgery can be treated by clinicians experienced in these techniques such as breast, gynaecological plastic or dermatological surgeons for advice and treatment.

If patients demonstrate obvious distress and anxiety relating to the nature of the outcome following surgical procedure, sensitive discussion and opportunity for counselling can be offered if deemed appropriate.

Odour

It is clear that psychological adjustment is intimately related to physical symptoms and disease burden. Some symptoms in particular may pose a substantial emotional burden by their very nature and their propensity to compromise social interactions and relationships (see Section 2.3). For these reasons, expert management to reduce or eliminate such symptoms, is likely to result in improved emotional adjustment for the patient, and reduce the burden and distress to caregivers.

There is a range of strategies useful in reducing or eliminating symptoms, depending on the source of the odour, with the key resource person being the stoma therapist or the specialist nurse.

Stomas: Well fitting appliances and odour suppressing tablets, eg aspirin in the bag, are helpful (**Level IV**).¹⁹⁹ Oral charcoal has also been suggested.

Enterocutaneous fistulae: Active assistance from a stomal therapist in devising containment of any discharge is vital and surgical opinion should be sought regarding the possibility of surgical intervention, even in those with advanced disease. For example, percutaneous pyelostomy may be considered as urinary diversion in the terminally ill where a formal major urinary diversion is contra-indicated, bearing in mind technical aspects of nursing care.

Incontinence: In the case of faecal incontinence active bowel management to keep the bowel clear is indicated, unless the patient is clearly in the terminal phase of the illness. Catheterisation may solve the problem of urinary incontinence.

Vaginal odour: resulting from infection of necrotic tumours can be managed with metronidazole delivered either orally or topically (**Level IV**).⁶²⁰ Even in advanced terminal disease, palliative radiation using one or several large fractions may decrease these problems especially if this is in association with bleeding (**Level IV**).^{199,200}

Malignant wounds: Odour associated with malignant wounds results from infection associated with necrotic tumours. As with vaginal odour, oral or topical metronidazole and radiation therapy can significantly reduce the odour (**Level IV**).⁶²⁰

Fungal infection in skin folds, groin or genital regions: Careful hygiene and antifungal creams help the immediate infection. On a longer term basis maintenance of the skin's acid mantle may decrease these problems. Diluted vinegar (1:3) with water as a rinse may help.

Halitosis

- Pilocarpine has been used to increase saliva production and relieve symptoms following radiation for head and neck cancer (**Level II**),⁶²¹ (**Level III-3**)⁶²²
- Reduction of oral flora by good oral hygiene brushing teeth and cleaning of the buccal mucosa is the first step in the management of halitosis. Antibiotics and Metronidazole may be helpful if there is a necrotic tumour in the oropharynx or lungs.⁶²³

Communication difficulties

Support from speech therapists/pathologists is recommended for patients with communication difficulties as this has been found to be strong predictor of communication adaptation.⁶²⁴ For patients who have had a total laryngectomy, rapid, effective restoration of voice and speech is one of the primary focuses of rehabilitation and is pivotal to the prevention of potential psychosocial and economic consequences (**Level IV**).²⁶⁷ Method and success of voice restoration will vary between patients. Sixty percent of patients who have had a laryngectomy report being satisfied with speech rehabilitation programmes²⁶⁶ and more than half achieve successful communication by oesophageal speech. Success in this is usually associated with minimal problems in other areas.²⁰⁸

Nutrition

Patients suffering from nutritional deficiencies may benefit from consultations with a nutritionist. For some, for instance patients with head and neck cancer, this may be most beneficial before the start of treatment as thorough nutrition assessment and management before treatment can have significant impact on the course of treatment and the patient's quality of life (**Level IV**),⁶²⁵ particularly in view of the fact that alcohol abuse is a risk factor for these cancers, and is often associated with poor nutrition and general health.

Numerous strategies including education, dietary supplements and appetite stimulants (**Level II**),²⁷³ or enteral tube feedings (**Level II**),²⁷⁴ (**Level III-3**),²⁷⁵ are useful in improving the nutritional status and quality of life of the patient. However, as noted previously in Chapter 2, some patients experience distress with enteral tube feeding.

A multidisciplinary approach including pre-therapy dental evaluation, oral care, antibiotic therapy and analgesic therapy can decrease oral discomfort and ameliorate or prevent oral complications that impact on nutritional status.^{626,627} Teaching patients and significant others how to perform oral assessments correctly so that they can report oral changes is also helpful.⁶²⁷

Respiratory symptoms

Patients with respiratory symptoms may benefit from exercises in breathing control, activity pacing and relaxation techniques (**Level II**)⁶²⁸ conducted by therapists experienced in these techniques such as physiotherapists or occupational therapists. For patients with pleural effusions, pleural drainage will relieve the symptoms but there is a high recurrence rate. Systemic therapy, change in systemic therapy or other medical or surgical procedures may be required. A full discussion of the treatment of pleural effusions can be found in the clinical practice guidelines for the management of advanced breast cancer.³⁷²

Other

Consultation with physiotherapists or occupational therapists may be beneficial for patients with incontinence, bowel or swallowing difficulties. Dental assessment at the time of diagnosis, and regular dental review, is recommended for patients with head and neck cancer as this has been shown to decrease the risk of dental complications (**Level IV**).¹⁹⁰ Patients experiencing erectile dysfunction require medical management by a specialist with an interest in the area.

For all people who have been treated for cancer, care needs to be taken to ensure that returning to work after a period of absence is well planned, taking into account the person's overall physical health and psychological well-being. It may be necessary to consider a gradual re-entry to the workforce, and open discussion with patients about their expectations and concerns is valuable in this regard.

General health condition

Open discussion about diet, nutrition, supplements, natural therapies (refer to discussion in Section 3.2.3) etc would be beneficial as many patients may choose to explore these options in efforts to improve their general well-being. Offering referral to a nutritionist and or advice on how to access safe and appropriate information is also worthwhile. In addition exercise may be beneficial, especially in cases where weight loss is a problem. A review of the role of exercise in women with breast cancer has suggested that exercise as an adjunctive treatment may have a favourable impact on weight gain.⁶⁰⁰

Table 3.7C: Effective psychological and complementary strategies and techniques that can be utilised by treatment team members to reduce the impact of physical symptoms

General	Opportunity for sensitive discussion and the expression of thoughts and feelings
Chemotherapy induced nausea/vomiting	Progressive muscle relaxation, guided imagery, systematic desensitisation, support and education, meditation, relaxation, exercise (Level I) , ¹⁵ (Level II) , ^{525,607-611} (Level III-2) , ⁴⁵⁵ (Level III-3) ^{600,612}
Pain	Progressive muscle relaxation, guided imagery, distraction, controlled breathing, meditation, prayer ^{212,493,614,615} (Level I) , ^{15,212} (Level II) , ⁶¹⁶ (Level III-3) ⁶¹⁷
Fatigue	Exercise, relaxation (Level II) , ⁶¹¹ (Level III-3) ⁶⁰⁰
Respiratory symptoms	Exercises in breathing control, activity pacing and relaxation techniques (Level II) ⁶²⁸
Nutrition	Education and nutrition therapies are useful in improving nutritional status and quality of life (Level II) ^{273,274}

Screening for Major Psychological Disorder

The prompt recognition and effective treatment of disorders such as anxiety and depression are critical aspects of care in oncology.³⁷⁴

Due to the serious consequences of failure to recognise conditions such as depression, it is important to have a comprehensive approach to diagnosis³⁷⁵ part of which includes attention to risk factors and active monitoring of symptoms. Risk factors for adverse psychological outcomes are outlined in Table 3.7D. There may be some variation with the type of cancer. For example, young age at onset of disease and having children under 21 years of age are risk factors for women with breast cancer.⁶²⁹⁻⁶³¹ In addition to attention to risk factors it is also important to be aware of symptoms such as irritability, social withdrawal, and increased difficulty coping with physical symptoms.

The nature and severity of psychological distress can vary over time; hence it is worthwhile to elicit emotional concerns regularly during treatment, particularly at times of known risk such as the diagnosis of recurrence. It is also important to be aware of symptoms such as irritability, social withdrawal, and increased difficulty coping with physical symptoms. Based on more general research about clinical depression, early diagnosis can lead to more effective treatment. Tables 3.7B and 3.7E outline recommended procedures for the routine screening of patients for psychological problems.

Table 3.7D: Factors associated with an increased risk of psychosocial problems

Factors	Research Studies
<p>Characteristics of the individual:</p> <ul style="list-style-type: none"> • younger • single, separated, divorced or widowed • living alone • children younger than 21 years • economic adversity • lack of social support, perceived poor social support • poor marital or family functioning • history of psychiatric problems • cumulative stressful life events • history of alcohol or other substance abuse • gender 	<p>Level III-1^{629,630}</p> <p>Level III-2^{11,632}</p> <p>Level III-3^{51,99,392,631,633-637}</p>
<p>Characteristics/stages of disease and treatment:</p> <ul style="list-style-type: none"> • at the time of diagnosis and recurrence • during advanced stage of the disease • poorer prognosis • more treatment side-effects • greater functional impairment and disease burden • experiencing lymphoedema • experiencing chronic pain • fatigue 	<p>Level III-2^{13,238,638-640}</p> <p>Level III-3^{3,193,595,634,641-643}</p> <p>Level IV⁶⁴⁴</p>

Note: references are from a variety of cancers as follows: Generic^{3,11,164,595,636,639,640}; Breast^{13,61,193,238,392,629-633,637,638,641}; Head and neck^{634,635}; Hodgkin's Disease⁶⁴⁴; and Lung^{99,343,642,643}

For more detailed information about breast cancer references, see report by Turner *et al*,²⁶ available from the NBCC.

The use of self-report questionnaires for screening and monitoring of anxiety and depression

Medical practitioners in both medical oncology and general practice settings have been found to have difficulties identifying patients with depression (**Level III-2**),⁶⁴⁵ (**Level IV**).^{594,596,646,647} Clinical audit and prospective studies indicate that clinicians are frequently unaware of psychological concerns, for example sexual problems and disorders such as depression, experienced by their patients (**Level III-2**).⁶⁴⁵ In one study, oncology staff correctly identified 79% of anxiety problems but misdiagnosed 40% of patients as anxious who were not, and only identified 40% of patients with a depressive illness (**Level IV**).⁶⁴⁷

The use of questionnaires in oncology settings has been suggested as a way of improving the identification of patients most likely to be clinically anxious or depressed. There are a number of self-report questionnaires that have been used in research and clinical settings to monitor change in anxiety and depression symptoms, and to detect people likely to meet criteria for an anxiety or mood disorder. These include the General Health Questionnaire (GHQ28 or GHQ12),⁶⁴⁸ the Rotterdam Symptom Check List (RSCL)⁶⁴⁹ and the Hospital Anxiety and Depression Scale (HADS).⁶⁵⁰

However, attempts to establish the validity of the use of self-report psychological questionnaires as psychiatric screening instruments in oncology have so far had mixed results (**Level III-2**).⁶⁵¹ One multi-centred trial, however, found that the best results in detecting people with major psychological problems were obtained by matching the type of questionnaire with the person's current disease and treatment status (**Level III-2**).⁶⁵² Further work needs to be done before specific recommendations can be made. Any use of questionnaires for this purpose should be done in consultation with a psychologist who is trained in questionnaire use and analysis.

Key point

Medical practitioners have been found to have difficulties identifying, or are unaware of, psychological concerns of their patients, or of disorders such as depression (**Level III-2**),⁶⁴⁵ (**Level IV**).^{596,646,647}

Table 3.7E: Recommended steps for screening people with cancer for significant psychological problems

These steps are recommended in conjunction with the general interactional skills in Table 3.1.

Identify and document high risk factors (Table 3.7D)

- High risk characteristics of the patient
- High risk disease characteristics

Ask a patient about their general psychological and emotional well-being

Ask about specific clinical issues including

- Anxiety
- Depression
- Interpersonal functioning
- Coping with physical symptoms
- Body image and sexuality

Referral for counselling (See also Table 4.1A)

If you or the patient is concerned about their emotional well-being you should consider a referral for counselling.

- Inform the patient about the benefits of both individual and group counselling and ask them if they have any questions
 - Provide the patient with information about available individual or group counselling
 - Ask the patient if they would like a referral and assistance arranging the appointment (see also Figure 2)
 - Consider endocrine assessment if a treatment-induced hormonal dysfunction is likely
-

Refer to Figure 2 for a summary of the process to be followed to ensure the psychological needs of patients are met, including screening for and referral of patients with significant psychological problems.

CHAPTER 4 REFERRAL FOR SPECIALISED CARE

4.1 TYPES AND BENEFITS OF SPECIALISED CARE

People with cancer who are experiencing significant psychological distress or who have significant physical impairment or severe physical symptoms that impact on their quality of life require specialised interventions. These include psychological and/or other supportive interventions for specific physical difficulties, eg as physiotherapy, speech pathology, etc. Table 4.1A outlines the appropriate service provider and specialised interventions with demonstrated effectiveness for specific problems. Collaboration between the treatment team, including general practitioner, and mental health specialists, is crucial to decreasing the psychological burden experienced by people with cancer with significant psychological distress. Recommendations about how to make a referral are discussed in detail in Section 4.3. When a patient is referred to specialised care, it is important to follow up at a later date, whether the referral was taken up by the patient, and also whether the referral was appropriate.

It should be noted that local circumstances and the availability of resources may limit the opportunity to implement some of the recommendations. For example, difficulties in obtaining access to specialist staff such as psychiatrists, clinical psychologists or specialist oncology nurses may limit the implementation of some recommendations. Depending on regional and site specific constraints, and the training of staff, some interventions may be appropriately provided by a general practitioner or specialist registered nurse.

Psychological therapies

Psychological interventions include cognitive behavioural therapy, psychotherapy, group therapy, family and/or couple therapy, telephone counselling, and complementary therapies. Features of therapy common to all psychological interventions include empathetic manner, listening, affirmation, reassurance and support.

The most appropriate psychological therapy will depend on the patient, on the issues at hand and the training and skills of the therapist. Therapies may be delivered individually, or via a group or family model and may be face-to-face or remote. While some people will be more comfortable with the privacy of individual counselling, others will benefit from group counselling where they can gain from sharing the commonality of their experience.

Benefits of psychological therapies

There is clear evidence that psychosocial interventions are effective in reducing distress, and promoting adjustment of patients with cancer, much of the data being Level I or II evidence.²⁸ In some cases it may also reduce the severity of physical symptoms suffered by the cancer patient (**Level I**).¹⁵ Table 4.1B outlines the types and benefits of therapies available and Table 4.1C provides a brief summary of the effectiveness of therapies/intervention techniques for specific problems.

In a meta-analysis of 45 randomised controlled trials in adults with cancer, those receiving psychological therapies showed statistically significant mean improvements of 12% in emotional adjustment, 10% in social functioning, 14% in treatment- and disease-related symptoms, and 14% in overall improvement in quality of life, compared to those not receiving psychological therapy

(Level I).¹⁷ In most trials, the therapy was provided by a specially trained counsellor, nurse, social worker or psychologist. However, greater effects have been demonstrated when psychological therapies were conducted by more highly trained therapists and continued for longer periods of time **(Level I).**¹⁶

Although many interventions have been directed towards patients themselves, a recent review highlights that interventions that provide support for partners of patients with cancer are likely to be effective in reducing distress.⁶⁵³ Furthermore, there may be indirect benefits for patients whose partners have participated in such a program. In a study evaluating a six-week weekly psycho-educational group program for partners of 36 patients with cancer, three-month follow-up evaluation showed reduced mood disturbance in patients (who did not attend the program themselves) as well as partners **(Level II).**⁶⁵⁴

Most of the studies of psychosocial interventions have evaluated face-to-face individual or group support. Information about novel service delivery methods is now emerging. A small study evaluated a telephone counselling service in 14 women receiving high-dose chemotherapy, and 10 male partners. On average the women received 16 sessions, the male partners 11 sessions. Although participants appeared satisfied, rating the service as good to excellent, as yet there is no data about other outcomes such as mood and anxiety **(Level III-3).**⁶⁵⁵

Trials comparing the relative effectiveness of different types of psychological interventions have indicated that most therapies have a similar effect **(Level I).**¹⁵⁻¹⁷ It is evident for example that professionally-led group therapies are as effective as individual-based therapy **(Level I).**¹⁶ It may be that the features of therapy common to all psychological interventions such as empathetic manner, listening, affirmation, reassurance and support generate the observed outcome.

Specialised services for specific physical difficulties

Specialist services or therapies, accessed as needed, can markedly improve cancer patients' physical well-being and functioning, and are therefore likely to improve emotional well-being. Specialist services include speech therapy/pathology, physiotherapy, occupational therapy, nutritional services, dentistry, etc (see Table 4.1A for a complete list of therapies or services). Patients may need to see more than one service provider.

Benefits of specialised services for specific physical problems

It is beyond the scope of these guidelines to include comprehensive details of the impact of each specific specialised service on the physical well-being of the patient with cancer. Research in each of the relevant domains does however indicate that these services assist in reducing pain, and or restoring or improving physical functioning or appearances.

The following table outlines the appropriate service provider and specialised interventions with demonstrated effectiveness for specific problems experienced by people with cancer. It should be noted that although there are no studies demonstrating the effectiveness of pastoral care, clinical experience and patient expectations indicate that it is worthwhile to consider the particular existential and spiritual needs of the individual and offer referral for pastoral care and support as desired by the patient.

Table 4.1A: A guide to appropriate referral and specialised interventions for specific problems

Problem	Discipline to refer to	Specialised interventions with demonstrated effectiveness
Anxiety	Clinical psychologist/ Psychiatrist	Education; cognitive behavioural therapy including relaxation therapy or graded exposure; supportive psychotherapy (including existential therapy); crisis intervention; drug therapy (see Section 4.2); alone or in combination
Depression	Clinical psychologist/ Psychiatrist Social worker*	Education; cognitive behavioural therapy including problem-solving, and challenging negative cognitions; supportive psychotherapy (including existential therapy); often combined with antidepressant medication. In severe cases, ECT may be considered, or psycho-stimulants in those with advanced disease.
Suicidal ideation	Psychiatrist	Thorough assessment, identification and treatment of any specific stressors including pain, other physical symptoms, delirium. Treatment of identified depression, anxiety (see above and Section 4.2)
PTSD	Clinical psychologist/ Psychiatrist	Cognitive behavioural therapy; supportive psychotherapy (including existential therapy), often in combination with antidepressants such as SSRIs (see Section 4.2)
Body image concerns	Clinical psychologist/ Psychiatrist Social worker*	Cognitive behavioural therapy; supportive psychotherapy; crisis interventions; complementary therapies, eg exercise. Treatment of depression or anxiety which can compound the body image distress
Sexuality concerns	Clinical psychologist/ Psychiatrist Social worker* Endocrinologist	Personal and or couples counselling Endocrine assessment and or therapy if hormonal basis for the problem appears likely
Interpersonal problems	Clinical psychologist/ Psychiatrist Social Worker*	Couples counselling; family counselling
Severe emotional problems	Clinical psychologist/ Psychiatrist	Cognitive behavioural therapy; supportive psychotherapy

Physical symptoms	Clinical psychologist/ Psychiatrist Other specialists	Education; cognitive behavioural therapy including relaxation therapy, guided imagery; supportive psychotherapy; complementary therapies such as exercise; speech therapy, physiotherapy, occupational therapy, nutritional services, dentistry, endocrinology, reconstructive surgery, specialist pain services, odour management
Fertility concerns	Clinical psychologist/ Psychiatrist Endocrinologist Fertility clinic/ Women's Health Nurse/Family Planning	Personal and or couples counselling Hormone assessment and or therapy Fertility counselling, storage of ovarian tissue/oocytes/embryos and sperm, <i>in vitro</i> fertilisation

Notes:

*Only applies if the social worker is trained in this area as the skills required are not generic.

In addition to the specialities listed above, there may be other local practitioners trained in the interventions listed eg occupational therapists, specialist nurses. Many GPs will also have training in the above interventions.

For people experiencing sexual concerns referral to a gynaecologist/ urologist is also recommended because of all the practical issues involved.

Table 4.1B: Types of interventions and their impact on patients with cancer

Type	Description/Benefits	Research
<p>Cognitive behavioural therapy</p>	<p>Includes cognitive, cognitive behavioural and behavioural therapies. Teaches skills in problem-solving, reframing attitudes, eg challenging “black and white” thinking, coping with stress and anxiety. Relaxation therapy, guided imagery or cognitive skills might be used in dealing with stressful situations such as particular treatments, or to reduce nausea associated with chemotherapy. Techniques to enable gradual adaptation might also be included</p> <p>Improvement in emotional distress, coping, anxiety, depression and psychiatric morbidity; Decrease in nausea, vomiting and insomnia; Increase in control over illness</p> <p>For more detailed descriptions refer to: Moorey & Greer, 1989;⁶⁵⁶ Rose, 1989;⁶⁵⁷ Ellis, 1992;⁶⁵⁸ Kissane <i>et al</i>, 1997¹³⁸</p>	<p>Level I^{15,17} Level II⁶⁵⁹⁻⁶⁶² Level III-1⁶⁶³ Level III-2⁶⁶⁴</p>
<p>Supportive psychotherapy</p>	<p>Encourages the expression of emotions, validates the experiences of the individual, and offers support through emphatic listening and encouragement, and provision of information. Reflects on the strengths of the individual and encourages use of adaptive coping techniques. Sometimes called supportive, existential or supportive-expressive</p> <p>Improvement in mood, coping and physical and functional adjustment</p> <p>For more detailed descriptions refer to Spiegel & Spira, 1991;⁶⁶⁵ Mullan, 1992⁶⁶⁶</p>	<p>Level I^{15,17} Level II⁶⁶⁷</p>
<p>Group therapy</p>	<p>Places emphasis on sharing of experiences among patients with a comparable stage of disease. Participants feel that their experiences are validated, and they can contribute in a meaningful way to the well-being of other members of the group. Can use cognitive behavioural or supportive psychotherapy, and include educational and information components</p> <p>Improvement in mood, coping and adjustment, anxiety and depression; Positive immune function changes</p>	<p>Level I¹⁶ Level II^{564,565,668-670}</p>
<p>Family therapy</p>	<p>Enhances improved communication, cohesion and conflict resolution within the family system, including the needs of children. Can use cognitive behavioural or supportive psychotherapy</p>	<p>Level IV^{549,563}</p>

Couples therapy	<p>Targets problems and issues within the couple relationship. Can use cognitive behavioural or supportive psychotherapy</p> <p>Reduces levels of depression and psychological distress</p> <p>Beneficial in increasing sexual satisfaction</p>	<p>Level II^{548,568,671}</p> <p>Level III-3⁶⁷²</p>
Telephone counselling	<p>Provides geographically-isolated patients with an opportunity for cognitive behavioural or supportive psychotherapy interventions</p> <p>Also useful for providing casework support, eg reassurance, information provision and referral</p>	<p>Level II⁵⁶⁶</p> <p>Level III-3⁶⁵⁵</p> <p>Level IV⁶⁷³</p>
Other therapies	<p>Other therapies may include art therapies, eg music, painting, reading and poetry, wellness programs, meditation, hypnosis, acupuncture, relaxation, exercise, prayer, laughter etc.</p> <p>Improvement in mood, coping, anxiety, depression, breathing; Reduction in nausea, pain</p>	<p>Level I^{15,17,674}</p> <p>Level II^{607,611,675,676}</p> <p>Level III-3^{600,677}</p> <p>Level IV⁶⁷⁸⁻⁶⁸⁰</p>
Other specialist services	<p>Includes speech therapy, physiotherapy, occupational therapy, dentistry, endocrine therapy, plastic surgery, reconstructive surgery, nutritionist, fertility services, specialized pain services</p> <p>Target specific physical symptoms or impairments resulting from the disease or treatment. Assist in reducing pain, restoring or improving physical functioning or appearance</p>	<p>Refer to research in relevant domains</p>

Note: references are from a variety of cancers as follows: Generic^{15-17,549,563-565,568,607,660-662,664,668-670,663,667}, Breast^{548,566,611,655,659,671-673}, Hodgkin's Disease⁶⁰⁰ For more detailed information, see also report by Kissane & Burke²⁴ available from the NBCC.

Table 4.1C: Demonstrated effectiveness of therapies/intervention techniques for specific psychological problems

Problem	Effective intervention techniques	Evidence
Anxiety	Relaxation therapy, guided imagery, systematic desensitisation, problem-solving, crisis intervention, supportive interventions, other combinations of education and behavioural or non-behavioural interventions, and anti-anxiety medications	Level I ^{15,16} Level II ^{661,681}
Depression	Relaxation therapy, guided imagery, psycho-education, problem-solving, supportive interventions, other combinations of education and behavioural or non-behavioural interventions, and anti-depressants and cognitive behavioural therapy, and electroconvulsive therapy (ECT), taking account of the specific physical status of the patient	Level I ^{15,16,603-605} Level II ^{569,580,661,671,682}
PTSD	Supportive psychotherapy and cognitive behavioural interventions, often in combination with antidepressants such as SSRIs (see Section 4.2)	Level I ⁶⁸³
Physical symptoms	Relaxation therapy, guided imagery, systematic desensitisation, supportive interventions and education together with cognitive behavioural interventions; complementary therapies, exercise	Level I ¹⁵ Level II ^{525,607-609,611,661} Level III-3 ⁶⁰⁰
Body image concerns	Cognitive behavioural interventions, supportive interventions, crisis interventions, complementary therapies, eg exercise	Level II ⁵²⁷
Sexuality concerns	Personal and or Couples therapy	Level II ⁵⁴⁸
Interpersonal problems	Couples therapy, Family therapy	Level III-3 ⁶⁷²

Note: references are from a variety of cancers as follows: Generic^{15,16,525,607-609,661,682}, Breast^{527,548,569,580,611,671,672,681}, Hodgkin's Disease.⁶⁰⁰ For more detailed information, see also report by Kissane & Burke²⁴ available from the NBCC

4.2 TREATMENT OF ANXIETY AND DEPRESSION

It is important for all health professionals involved in the care of patients with cancer to have an understanding of common conditions such as anxiety and depression, and to be aware of the effective treatment modalities that exist for these conditions. Staff who are inadequately informed about conditions such as anxiety and depression are less likely to recognise these conditions, and be able to appropriately discuss treatment options or referral for such patients. In addition, staff who are well-informed will be able to more confidently support the patient who is receiving specialised psychological treatment. In this context, depression refers to a pervasive and sustained lowering of mood, often associated with tearfulness, guilt

or irritability, and loss of pleasure or interest in usual activities. Anxiety refers to a diffuse, unpleasant, often vague feeling of apprehension, often associated with bodily sensations of pounding heart or sweating.

Treatment of anxiety and depression in the cancer patient must include attention to the complex physical problems that may be involved, in particular pain which is a major risk factor for depression (**Level III-2**).^{639,684} Psychotherapy, along with pharmacotherapy, is regarded as an integral part of treatment of anxiety and depression,⁶⁸⁵ and has been demonstrated to have a positive effect on depression in patients with cancer (**Level II**).¹⁴⁹ In the patient with cancer, psychotherapy ideally includes specific attention to the unique meaning of the cancer, and the fears and concerns of the particular patient. Specific components may include facilitation of emotional expression, and coping skills training, as well as cognitive techniques to deal with distressing thoughts and feelings.⁶⁸⁴ Cognitive behavioural and stress management techniques have been shown to reduce depression in women with breast cancer (**Level III-2**).⁶⁸⁶ See also Table 4.1B.

A range of pharmacological agents have been shown to have an effective role in the management of anxiety or depressive disorders. Selection of the particular medication involves a careful risk-benefit analysis matching the properties of the drug against the patient's physical status, the potential for drug interactions and key symptoms that are of concern to the patient.⁶⁸⁷ In many instances, a psychiatrist will initiate treatment with these medications. However it is important that all members of the treatment team recognise the potential role of medication as part of the comprehensive treatment of psychological distress in people with cancer.

Anxiety

The treatment of acute anxiety states and anxiety disorders often requires pharmacotherapy in addition to relaxation or other psychological interventions. The drugs used for treatment of anxiety include benzodiazepines, antipsychotics, antihistamines and antidepressants. Choice of a particular agent depends on the acuteness or chronicity of the anxiety state, the drug's absorption rate, the available route for administration, concurrent medical problems and potential drug-related adverse effects.⁶⁸⁸

- **Benzodiazepines:** These are the mainstay of pharmacological treatment of acute anxiety and panic. Shorter-acting benzodiazepines, such as alprazolam, are safest but breakthrough anxiety may occur, necessitating substitution with a longer-acting benzodiazepine, such as diazepam. For those with hepatic disease, selection of an agent for which blood levels are minimally affected by the liver metabolism, such as oxazepam, is recommended.¹⁶⁴ Long term use of benzodiazepines has been associated with dependence. Benzodiazepines should never be ceased abruptly because of the risk of withdrawal symptoms, which may include seizures.
- **Selective Serotonin Reuptake Inhibitors (SSRIs):** SSRIs have a useful role in the longer-term management of panic (**Level IV**).⁶⁸⁹
- **Neuroleptics:** In cases of extreme agitation, low doses of antipsychotics, such as haloperidol may be used, closely monitoring for the risk of extrapyramidal adverse effects.¹⁶⁴ The atypical antipsychotic agents, (such as risperidone), are associated with fewer side-effects and likely to be of benefit in patients with cancer, although currently there are no large studies of their use in the cancer population.

Depression

The treatment of depression will incorporate psychotherapeutic interventions and the use of medication. There is clear evidence of the efficacy of antidepressant medication in treating depression in the medically ill, including patients with cancer (**Level I**).^{690,691} There is no evidence that any particular antidepressant is superior to another (**Level I**).⁶⁹² The concern that antidepressant therapy poses an unacceptable side-effect burden is not supported by research. In one study, about 80% of patients with cancer receiving antidepressants showed a good clinical response, the majority having no significant adverse effects (**Level IV**).⁶⁹³ Starting with a low dose of the drug and increasing the dose slowly is likely to minimise the occurrence of side-effects.

- **Tricyclic antidepressants:** The tricyclic antidepressants have been used for many years for the treatment of depression. Their sedating properties are particularly useful for management of the agitated, depressed person with insomnia.¹⁶⁴ Their potentiation and enhancement of opioid analgesia is also useful for those with pain.⁶⁹⁴

Anticholinergic side-effects may aggravate stomatitis secondary to chemotherapy and may exacerbate constipation. These drugs also have the potential to affect cardiac rhythm, patients with pre-existing interventricular conduction delays being at increased risk.⁶⁸⁷ Patients with cancer may respond to tricyclic antidepressants at a lower dose than physically healthy people.

- **Selective Serotonin Reuptake Inhibitors (SSRIs):** SSRIs have been demonstrated to be useful in treating depression in the medically ill, including patients with cancer (**Level I**).⁶⁹⁰ Fluoxetine has been demonstrated to be effective in patients with cancer (**Level II**),⁶⁹⁵ in people with medical illness⁶⁹⁶ and has also been demonstrated to be effective in treating depression in women with advanced cancer (**Level II**).⁶⁹⁷ The half-life of fluoxetine, however, is long, with active metabolites, and in those with hepatic or renal dysfunction, short-acting drugs, such as sertraline and paroxetine, are preferable.⁶⁸⁷

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

- **Selective Noradrenergic Reuptake Inhibitors (SNRIs):** SNRIs, such as venlafaxine, selectively inhibit reuptake of both noradrenaline and serotonin. They are associated with fewer anticholinergic, histaminic, adrenergic effects than tricyclic antidepressants, and no monoamine oxidase inhibition. In patients with hepatic disease, venlafaxine may be less likely to disturb protein-binding of other medications than the SSRIs.⁶⁸⁷
- **Electroconvulsive therapy (ECT):** ECT may be considered in severe cases, particularly if suicidal ideation is prominent, with careful consideration of the individual's particular symptoms and disease stage. ECT has demonstrated efficacy in the treatment of severe depression, and is generally well-tolerated even in those with concurrent medical conditions (**Level I**).^{603,605,683}
- **Psychostimulants:** Patients with advanced cancer may experience some improvement in depressed mood, appetite and well-being when treated with low-dose psychostimulants.⁶⁹⁸ They are generally well-tolerated, and a particular benefit in terminally-ill patients is the rapid onset of action.⁶⁹⁹ Side-effects include nervousness, over-stimulation, mild increases in blood pressure and pulse rate, and tremor.¹⁶⁴ Long-term use of these drugs is associated with tolerance and dependence.

4.3 HOW TO MAKE A REFERRAL

Establishing optimal methods for referring patients to professional help is vital in ensuring good psychosocial care for patients with cancer. All health professionals need to develop their own referral network for supportive and psychological care of their patients. This network would optimally comprise psychiatrists, clinical psychologists, social workers and occupational therapists with expertise in cancer issues and with whom the health professional can communicate about their patients. Comprehensive care of the individual may also require the involvement of other specialists, eg physiotherapists, speech pathologists, dentists, endocrinologists, nutritionists, reconstructive/plastic surgeons, fertility clinics etc.

It should be noted that local circumstances and the availability of resources may limit referral options and the networks that can be developed.

Developing a referral network

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

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

For those working within the private health sector, the lack of ready access to an existing multidisciplinary team may mean the provision of psychosocial support for patients poses some difficulty. Given the significant contribution of psychosocial factors to overall quality of life, it is crucial that clinicians working in the private sector develop a referral network.

Optimal methods for referral and uptake of referral

A referral is only effective if taken up by the patient. A recent study conducted at the Peter MacCallum Cancer Institute in Australia (**Level II**)⁷⁰⁰ evaluated an intervention designed to improve psychosocial care, in which computerised patient-completed questionnaire data were provided instantly to a patient advocate, whose role was to facilitate patient support and referral. The study failed to demonstrate a difference between the intervention and control groups. The authors speculated this could have been because many patients failed to take up referrals made by the patient advocate to psychosocial professionals.

There are very few studies in the oncology field relating to optimal methods of referral to psychosocial professionals. There are studies documenting health professionals' attitudes to psychosocial interventions⁷⁰¹ and others demonstrating that both the establishment of a formal psychiatric liaison service (**Level III-2**)⁷⁰² and staff communication training in eliciting emotional cues (**Level III-3**)⁷⁰³ result in increased referrals. Evidence is not available for practical strategies to improve the uptake of referrals. However professional views concerning barriers to effective referral, and possible strategies for addressing these, were gathered at an Australian workshop for nursing and psychosocial health professionals involved in cancer

care. These have been summarised below and may provide assistance to healthcare professionals and institutions in addressing the issues around psychosocial referrals (see Appendix G for a more detailed summary).

Discussing psychosocial referral with patients and their families

Some people may refuse referral. They may not want to acknowledge psychosocial difficulties or their difficulty in coping with these. Such attitudes might also come from patients' families who feel they can look after their own or fear an adverse community response to psychosocial referral. Patients might also resist referral if they do not wish to disclose concerns to another person, or want to stay with a member of their treatment team with whom they are already comfortable.

To overcome patient barriers, it is helpful to find an acceptable opening by exploring physical issues like pain, and then moving to emotional issues. For example:

'I notice you said you are fine, but you are not sleeping at night. That is an important problem. Perhaps we could help you with that.'

It is important to recognise that the timing may not be right and it may be necessary to try again at another time. The literature suggests that many people focus on emotional issues after the treatment is over.

Stigma can be overcome by normalising emotions and psychosocial referral. Comments such as the following may help:

'Things were fairly normal for you but now you are undergoing an extraordinary experience, and it is natural that you would need help.'

The use of analogies may also be helpful. For example:

'People wouldn't hide a broken leg, or use a band-aid to fix it up – why should we respect emotional needs less?'

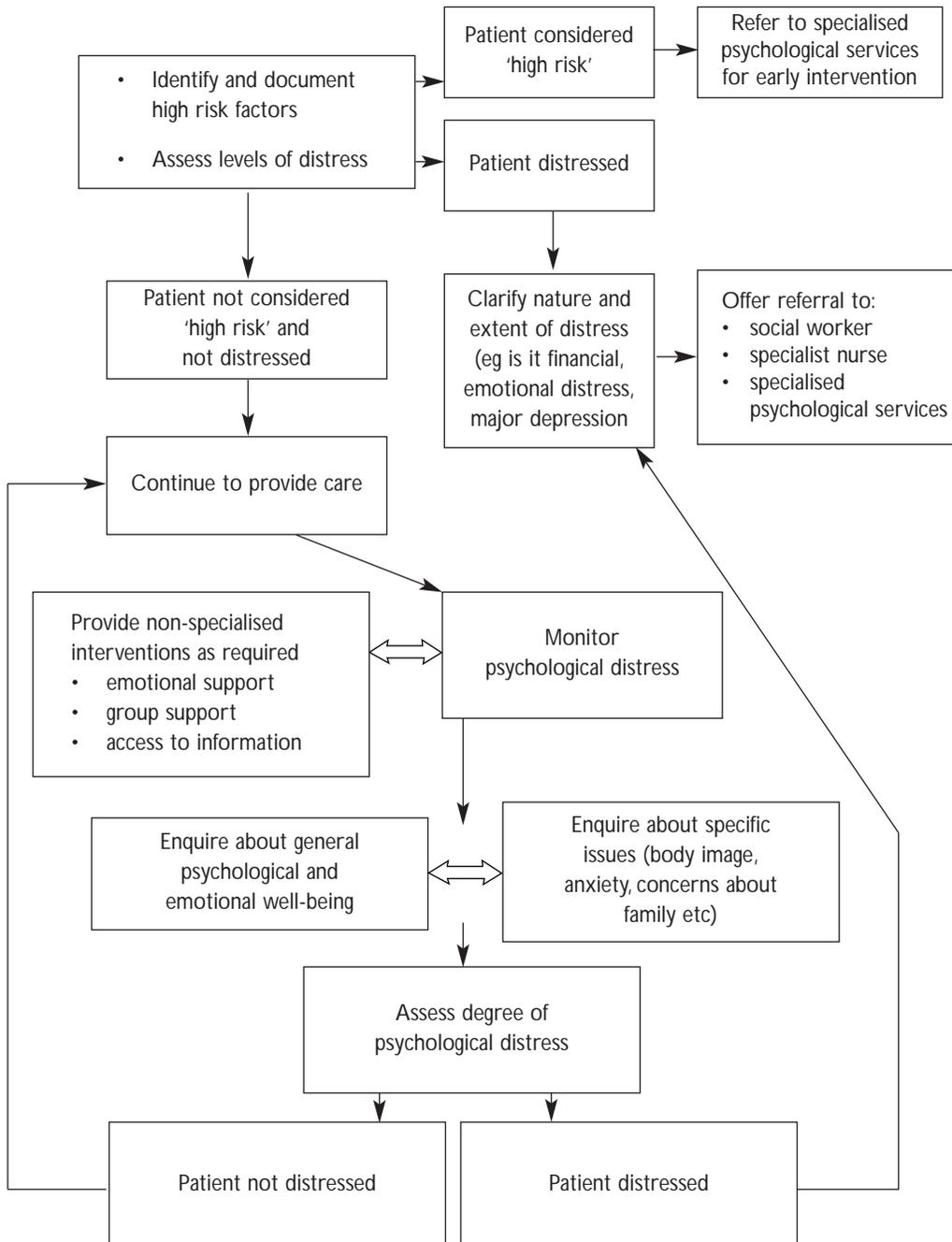
'I know you are more than just your cancer.'

Ideally, psychosocial professionals should be part of the treatment team and introduced as an available resource from the beginning. If necessary, advice should be obtained about what is culturally appropriate for the patient and their family.

It may be necessary for health professionals to offer to communicate separately with family members who may see the referral as negative, and to work with the patient on how they will respond to negative feedback.

The following chart provides an easy reference for the process to be followed to ensure the psychological needs of the patient are met. It should be noted that these needs may be met in acute care or in a community setting. It may be helpful to read this in conjunction with Table 3.7B.

Figure 2: Summary of care and referral to psychological care



CHAPTER 5 ISSUES REQUIRING SPECIAL CONSIDERATION

5.1 CULTURE

Cultural and linguistic diversity

Australia has one of the most multicultural populations in the world. In 1996 Census, 41% of the total Australian population was either born overseas or had at least one parent born overseas, and 13% born in a Non English speaking background (NESB) country. Australians speak 193 languages, and 15% speak a language other than English at home.⁷⁰⁴ The pattern of post-World War II migration, mostly from Europe, has resulted in a relatively higher mean age among NESB populations. Ageing of the population is associated with increased cancer morbidity and mortality.

Language barriers and lack of knowledge of the Australian health care system limit access of NESB people to health information and health care services.⁷⁰⁵ In the last decade, there has been an increased emphasis on programs communicating cancer-preventive messages to the general public and promoting practices associated with its early detection. Some of these programs addressed cultural and linguistic diversity of Australia's population by translating and printing materials into community languages. While good-quality printed materials play a role in promoting cancer preventive actions, there is also a need for development of comprehensive NESB communication strategies that are both culturally and linguistically appropriate.

People from culturally and linguistically diverse backgrounds, especially those whose English proficiency is poor, experience particular difficulties utilising existing health care services. While the specific needs and sensitivities of people from diverse cultural and linguistic backgrounds will vary, there are a number of issues that are likely to be important to most communities. Therefore, utilisation of interpreting services is one of the strategies to improve access of people with limited English skills to existing health services (see Tables 5.1A and 5.1B).

Working with interpreters

When involving an interpreter, the practitioner should explain the interpreter's role and the issues of confidentiality to the client. The client must agree to the interpreter being present at the consultation.

Professional interpreters who are accredited by the National Accreditation Authority for Translators and Interpreters (NAATI) are strongly recommended. Involvement of family members, friends or other unqualified people to assist with interpreting is not prudent practice. For various reasons family/friends may seek to censor or alter information, or their language skills may also be inadequate. Where possible, the gender of the interpreter and the client should be matched.

Interpreted consultations are most effective if the health professional talks directly to the individual, rather than to the interpreter, keeping sentences short and pausing after a few sentences to allow time for the interpretation.

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

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

Provision of information

If possible, information provided to people whose native language is not English should be in their own language (**Level IV**).⁷⁰⁶ Written information in community language booklets is available from the State and Territory cancer organisations. For details about other sources of written information, see Appendix E.

The Multicultural Cancer Information Service (MCIS) is a telephone service provided by the Cancer Council NSW. This service provides information and emotional support for people with cancer, their families and friends, in five languages: Arabic, Cantonese, Greek, Italian and Mandarin. Health professionals and community workers can also make use of the service. The MCIS is confidential, and special attention is paid to cultural sensitivities. Although the service is only promoted within NSW, it can be accessed by all Australian callers for the cost of a local call. Contact details are included in Appendix H.

Consent to medical treatment or other procedures can not be given by the patients without their clear understanding of such treatment and procedures. This reinforces the need to involve high quality interpreters in consultations where cancer treatment or other procedures are explained in order to obtain an informed consent.

Cultural sensitivities

It is important to be aware that people from linguistically or culturally diverse backgrounds may have a number of cultural sensitivities (**Level IV**).^{706,707} There may also be diversity within cultural groups, as well as between cultures. Some of these cultural issues will be similar across a number of ethnic groups, while others may be relevant to one group only.

A recent report examined cultural issues relating to breast cancer.⁷⁰⁸ This report identified several issues relevant across a number of cultural groups and cancer diagnoses. These include the following:

- many people will prefer to see a medical professional of their own sex. If that is not possible, for female patients a female nurse or counsellor should be present during the consultation
- a diagnosis of cancer may be viewed as a death sentence, regardless of the actual prognosis
- a diagnosis of cancer may be viewed as shameful, so sensitivity and reassurance may be required

- religion may play a fundamental role in the person's attitude toward their disease and treatment. Spiritual support from their religious group may be important
- family and extended families have a central role in many cultures. Rights, responsibilities and decision-making are often shared by family members, and this may influence the choice of treatment.

Support and support services

The concept of support may not be familiar to people from diverse cultural backgrounds. It will be important to explain the concept of support in the Australian context, what it means, and to give examples of the types of support available. Encourage people to seek support from family and friends, and community, ethnic and religious organisations, if appropriate. Wherever possible, offer the patient the opportunity to bring family members/friends with them to consultations and treatment.

In some cultures, it is not considered appropriate to seek support from outside the family. It is important to explain that formal support services can offer detailed information about cancer, and may also offer the opportunity to talk to someone who has actually experienced the disease themselves. For example, the BCSS offers volunteers from a number of ethnic backgrounds, so it may be possible for women to talk with someone from a similar background who has breast cancer.

Table 5.1A: Recommended steps involved in dealing with cultural issues

Working with interpreters

- Book a trained interpreter from the Translating and Interpreting Services (TIS) if the person is not proficient in English - 13 14 50
- Explain the role of the interpreter and how confidentiality is maintained. Ensure that the person agrees to their presence
- Talk directly to the patient rather than the interpreter, keep sentences short and pause after a few seconds to allow for interpretation

Provision of culturally sensitive services and support

- Ask how the patient feels about their disease and treatment, and what meaning it has for them within their culture, in particular cultural or religious issues which may influence treatment
- Assess the patient's understanding of their disease, treatment and prognosis
- Always be aware of culturally-specific and individually-specific values, beliefs and modes of behaviour
- Provide culturally-appropriate health care workers, when possible
- Provide women with access to a female medical professional or nurse, when possible
- Explain how confidentiality is achieved within the medical setting
- Offer to discuss issues and treatment options with the patient's family
- Explain the importance of social support and encourage the patient to seek support from family, friends, support services and local cancer organisations
- Arrange follow-up and support

Provision of information

- Provide written information in the appropriate language, if available
 - Information provided during the process of obtaining informed consent to medical treatment or procedures should be presented in the client's preferred language
-

People from Aboriginal and Torres Strait Islander backgrounds

There are limited data about the support needs of people with cancer in Aboriginal and Torres Strait Islander populations. It has been shown that Aboriginal and Torres Strait Islander women with breast cancer often do not receive culturally appropriate management and support.⁷⁰⁹ While there is great diversity amongst these communities, and each community may have their own specific guidelines, awareness and consideration of the following issues discussed below are recommended. In addition it is recommended that health professionals working in a particular community explore the community guidelines with them.

Community links – awareness, networking and utilisation

A range of different health workers are available to support, interpret, advocate and explain on behalf of Aboriginal and Torres Strait Islander people. In different areas these health workers may include Aboriginal Health Workers, Aboriginal Liaison Officers, Aboriginal Health Education Officers and Aboriginal Nurses. They can be contacted through a range of organisations that are detailed in the Appendix I.

Provision of information

There is very little culturally-specific information written for Aboriginal and Torres Strait Islander people, which makes it difficult for people with cancer to access adequate information about treatment options.⁷⁰⁹ The contacts listed above, as well as some State and Territory cancer organisations, have information about what is available, and where to obtain it.

Cultural sensitivities

It is important to be aware that people from Aboriginal and Torres Strait Islander backgrounds may have a number of cultural sensitivities. Ignoring these cultural values can threaten the identity, security and ease of the patient, and have significant consequences on the provision of treatment for their cancer.^{709,710}

Issues that may be relevant to Aboriginal and Torres Strait Islander people include the following:

- many people may be concerned about how, and if, their personal information is protected from other health professionals, researchers and members of their own community. Clinicians should not only ensure confidentiality, but also explain how this is achieved
- breast and gynaecological cancers are considered to be part of the realm of women's business. Consequently, the use of female health professionals will improve the acceptability of diagnosis and treatment
- the significance of 'shame' for Aboriginal people is not well understood by the non-indigenous community. It is more than a sense of guilt or disgrace; it is a powerful emotion resulting from the loss of the extended self; that is, identity in terms of kinship, ritual and spiritual relationships, and responsibilities. Shame may be experienced when a person acts, or is forced to act, in a manner not sanctioned by the group and that is in

conflict with social and spiritual obligations. It may also be experienced when an individual is singled out for either praise or blame. In the health care setting, shame is perhaps the most complex and sensitive Aboriginal issue of which to be aware.

- family and kinship is central to the well-being of Aboriginal and Torres Strait Islander people. Clinicians should be aware that family responsibilities may impact greatly on treatment decisions and that involving family in the decision-making process may increase the acceptability of treatment options, as well as completion of, and compliance with, treatments
- the concept of 'support' is often not well understood; therefore, an explanation of social support, including examples of available services (such as the BCSS) and how they can be accessed, should be given to Aboriginal and Torres Strait Islander people
- Aboriginal people understand individual illness in terms of its impact on a person's ability to fulfil social and spiritual commitments. If treatment is seen to have a negative impact on a person's social or spiritual role, it is not uncommon for it to be refused or discontinued.⁷¹⁰

Table 5.1B: Recommended steps involved in providing psychosocial support to Aboriginal and Torres Strait Islander people with cancer

Providing psychosocial support to Aboriginal and Torres Strait Islander people with cancer

- Recognise that there is great diversity among communities in terms of culture and societal obligations
 - Be aware of the importance of potential conflicts between illness and treatment and a patient's social and spiritual obligations
 - Use indigenous health and community services to help provide information and support and to interpret and advocate for the patient
 - Provide women with access to a female medical professional or nurse, when possible
 - Explain how confidentiality is achieved within the medical setting
 - Direct questioning and eye contact may be difficult for many people
 - Assess the person's understanding of their disease, treatment and prognosis
 - Offer to discuss issues and treatment options with the patient's family and involve them in decision-making
 - Explain the importance of social support and encourage the person to seek support from family, friends, support services and local cancer organisations
 - Provide written information in the appropriate language, if available
 - Arrange follow-up and support
-

Responding to young patients with cancer

The diagnosis of cancer in young adults seems particularly incongruous, and treating such patients is often highly stressful for staff.⁷¹¹ In addition to the sense of identifying with the person ('It could be me'), staff may experience distress and guilt about the needs of the offspring of such patients, compounded by the lack of services and resources available to assist families coping with a parent with cancer.

Health professionals tend to cope by avoiding or distancing themselves in situations where they expect that they themselves will experience anxiety and distress.⁷¹² However, there is evidence that younger patients are more vulnerable to psychosocial distress in the context of cancer,^{629,631} and 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. Participation in communication skills training is a powerful way of improving the ability to respond to the specific needs of younger patients,⁷¹² as is access to specialised health professionals who can assist in supporting staff, and treating disorder in patients.

Responding to the older patient with cancer

With the aging of the population, issues surrounding cancer in the elderly will become more pronounced. More cancers will be diagnosed and treated in this age group, with the potential for increased numbers of elderly cancer survivors.

The elderly are not a homogenous population with respect to health and life expectancy, ability to cope with the physical and psychosocial aspects of cancer, and expectations for treatment and support.^{713,714} It is important to be wary of making presumptions about the patient's attitudes or needs based on stereotypes about age, as there is evidence that physicians tend to rate the quality of life of older patients with chronic disease significantly lower than ratings made by patients themselves (**Level III-3**),⁷¹⁵ and there are suggestions of under diagnosis and under treatment of older patients with cancer.⁷¹³ Older patients may present complex co-morbid problems, however with careful monitoring, conventional therapies are usually well-tolerated.^{716,717}

In older patients, it is particularly important to attend to the practical issues of coping with the limitations imposed by diagnosis and treatment.⁷¹⁸ Specific and early attention should also be paid to pre-existing social problems such as alcoholism, and psychiatric disorders, such as depression.⁷¹⁷ Clinicians may need to question sensitively to discern the psychosocial needs of older patients, which may be hidden under stoicism or the desire to be compliant. In one study, two-thirds of elderly patients with cancer said they experienced problems or concerns, but only 50% received adequate assistance in dealing with their emotional needs and 69% did not receive sufficient spiritual support.⁷¹⁹ There is little information about the acceptability and effectiveness of psychosocial interventions in elderly patients.

5.3 GEOGRAPHY

Emotional needs of rural patients with cancer

The limited available data suggests that patients with cancer who live in rural and remote communities have emotional needs and concerns similar to those experienced by patients living in urban areas. Studies of rural persons with cancer report psychological needs relating to emotional concerns, fear of recurrence, worry about the family, interpersonal relationships and communication.^{300,301,720,721}

Studies comparing rural and urban population report few differences between these groups in the nature and extent of these emotional needs, although time spent away from home for treatment is disruptive of family life and work.^{85,453,721,722}

Geographical isolation, travel and financial issues

Clinicians referring people from rural and remote communities to diagnostic, treatment and support services for cancer should ensure that the patients and their families are informed about assistance that is available to help with travel and accommodation costs that may be incurred (see Section 3.4).

Descriptive studies suggest that people with cancer living in rural areas are more likely to report problems and greater concerns associated with travel for treatment and follow up care.^{300,301,723} One study has also suggested that, while women residing in non-urban, rural and remote areas do not appear to incur substantially greater out-of-pocket expenses for medical services involved in screening, diagnosing and treating breast cancer in comparison with their urban counterparts, there may be additional travel and accommodation costs for this population.⁷²⁴

A survey of women with breast cancer found that 32% had to travel more than 100 kilometres for surgery. Sixty three percent of women who needed radiation therapy had to travel greater than 100 kilometres to receive it, and were, on average, away from home for 43 days, and 36% had to travel to receive their chemotherapy, which took them away from home for an average of 20 days. Only 44% of these patients received any financial assistance, and some of these people had trouble organising and obtaining the assistance they did receive. One quarter of rural women surveyed were unaware that financial assistance was potentially available.⁸⁵ (See also Section 2.4).

Social support

Geographical and social isolation may present rural people with cancer with greater difficulties in accessing social and practical support, although limited data is available about their use of social and professional support networks. Descriptive studies have reported that patients and families from rural areas perceive that geographical isolation may make it more difficult to access health and community support services and programs.^{301,725,726}

Treatment team members should be aware of telephone and Internet peer support groups that may assist rural patients to overcome the lack of readily accessible community support (see Section 3.3).

Rural lifestyle

Some authors have suggested that the rural lifestyle is associated with a greater self reliance and independent lifestyle, and that people from rural health may define health in more practical and functional terms.⁷²⁷⁻⁷²⁹ While there are few studies that have investigated health beliefs and practices of rural patients with cancer, rural patients with cancer may, on average, rate functional aspects of quality of life more highly than patients from urban areas.⁷³

Specific programs and interventions for providing support to people with cancer in rural settings

A variety of models for providing cancer services to rural communities have been reported, including rural hospital initiatives, shared care/outreach programs, and tele-oncology.⁷³¹ While these studies suggest shared outreach care was safe and could make specialist care more accessible (**Level III-2**),⁷³¹ they have focused primarily on provision of treatment services rather than on programs or interventions for providing psychosocial care. Studies have demonstrated some benefits of education and support provided by specialist cancer nurses for patients in rural areas in terms of improved knowledge and psychosocial support (**Level IV**).^{732,733} However, a demonstration project evaluating the role of specialist breast nurses in treating women with breast cancer has noted some limitations to the role in rural settings. The case study identified that the rural breast nurse treated significantly fewer women than urban specialist nurses, and had less access to a larger multidisciplinary team to facilitate coordination of care (**Level IV**) (see Section 3.5).

5.4 SEXUAL ORIENTATION

In general, homosexuals (gay men and lesbian women) and heterosexuals have similar health risks and concerns. However, homosexuals may be faced with some issues and concerns not experienced by their heterosexual counterparts.

It should be noted that there is a paucity of high-quality research about the health issues related to sexual orientation and the impact of cancer on those who are homosexual. Most of the literature consists of reports, review articles and descriptive studies. There is however considerable research about HIV/AIDS that appears relevant. Studies report high levels of illness concerns, social isolation, and lack of support in the homosexual population which are associated with psychological distress, anxiety and depression.^{350,734-738}

The health issues related to sexual orientation

Difficulties experienced by homosexuals

Individuals who identify themselves as homosexual often experience discrimination, violence, and social isolation,^{739,740} all of which impact on health and wellbeing. In this population there are higher rates of depression, suicide, substance abuse/alcoholism, cardiovascular disease and certain cancers than in the heterosexual population.⁷³⁹⁻⁷⁴² For some homosexuals the stress of cancer can be a reminder of earlier stresses,^{94,743-745} resurgence of stigmatisation and self doubt affecting sense of identity and well being.⁷⁴⁵

Attitudes of health professionals

Homosexuals may encounter homophobic attitudes and heterosexist assumptions when accessing health services. This may result in discrimination,^{94,743,744} and can be compounded if health professionals lack sensitivity and/or have limited knowledge of homosexual health issues and are therefore unable to answer questions about health risks.^{739,740,744} These factors may lead to avoidance or delay in seeking care and follow-up treatment, and be associated with the individual changing practitioners frequently.^{94,739,743,744,746} Individuals may not receive appropriate interventions, education, or information^{94,740,744} if they have fewer health checks and less screening and consequently, may experience reduced quality of medical care.

Cancer risk and screening

Evidence from review articles, large multi-centre studies and case studies indicate that gay men are at increased risk of anal cancer⁷⁴⁷ (**Level IV**),⁷⁴⁸ Kaposi's sarcoma, Non-Hodgkins lymphoma, leiomyosarcoma and possibly Hodgkins Disease, testicular cancer and conjunctival cancer (**Level IV**).⁷⁴⁸ Homosexuals with HIV/AIDS are at increased risk of Hodgkins Disease, liver cancer, cancer of the salivary glands,⁷⁴⁹ Kaposi's sarcoma⁷⁵⁰ and lymphoma.^{750,751}

Findings from primarily descriptive studies suggest that lesbians may be at higher risk of cervical, breast and ovarian cancer^{740,742,744,752,753} (**Level IV**).^{754,755} Studies have shown that lesbians have less frequent screening for cervical cancer.^{741,742,744} (**Level IV**).^{754,755} In one study of 100 lesbians, a quarter of the women indicated they had not had a pap smear within the last 3 years including 7.6% who had never had a pap smear (**Level IV**).⁷⁵⁴ There is an incorrect assumption among both women⁷⁵³ and some health professionals^{744,752} that lesbians do not need routine pap smears because of their sexual orientation. However they may be at risk for human papilloma virus, one of the major causes of cervical cancer, through contact with women who may have had previous male partners.⁷⁵² Lesbians may be at increased risk of breast and ovarian cancer due to lower use of oral contraceptives, and lower likelihood of having children or breast feeding,^{740,744} however breast screening and breast self-examination appears to be less frequent in this population⁷⁴⁴ (**Level IV**).⁷⁵⁵

Impact of cancer on homosexual individuals

A descriptive study exploring the impact of breast cancer on lesbian and heterosexual women⁷⁵⁶ identified no significant difference in psychological outcomes in relation to mood, sexual activity or relationship issues. Lesbians experienced fewer problems with body image, being more comfortable showing their bodies to others both prior to and following breast cancer. Lesbians were more likely to obtain social support from their partners and friends while heterosexuals received more support from relatives. Lesbians were less satisfied with their physician's care and the inclusion of their partner in medical treatment decisions.

In a study exploring the psychological impact of Kaposi's sarcoma,⁷⁵⁷ patients ranked fear of Kaposi's sarcoma as high as fears of death, neurological impairment, pain, social stigma and disfigurement. Severe weight loss, Kaposi's sarcoma affecting visible parts of the body, and other skin cancers associated with deformity or severe scarring can lead to a dramatic loss of self esteem, avoidance of social situations and depression.

General interactional skills to improve care

An individual's sexual orientation can affect levels of comfort with treatment interventions, ability to obtain emotional support and coping, and communication with health care

providers.⁹⁴ Non disclosure of sexual orientation is common due to fear that negative responses will lead to reduced standards of care.^{94,740,743,744,746}

Health professionals can improve health seeking behaviours and provide more effective care and improved interaction with homosexuals by: (see also Section 3.1)

- providing an environment in which patients feel safe and are encouraged to discuss their sexual orientation⁷⁴⁰
- recognising the barriers to care that may have been previously experienced^{741,758}
- adopting an inclusive approach⁷⁴¹
- being supportive and non-judgemental⁷⁵⁹
- communicating sensitively⁷⁴⁶
- maintaining a non-homophobic attitude⁷³⁹
- distinguishing sexual behaviour from sexual identity⁷³⁹
- maintaining awareness that personal attitudes may affect clinical judgement⁷³⁹
- communicating with gender neutral terms.⁷³⁹

The approaches to exploration of specific concerns (as in body image and sexuality - see Section 3.7) may provide a useful guide for the framing of questions in this context.

Providing emotional and social support

Health professionals should encourage and help patients to use existing sources of positive social support and assist in finding support networks.

While there are few studies about the effectiveness of emotional and social support for homosexuals with cancer, parallels can be drawn from studies of HIV patients. Social support, either in the form of support groups or confiding relationships, has been found to decrease stress and depression, feelings of hopelessness, and to facilitate empowerment **(Level II)**,⁷³⁴ **(Level III-3)**.⁷⁶¹ Emotionally sustaining help is rated by individuals as more desirable, available, frequently used and useful than problem-solving types of help.⁷³⁷

Psychological interventions

Psychological interventions can be effective in increasing morale, self esteem, coping ability and sense of personal control, as well as improving social and physical functioning, reducing distress, anxiety, and depression and should therefore be an integral aspect of care^{738,745} **(Level III-3)**.⁷⁶²

Only a few studies have investigated the effectiveness of psychological interventions for homosexuals with cancer and these are mainly in the areas of breast cancer and Kaposi's sarcoma. Interventions reported as effective in the HIV/AIDS literature, in either individual or group format, include psycho-educational interventions, cognitive behavioural therapies and supportive-expressive therapies^{738,745,763-765} **(Level III-3)**.⁷⁶² See also Table 4.1B for more information about these interventions and their benefits.

Cognitive behavioural interventions

Interventions that focus on problem solving techniques, coping strategies, health education, eliciting social support, stress management techniques (such as relaxation training and exercise), emotional support and crisis intervention have been found to be helpful in reducing anxiety and depression, and teaching more positive ways of coping, including seeking and improving satisfaction with social support^{738,763,765} (**Level III-3**).^{761,766} Interventions may also need to address the impact of stigmatisation on personal identity and well being.^{738,745,764}

For patients with highly visible cancers such as Kaposi's sarcoma, or those with extreme weight loss, intensive help may be needed to assist the patient to mobilise resources and face feared situations, as well as practical cosmetic advice.⁷³⁸

Psycho-educational interventions

Interventions that provide information about the implications of the disease, the nature of treatments, advice about diet, exercise and minimisation of substance misuse may help patients acquire a sense of control and mastery.⁷³⁸

Supportive expressive group therapy

Supportive expressive group therapy has been found to be effective in helping lesbians with breast cancer adjust to their illness (**Level III-3**).⁷⁶² In this study, the standard supportive-expressive intervention (see Table 4.1B) was not altered in any way except that the co-leaders of each of the sessions were lesbians. Over 12 month follow-up participants reported reduced emotional distress, intrusive thoughts and avoidance, and improved coping. These women also reported a reduction in conflict in the home, less pain and better sleep.

Partner support

Individual and group support, whether formal or informally led by peers, can be beneficial for partners and relatives of homosexuals with cancer, particularly after bereavement.⁷³⁸

APPENDICES

APPENDIX A: CLINICAL PRACTICE GUIDELINES FOR THE PSYCHOSOCIAL CARE OF ADULTS WITH CANCER: STEERING GROUP

The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancers Steering Group was established in 2001 to guide the development of the *Clinical practice guidelines for the psychosocial care of adults with cancer*. These guidelines are an extensively revised and expanded version of the *Psychosocial clinical practice guidelines: providing information support and counselling for women with breast cancer*²⁸ and are applicable to adult patients with cancer.

The Steering Group is a multidisciplinary working group comprising representatives from a range of cancers (including the five most frequently occurring cancers in Australia, as identified in Appendix D) and from a range of specialties.

Terms of Reference

- To assist in reviewing the relevant research about psychosocial issues and cancer in order to develop psychosocial guidelines relevant/applicable to all adult cancers
- To oversee the review of the *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer* to determine the areas where modifications need to be made and/or where new issues need to be incorporated to make them relevant/applicable for all adult cancers
- To assist in the development of psychosocial clinical practice guidelines for adult patients with cancer by drafting material and by reviewing material drafted by other members of the steering group
- To ensure that the guidelines are developed in accord with the NHMRC *A Guide to the development, implementation and evaluation of clinical practice guidelines*.

Membership of the Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer Steering Group

Dr Jane Turner (Chair)
Psychiatrist

Department of Psychiatry
University of Queensland
Royal Brisbane Hospital,
Herston, QLD

Dr Mark Bentley
Oncologist

Haematology Oncology Consultant
Mater Adult Hospital
Raymond Terrace
South Brisbane, QLD

Associate Professor Phyllis Butow Psychologist	Deputy Director Medical Psychology Research Unit Royal Prince Alfred Hospital, NSW
Dr Margaret Davy Oncologist	Department of Gynaecological Oncology Royal Adelaide Hospital Adelaide, SA
Mr Peter Loder Surgeon	Westmead Hospital Westmead, NSW
Professor Robin Marks Clinician	Department of Dermatology St Vincent's Hospital Fitzroy, VIC
Dr Carole Pinnock Research Scientist	Repatriation General Hospital Daw Park, SA
Dr Karen Pedersen Senior Project Officer	National Cancer Control Initiative Carlton, VIC
Dr Nicole Rankin Manager, Psychosocial Programs	National Breast Cancer Centre Camperdown, NSW
Professor Sally Redman Former Chief Executive Officer	National Breast Cancer Centre Camperdown, NSW
Emeritus Professor Tom Reeve Executive Director	Australian Cancer Network Sydney, NSW
Dr Lesley Russell Consultant	National Breast Cancer Centre Camperdown, NSW
Ms Suzanne Steginga Deputy Director	Community Services, QLD Cancer Fund Spring Hill, QLD
Mr Norman Thompson Consumer	Association of Prostate Cancer Support Groups Prospect, NSW
Dr Momo Tin Radiation Oncologist	Sydney Cancer Centre Camperdown, NSW
Associate Professor Kate White Nursing	School of Nursing and Public Health Edith Cowan University Churchlands, WA
Ms Siggi Zapart Project Officer	National Breast Cancer Centre Camperdown, NSW

APPENDIX B: PERSONS INVOLVED IN THE DEVELOPMENT OF THE PSYCHOSOCIAL CLINICAL PRACTICE GUIDELINES: PROVIDING INFORMATION AND SUPPORT FOR WOMEN WITH BREAST CANCER

These lists provide only names and specialties. For full details, refer to the *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer*.

Membership of the NBCC Psychosocial Expert Advisory Group

Dr Jane Turner (Chair)	Psychiatrist
Dr Fran Boyle	Medical Oncologist
Associate Professor Phyllis Butow	Psychologist
Professor Jill Cockburn	Behavioural Scientist
Professor David Kissane	Psychiatrist
Ms Penny La Sette	Consumer Representative
Dr Amanda McBride	General Practitioner
Miss Suzanne Neil	Breast Surgeon
Ms Marcia O'Keefe	Breast Cancer Consumer/Advocate
Professor Sally Redman	Chief Executive Officer, NBCC
Professor Martin Tattersall	Medical Oncologist
Ms Heather Wain	Social Worker
Associate Professor Kate White	Nursing
Ms Robyn Wicks	Consumer

NBCC Secretariat

Dr Cindy Davis, Behavioural Scientist

Dr Afaf Girgis, Behavioural Scientist

Mr Michael Parle, Clinical Psychologist

Project Officers: Dr Fiona Rolfe, Mr Michael Sharp, Ms Phillippa Williams,
Ms Donna Rose, Ms Liz King

NBCC Clinical Advisors

Emeritus Professor Tom Reeve, Executive Director, Australian Cancer Network

Dr Fran Boyle, Oncologist, Royal North Shore Hospital

Professor Alan Rodger, Radiation Oncologist, William Buckland Radiotherapy Centre

Dr Helen Zorbas, Clinical Director, NBCC

APPENDIX C: GUIDELINE DEVELOPMENT PROCESS

The guidelines were funded through the NCCI and developed by the NBCC, through a multidisciplinary Steering Group and secretariat staff (see Appendix A) in a manner consistent with that prescribed by the NHMRC, and according to the standards indicated by the Quality of Care in Health Outcomes (QCHOC).

Purpose and Scope of the guidelines

Need for generic evidenced based clinical practice guidelines

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

- evidence based information and treatment recommendations are documented in a series of clinical practical guidelines (see Appendix E) but these only provide general information about optimal standards of psychosocial care or devote one chapter to the area
- some consensus guidelines have been developed for specific aspects of information-giving in cancer care (eg NSW Cancer Council's *Breaking Bad News*)³⁹¹
- The *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer*²⁸ is the only comprehensive psychosocial guidelines document currently available in Australia.

Emerging evidence in the discipline of psycho-oncology suggests that there are similar themes in the psychological needs of people with cancer at different cancer sites. Therefore there is potential clinical value in developing generic psychosocial guidelines.

Target audience

These psychosocial clinical practice guidelines were developed to equip all health professionals with evidence-based recommendations for optimal psychosocial care throughout the different stages of care, according to individual needs.

Scope of the guidelines

The objective of the guidelines is to assist clinician/health professional and patient decisions about psychosocial care by providing a framework within which to apply a clinician's/health professional's judgment and to assess and consider the patient's individual needs and circumstances.

The guidelines are confined to the psychosocial aspects of care for all adults with cancer and their families. They cover care related to all stages of the disease as well as survival. Topics covered include: the way information about diagnosis and treatment may be delivered to a patient and their family; how the members of the treatment team can provide emotional support; how they can respond to specific psychological and physical concerns, screen for, acknowledge and where necessary refer on more significant psychological problems; ensuring continuity of care, facilitating the transition from curative to palliative care; providing end of life support, or support for survivors; practical issues such as the availability of, and access to, services and prostheses/aids, and or financial assistance for these; and specific issues such as culture (including the use of interpreters), geography and assistance for people from rural areas, and age issues.

Outcome focussed

The primary focus of the *Clinical practice guidelines for the psychosocial care of adults with cancer* is to improve psychosocial and quality of life outcomes of the patient and their family. Key outcomes may include the following:

Information and satisfaction with care

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

Psychological outcomes

The guidelines recommend evidence-based strategies to improve the early detection, referral and treatment of patients with elevated levels of anxiety and depression, as well as specific psychological conditions, such as body image distress. Recommendations are also made for the provision of support and, where necessary, appropriate referral to specialised physical and psychological services for patients experiencing distress as a result of physical symptoms. The guidelines also make recommendations to assist in the reduction of event-specific distress, such as communication of news of diagnosis or preparation for a treatment. It is anticipated that measurable psychological outcomes may include: levels of anxiety and depression; the prevalence, severity and chronicity of body image and sexual distress; interpersonal problems; and changes to the psychosocial component of chronic and impairing physical symptoms associated with cancer and its treatments.

Social functioning

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

Best available evidence

The comprehensive literature reviews, which formed the basis of the *Psychosocial clinical practice guidelines: information, support and counselling for women with breast cancer*; and the specific studies commissioned by the NBCC Psychosocial Working Group to investigate areas of need identified in the reviews, have been utilised, and to some extent, form the basis of these guidelines. These reviews covered the scientific literature prior to 1997 and identified and synthesised the best available evidence about the key practice related psychosocial aspects of care. Comprehensive literature searches were also conducted to identify additional relevant studies from 1997 to 2002.

Evidence was predominately obtained from research in the following cancers known to be the most frequently occurring cancers in Australia: colorectal, breast, prostate, melanoma, lung, gynaecological and Non-Hodgkin's lymphoma. Head and neck cancers that result in high impairment and pancreatic cancer which has a high mortality were also included (see appendix D for incidence details).

The reviews and the subsequent literature searches included the following aspects of psychosocial care:

- the nature, severity and impact of cancer on the emotional well-being of people with cancer, including how to identify those who may benefit from additional psychosocial support
- psychosocial support that is appropriate to be offered by members of the treatment team
- psychosocial support that is appropriate to be offered by groups outside the treatment team
- strategies for information-giving for health professionals providing care for people with cancer, including telling a person they have cancer, discussion of treatment options and prognosis.

The reviews and subsequent literature searches also included specific searches in areas identified by members of the Steering Group as being applicable (for example, specific physical difficulties, survival issues, gender issues). In these cases some of the searches covered cancer areas outside those identified above.

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

Studies from specific cancers, general oncology and health literatures were examined during the review process. In many cases the supporting research is specifically related to a single cancer type. In other instances the clinical issue has relevance to cancers in general, for example discussing the diagnosis of cancer. Because of the variations in the extent to which some themes and cancer types have been researched, there is an imbalance in the evidence available. Therefore, in these guidelines the best available evidence is cited, and any major deficiencies in the evidence base noted.

The reader is referred to the primary review documents from the *Psychosocial clinical practice guidelines: information, support and counselling for women with breast cancer* for detailed descriptions of the review methodology and a comprehensive discussion of the literature reviewed up to 1997. These reviews are available from the National Breast Cancer Centre on request and as noted above, cover the scientific literature for cancer, not just breast cancer. The completed reviews include:

Psychosocial impact of breast cancer: a summary of the literature 1986-1996,²⁶

*Psychosocial support for breast cancer patients provided by members of the treatment team; 1976-1996*²⁵; and

*Psychosocial support for breast cancer patients: a review of interventions by specialist providers – A summary of the literature 1976-1996*²⁴

Supporting research reviews:

- *Breaking bad news: a review of the literature*²⁰
- *Effectively discussing treatment options for women with breast cancer: a review of the literature*²¹
- *Preparing women diagnosed with breast cancer for mastectomy or breast conserving therapy: a review of the literature*²²
- *Talking about prognosis with women with early breast cancer*.³⁶⁸

The comprehensive literature searches conducted to identify relevant studies post 1996 utilised the same review methodology as that outlined in the primary review documents. The exception being the use of additional key words to those cited.

Consultation process

The guidelines have undergone an extensive consultation process. The key aspects of this process and a list of all submissions received are outlined below.

Key aspects of the consultation process underpinning the guideline development

- Public consultation as required by NHMRC, initiated in June 2002. Modifications were made, based on submissions received by the end of August 2002 (listed below).
- The guidelines were also sent out to relevant experts, representatives of the professional colleges and consumer representatives. Modifications were made, based on submissions received by the end of August, 2002 (listed below).
- Modifications to the guidelines were presented to the Clinical practice guidelines for the psychosocial care of adults with cancer steering group in September 2002 with subsequent modifications by the Steering group.
- Final draft submitted to the NHMRC for endorsement.

Submissions received from the 'Public' and 'Additional' consultation

Dr Paul Ireland

Deputy Director
National Cancer Control Initiative
1 Rathdowne St
Carlton Vic 3053

Dr David Boadle

Chief Health Officer
Department of Health & Human
Services, Tasmania
GPO Box 125B
Hobart TAS 7001

Dr Paul Mercer	Member of the Quality Care Committee, Royal Australian College of General
Practitioners	
	Silky Oaks Medical Clinic GPO Box 51193 Manly QLD 4179
Ms Lisbeth Lane	Psychologist Illawarra Women's Health PO Box 61 Warilla NSW 2528
Mr Graeme Brien,AM	Executive Director Queensland Cancer Fund PO Box 201 Spring Hill QLD 4004
Ms Robyn Cross	Acting Deputy Director Integrated Health Care Program ACT Community Care Level 3,ACT Community Care Building Moore & Alinga Streets Canberra ACT 2601
Dr Will Cairns	President The Australian and New Zealand Society of Palliative Medicine Inc. The Townsville Hospital PO Box 670 Townsville QLD 4810
Dr Fran Boyle	Chair Medical Oncology Group Australia The Bill Walsh Cancer Research Laboratory Dept of Clinical Oncology Royal North Shore Hospital St Leonards NSW 2065
Dr Elizabeth Hindmarsh	Member of the Quality Care Committee, Royal Australian College of General
Practitioners	
	71 Glebe Point Road Glebe NSW 2037
Ms Susan Rooney	Chief Executive Officer Cancer Foundation of WA Inc 46 Ventnor Avenue West Perth WA 6005
Ms Lyn Swinburne	National Coordinator Breast Cancer Network Australia PO Box 4082 Auburn South VIC 3122

Ms Lin Oke and
Ms Jane Pearson
Ms Louise Koelmeyer

Chief Executive Officer
OT Australia
6 Spring Street
Fitzroy Vic 3065

Professor Peter Ravenscroft

Chairman
Australasian Chapter of Palliative Medicine
145 Macquarie Street
Sydney NSW 2000

Dr Andrew Penman and
The Cancer Education Research
Program, University of Newcastle

Chief Executive Officer
The Cancer Council NSW
PO Box 572
Kings Cross NSW 1340

Dr Liz Kenny and
Dr Michael Black

Dean
Faculty of Radiation Oncology
The Royal Australian and New Zealand
College of Radiologists
Level 9
51 Druiitt Street
Sydney NSW 2000

Mr Shane Solomon

Executive Director
Department of Human Services, VIC
Metropolitan Health & Aged Care Services
GPO Box 4057
Melbourne VIC 3001

Mr David Stokes and
Associate Professor J.Toumbourou,
National Chair, APS College of
Health Psychologists

Manager, Professional Issues
The Australian Psychological Society
Level 11
257 Collins Street
Melbourne VIC 3000

Dr H Lindner,
Victorian Chair, APS College of
Health Psychologists

Ms M Cobain
National Chair, APS College of
Counselling Psychologists

Dr S Ballinger
National Chair, APS College of
Clinical Psychologists

Mr A Stuart and
Ms K Robinson, Mental Health and
Special Programs Branch

First Assistant Secretary, Health Services Division
Commonwealth Department of
Health and Ageing,
Health Services Division
MDP 37, GPO Box 9848
Canberra ACT 2601

Ms Lucinda Daley

Social worker
Sir Charles Gairdner Hospital
Hospital Avenue
Nedlands WA 6009

Professor David Kissane

Director
Centre for Palliative Care
University of Melbourne and
St Vincent's Hospital
41 Victoria Parade
Fitzroy VIC 3065

Dr Richard White

Senior Staff Psychiatrist
Royal Prince Alfred Hospital
Missenden Road
Camperdown NSW 2050

Mr Max Gardiner

Support and Advocacy Committee
Prostate Cancer Foundation of Australia
PO Box 1332
Lane Cove NSW 1595 and
Cancer Voices NSW
PO Box 376
Vaucluse NSW 2030

Dissemination and Implementation

The psychosocial guidelines have a broad target area. This includes a range of health professionals involved in the care of adult patients with cancer, such as specialist clinicians, general practitioners, psychologists, nursing staff and social workers, and other groups including allied health organizations. The guidelines are also of interest to consumers. Strategies for dissemination and implementation of the guidelines have been considered, taking into account the wide range of interested parties and the potential need to tailor plans for various target groups.

Strategies for dissemination and implementation of the guidelines will be drawn from the NBCC and their experience obtained through the implementation of the *Psychosocial clinical practice guidelines: information, support and counselling for women with breast cancer*. Evaluation and updating processes will be in accordance with NHMRC guidelines.

Endorsement

The guidelines were endorsed by the National Health and Medical Research Council in April 2003 and will be circulated to relevant stakeholders as a critical first step to aid dissemination and implementation.

Dissemination

Information technology provides a means for ready access and dissemination of the guidelines, a particular consideration given the extensive target audience. The guidelines will be made available on the Internet websites of the NHMRC.

Subject to funding, copies of the guidelines will be made available to relevant professional groups, allied health organisations, State and Territory health authorities, cancer treatment centres, consumer groups, professional colleges and associations, public policy makers and professional journals.

The availability of the guidelines will be advertised through a variety of means. This will include notification to relevant:

- professional groups, colleges and associations
- Cancer Councils/societies
- Commonwealth, State and Territory health authorities
- consumer groups and organisations
- hospitals and cancer treatment centres
- University medical schools
- public policy makers.

The guidelines will be advertised through newsletters published by the NBCC, NCCI and other cancer organisations, and will be promoted through presentations at professional meetings and conferences.

Information about communication skills training programs already developed by the NBCC, which may assist health professionals to implement information aspects of the guideline recommendations, will be publicised.

Consultation/feedback

Since acceptability of the guidelines by relevant stakeholders is a critical first step towards their implementation, consultation is an integral part of the implementation process. The guidelines have undergone an extensive consultation process that included both a public consultation and additional consultation in which the guidelines were sent to professional colleges and associations, and other interested parties such as Cancer Councils/societies, consumer groups etc for review.

Consideration of local conditions and resource complaints

The guidelines have been framed in a manner that is flexible and mindful of the variation in local conditions and resource considerations. However, the opportunity to implement some of the recommendations may be limited by local circumstances and the availability of resources such as access to psychiatrists, clinical psychologists or specialist oncology nurses.

Economic implications

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

Some of these recommendations may lead to the patients themselves incurring costs for their psychological care.

There are some recommendations that may be difficult to implement within current resource arrangements, including the provision of trained professionals, such as psychiatrists or clinical psychologists. Consideration has been given to undertaking projects to explore what is required to meet these needs and develop resources, such as specialist nurses, in diverse treatment settings.

Evaluation

An important part of the guideline development and implementation process is the evaluation of their effectiveness. A strategy for evaluating the guidelines will be developed at the implementation stage.

Revision

The psychosocial guidelines reflect the best available knowledge at the time of their publication. The NBCC's Psychosocial Expert Advisory Group meets regularly and provides a mechanism to review advances in the field.

Further research

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

- sexuality and body image
- psychosocial needs of people with advanced cancer
- psychological intervention in palliative care and the transition to palliative care
- strategies to improve the detection of psychological difficulties in people with cancer
- psychosocial needs and the nature of support likely to benefit survivors of cancer
- management of chronic physical and cognitive symptoms, such as post treatment fatigue
- prevention and management of lymphoedema
- the information and support needs of the children of people with cancer
- the provision of support for patients who have concerns about new relationships post diagnosis
- support needs of people with cancer in Aboriginal and Torres Strait Islander communities
- the effectiveness of pastoral care
- optimal methods for psychosocial referral and practical strategies to improve uptake
- the acceptability and effectiveness of psychosocial interventions in elderly patients.

In addition, the review process has highlighted a number of other areas in which research is very limited. These include:

- body image in cancer areas other than breast cancer
- fertility for cancers other than testicular cancer
- lymphoedema in cancer areas other than breast cancer
- traumatic symptomatology in cancer areas other than breast cancer
- the development and evaluation of the role of specialist nurses in cancer areas other than breast cancer
- the use of social and professional support by people in rural areas.

APPENDIX D: INCIDENCE OF CANCERS IN AUSTRALIA IN 1998

The following incidence tables have been developed from information presented in *Cancer in Australia 1998*. Australian Institute of Health and Welfare (AIHW) 2001.

Table A.D.1: Most frequently occurring cancers in Australia in 1998*

Cancer	Persons
Colorectal	11289
Breast	10755
Prostate	9869
Melanoma	7891
Lung	7795
Gynaecological (Uterine, Ovarian, Cervical)	3483
Non Hodgkins Lymphoma	3208
Unknown Site	3167
Bladder	2803
Kidney	2191
Leukaemia's	2106
Stomach	1905
Head and neck	1750
Pancreatic	1729
Brain	1262

*This excludes non-melanocytic skin cancer.

Table A.D.2: Most frequently occurring cancers in Australia in 1998 by gender

Males		Females	
Cancer	Persons	Cancer	Persons
Prostate	9869	Breast	10665
Colorectal	6131	Colorectal	5158
Lung	5307	Melanoma	3493
Melanoma	4398	Lung	2488
Bladder	2068	Unknown Site	1538
Non Hodgkins Lymphoma	1742	Non Hodgkins Lymphoma	1466
Unknown Site	1629	Uterine	1399
Kidney	1333	Ovarian	1216
Stomach	1238	Pancreatic	869
Pancreatic	860	Cervical	868

APPENDIX E: RESOURCES AND CONTACTS FOR PATIENTS AND THE TREATMENT TEAM

RESOURCES

Resources for patients

Consumer guidelines

The following consumer guidelines are available from the National Health and Medical Research Council (NHMRC), the National Breast Cancer Centre (NBCC) or the Australian Cancer Network (ACN):

- *A guide for women with early breast cancer* (booklet)
Available from the NHMRC and/or the NBCC
- *A guide for women with metastatic breast cancer* (booklet)
Available from the NHMRC and/or the NBCC
- *Guidelines for the prevention, early detection and management of colorectal cancer: a guide for patients, their families and friends*
Available from the NHMRC and/or the ACN
- *Localised prostate cancer: a guide for men and their families*
Available free of charge from the ACN.

Other

Detailed information about other available consumer resources for specific cancers can be obtained from the Cancer Helpline or State and Territory cancer organizations outlined later in this section.

Resources for health professionals

Guidelines and recommendations

The following guidelines are available from The National Health Medical Research Council (NHMRC) publications website, the Australian Cancer Network (ACN), the National Cancer Control Initiative (NCCI), or specific cancer websites:

- *Clinical practice guidelines for the management of early breast cancer*
Available from the NHMRC and/or the NBCC
- *Clinical practice guidelines for the management of advanced breast cancer*
Available from the NHMRC and/or the NBCC
- *Clinical practice guidelines for the management of colorectal cancer*
Available from the NHMRC, the ACN, and/or the NCCI
- *Clinical practice guidelines for the management of colorectal cancer: a guide for general practitioners*
Available from the NHMRC, the ACN or the NCCI
- *Clinical practice guidelines for the management of cutaneous melanoma*
Available from the NHMRC and/or the ACN
- *Familial aspects of cancer: a guide to clinical practice*
Available from the NHMRC, and/or the ACN
- *Familial aspects of bowel cancer: a guide for health professionals*
Available from the NHMRC, and/or the ACN
- *General guidelines for medical practitioners about providing information to patients*
Available from the NHMRC
- *The pathology reporting of breast cancer: a guide for pathologists, surgeons and radiologists. Recommendations of the Australian Cancer Network working party*
Available from the NHMRC, the ACN and/or the NBCC
- *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer*
Available from the NHMRC and/or the NBCC
- *National palliative care strategy: a National framework for palliative care service development*
Available from the Commonwealth Department of Health and Ageing – Mental Health and Special Programs Branch.

At the time of publication, a number of other guidelines were also in development:

- Guidelines for the management of localized prostate cancer (final stage of NHMRC review, available from the Prostate Cancer Foundation of Australia)
- Guidelines for the management of lung cancer
- Guidelines for the diagnosis and management of lymphoma
- Guidelines for the management of epithelial ovarian cancer.

Other

Detailed information about other available clinician resources for specific cancers can be obtained from the Cancer Helpline or State and Territory cancer organizations outlined later in this section.

Resources for patients and health professionals

Detailed information about available resources for specific cancers can be obtained from the Cancer Helpline or State and Territory cancer organizations (see contact details listed later in this section).

The Internet also has a considerable amount of information about cancer. A good place to start searching the Internet is through the Home Page of reputable cancer organizations/associations or support networks. A list of recommended Internet sites is also available in Appendix J.

C O N T A C T S

To learn more about cancer and the services and support available to a patient and their family, the following contacts may be helpful.

Nationally

Cancer Helpline

The Cancer Helpline provides general information as well as information about local resources. This service can be accessed from anywhere in Australia for the cost of a local call, connecting to local cancer organisations:

Ph: 13 11 20

National Breast Cancer Centre (NBCC)

The NBCC is funded by the Australian Government to improve breast cancer control on a national level by: analysing research and making it readily available to women and health professionals; developing, disseminating and encouraging the adoption of clinical guidelines to improve the diagnosis, treatment and support of women with breast cancer; providing accurate and accessible information to well women, women with breast cancer, primary care providers and breast cancer specialists; developing a national monitoring system to provide information about all aspects of breast cancer. Contact details are:

Locked Bag 16

Camperdown NSW 1450,

Ph: (02) 9036 3030

Fax: (02) 9036 3077

Email: director@nbcc.org.au

Website: www.nbcc.org.au

The National Cancer Control Initiative (NCCI)

The NCCI is funded by the Australian Government and is a partnership between The Cancer Council Australia and the Department of Health and Ageing. The NCCI is a key expert reference body providing timely advice, identifying appropriate initiatives and making specific recommendations to the Commonwealth Government and other key groups regarding the prevention, detection, treatment and palliation of cancer for all Australians. The Initiative works closely with other bodies and is a National Health Priority Area Initiative of the Commonwealth Government. Contact details are:

1 Rathdowne St

Carlton VIC 3053

Ph: (03) 9635 5108

Fax: (03) 9635 5320

Email: enquiries@ncci.org.au

The Cancer Council Australia (TCCA)

Australia's national non-government cancer control organisation. Its members are the eight State and Territory cancer organisations. These work together to undertake and fund cancer research, prevent and control cancer and provide information and support for people affected by cancer. Contact details are:

Level 5, Medical Foundation Building

92-94 Parramatta Rd

Camperdown NSW 2050

Ph: (02) 9036 3100

Fax: (02) 9036 3101

Email: info@cancer.org.au

Website: www.cancer.org.au

Australian Cancer Network (ACN)

Established by The Cancer Council Australia and the Clinical Oncological Society of Australia to improve cancer management and promote collaboration between and with professional bodies across Australia. It extends the outreach of The Cancer Council Australia to a large number of professional colleges and societies. The ACN has developed and disseminated evidence-based clinical practice guidelines for several areas of cancer management.

Contact details are:

Mail: GPO Box 4708

Sydney NSW 2001

Ph: (02) 9036 3120

Fax: (02) 9036 3121

Email: acn@cancer.org.au

National Health and Medical Research Council (NHMRC)

Government body that brings together and draws upon the resources of all components of the Australian health system. It funds health and medical research, provides ethical guidance on health and medical research issues, and provides health advice. It publishes guidelines, information papers and pamphlets about a range of health issues, drawing on the best expert advice and ensuring that the published advice is both current and relevant for the Australian community. Contact details are:

GPO Box 9848

Canberra ACT 2601

Ph: (02) 6289 9184

Fax: (02) 6289 9197

Website: www.health.gov.au/nhmrc

BreastScreen Australia

Commonwealth initiative supported by all State and Territory governments that aims to detect breast cancer at an early stage in women aged 50 years and over. Some BreastScreen centres have designated counsellors available. Information about local BreastScreen services can be accessed from anywhere in Australia for the cost of a local call:

For more information phone: 13 20 50

National Cervical Screening Program

A joint Commonwealth and States/Territories initiative to prevent cervical cancer. The website includes information for health professionals and patients regarding cervical screening and potential risk factors for cervical cancer.

Website: www.cervicalscreen.health.gov.au

Breast Cancer Support Service (BCSS)

This free and confidential service extends practical and one-to-one social support to women diagnosed with breast cancer. BCSS support workers are themselves breast cancer survivors who are matched to the woman according to relevant social and treatment characteristics.

For more information phone: 13 11 20

Prostate Cancer Foundation of Australia

National organisation acting to reduce the impact of prostate cancer on Australian men, their families and the community by: providing access to information, support and counselling; funding research into the causes, detection, diagnosis and treatment of prostate cancer; and raising community awareness. Contact details are:

Shop 3/115 Longueville Road
Lane Cove NSW 2066
Ph: (02) 9418 7942 or 1800 220 099
Fax: (02)9420 3635
Website: www.prostate.org.au

Australian Council of Stoma Associations (ACSA)

The ACSA represents all stoma associations throughout Australia. It provides liaison with the Australian government and appliance suppliers and coordinates the Stoma Appliance Scheme. The ACSA also coordinates support services for ostomates throughout Australia and publishes a national journal. The ACSA can provide patients who have undergone stomal surgery access to local associations and support groups, and information and advice about locally available resources. Contact details are:

Website: www.australianstoma.org.au

Mental Health and Special Programs Branch

Department that provides information to health professionals, consumers, carers and families about the Commonwealth Government's national initiatives, available publications and resources in the area of mental health and special access programs such as Palliative care and Stoma appliances.

Website: www.mentalhealth.gov.au

Palliative Care Australia

Palliative Care Australia is the national peak body for palliative care in Australia with member groups in each of the States and Territories. Their goal is to work toward the relief of pain and suffering of dying people and the provision of the care they, and their families, need. Contact details are listed below. State and Territory contact details can be obtained from the national body.

PO Box 24
Deakin West ACT 2600
Ph: (02) 6232 4433
Fax: (02) 6232 4434
Email: pcainc@pallcare.org.au

State and Territory cancer organisations and associated numbers

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

The Cancer Council ACT

159 Maribyrnong Avenue
Kaleen ACT 2617
Ph: (02) 6262 2222
Fax: (02) 6262 2223
Email: actcancer@actcancer.org
Website: www.cancer.org.au/act/

The Cancer Council NSW

153 Dowling St
Woolloomooloo NSW 2011
Ph: (02) 9334 1900
Fax: (02) 9358 1452
Email: feedback@cancercouncil.com.au
Website: www.cancercouncil.com.au

The Cancer Council Northern Territory

Shop 3 Casi House
Van Derlyn Dr
Casuarina NT 0810
Ph: (08) 8927 4888
Fax: (08) 8927 4990
Email: uvstop@cancernt.org.au
Website: www.cancercouncilnt.citysearch.com.au

The Cancer Council Tasmania

140 Bathurst St
Hobart TAS 7000
Ph: (03) 6233 2030
Fax: (03) 6233 2123
Email: infotas@cancer.org.au
Website: www.cancer.org.au/tas

The Cancer Council Victoria

1 Rathdowne St
Carlton South VIC 3053
Ph: (03) 9635 5000
Fax: (03) 9635 5270
Email: enquiries@accv.org.au
Website: www.accv.org.au

The Cancer Council South Australia

202 Greenhill Rd
Eastwood SA 5063
Ph: (08) 8291 4111
Fax: (08) 8291 4122
Email: cancersa@cancersa.org.au
Website: www.cancersa.org.au

Cancer Foundation of Western Australia

46 Ventnor Ave
West Perth WA 6008
Ph: (08) 9212 4354
Fax: (08) 9212 4399
Email: cancerwa@cancerwa.asn.au
Website: www.cancerwa.asn.au

Queensland Cancer Fund

553 Gregory Terrace
Fortitude Valley QLD 4006
Ph: (07) 3258 2200
Fax: (07) 3257 1306
Email: qldcf@qldcancer.com.au
Website: www.qldcancer.com.au

Action and support groups

Breast Cancer Network Australia

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

PO Box 4082,
Auburn South Vic 3122
Ph: (03) 9805 2500
Fax: (03) 9805 2599
e-mail: beacon@bcna.org.au
<http://www.bcna.org.au>

OvCa Australia

OvCa Australia is a 'not-for-profit' organisation that aims to increase awareness of ovarian cancer, to promote the need for effective early detection and to provide support to women and families. OvCa has implemented a 'Buddy Support' program through which women with ovarian cancer can access one-to-one support from a volunteer who is themselves either a patient with ovarian cancer or a supporter or carer. Contact details are:

PO Box 2365

Fitzroy VIC 3065

Ph: 1300 660 334

Email: info@ovca.org

Website: <http://www.ovca.org>

The Support and Advocacy Committee of the Prostate Cancer Foundation of Australia

This association is part of the Prostate Cancer Foundation of Australia. It aims to represent the interests of all men diagnosed with the disease through a nationwide network of affiliated support groups, the leaders of which have usually experienced treatment successfully. Contact details for the association are:

Max Gardner, President Ph: (02) 9337 3371

Con Casey, Secretary Ph: (02) 9938 2426

Website: www.prostatehealth.org.au or www.prostate.org.au

Contact details for local support groups can be obtained through:

Ph: 1800 220 099

Website: www.prostate.org.au or www.prostatehealth.org.au

Australian Prostate Cancer Collaboration

The Australian Prostate Cancer Collaboration is an organisation that aims to reduce mortality and morbidity and improve the quality of life for men with prostate cancer, and to develop strategies for the prevention of the disease. It also provides men with access to local support groups and information and advice about locally available resources. Contact details are:

C/- Flinders Cancer Centre

Bedford Park, SA 5042

Phone: (08) 8204 4288

Email: cancer.centre@flinders.edu.au

Website: www.prostatehealth.org.au (Lions Australia Prostate Cancer website)

Men can also contact local Cancer Councils directly on the Cancer Helpline (13 11 20)

Other

For information about local action and/or support groups for specific cancers not listed above, or teleconference support, patients can contact local State and Territory organisations or the Cancer Helpline on 13 11 20.

Support groups for specific difficulties

Lymphoedema Associations & Support Groups

These groups provide information about lymphoedema, local services and resources and support. Some states and territories also have regional and special interest support groups. The National organisation can provide contact details for all state and territory organisations which in turn can provide details for local groups in their respective states.

The Lymphoedema Association of Australia

Dr Judith Casley-Smith (Director)

98 Cambridge Terrace

Malvern SA 5061

Ph: (08) 8271 2198

Fax: (08) 8271 8776

Email: casley@internode.on.net

Website: www.lymphoedema.org.au

The Australian Lymphology Association

8 Kergo Place

Wantirna South VIC 3152

Continence Support Groups

Continence Foundation of Australia

The Continence Foundation of Australia exists to serve the interests of incontinent people throughout Australia by improving access to and availability of services, providing information and advice and promoting education, support and research. The Foundation can provide contact details for all state and territory bodies. The Foundation can be contacted at:

AMA House 293 Royal Parade

Parkville VIC 3052

Ph: (03) 9347 2522

Fax: (03) 9347 2533

Website: www.confound.org.au

National Continence Helpline

The National Continence Helpline is a joint project of the Commonwealth Government and the Continence Foundation of Australia. It provides free, professional and confidential advice about any continence issue to people with incontinence, their families and carers. The Helpline also provides supplementary information for medical and allied health professionals

Ph: 1800 330 066

Look Good...Feel Better

A community service for women undergoing cancer treatment, sponsored by the Cosmetic, Toiletry and Fragrance Association of Australia Inc., dedicated to teaching women beauty techniques to help restore their appearance and self-image during chemotherapy and radiotherapy. Workshops are held every 6-8 weeks at selected cancer treatment centres. Further information and contact details for each state can be obtained from the:

National Helpline: 1800 650 960

Laryngectomy Associations and support groups

These groups provide information about local services, resources, meetings and support for people who have undergone laryngectomy. Contact details for the Secretaries of the Laryngectomy Associations for each state can be obtained from the:

The Cancer Council Australia Ph: (02) 9036 3100, Website: www.cancer.org.au or

Cancer Helpline: 13 11 20.

Stoma support

The Australian Council of Stoma Associations can provide patients who have undergone stomal surgery access to local associations and support groups.

Website: www.australianstoma.org.au

Erectile dysfunction support

The Prostate Cancer Foundation and the organisations and associations listed under the 'Peer Support Groups' section can provide patients with information about local associations and support groups. In addition patients can call the Cancer Helpline on 13 11 20.

Infertility support

Information can be obtained from local State and Territory organisations or from the Cancer Helpline on 13 11 20.

Other

For information about support groups for specific difficulties not listed above, patients can contact local State and Territory organisations or the Cancer Helpline on 13 11 20.

APPENDIX F: FINANCIAL ASSISTANCE FOR TRAVEL AND ACCOMMODATION

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

ACT	Interstate Patient Travel Assistance Scheme (IPTAS)
NSW	Isolated Patients' Travel and Accommodation Assistance Scheme (IPTAAS)
NT	Patient Assistance Travel Scheme (PATS)
QLD	Patient Travel Subsidy Scheme (PTSC)
SA	Patient Assistance Transport Scheme (PATS)
TAS	Patient Travel Assistance Scheme (PTAS)
VIC	Victorian Patient Transport Assistance Scheme (VPTAS)
WA	Patient Assisted Travel Scheme (PATS)

Patients should be advised that they may need to claim in advance in some states. In some states, support is available for family members, and some states also have patient accommodation available through the cancer organisations or hospitals at reduced costs. A list of available resources can be attained from each State and Territory cancer organisation or local hospital.

APPENDIX G: RECOMMENDATIONS FOR STRATEGIES TO OVERCOME BARRIERS TO EFFECTIVE PSYCHOSOCIAL REFERRAL

A workshop about *Communication Skills for Cancer for Nurses, Social Workers and Psychologists*, auspiced by the Clinical Oncological Society of Australia and the National Breast Cancer Centre, was held in Melbourne in June 2001. Ten groups of four to seven participants, each led by an expert facilitator, discussed (i) perceived barriers to effective referrals, and (ii) possible strategies to overcome barriers and optimise the referral process. A scribe in each group took extensive notes and the facilitators communicated the results back to the whole group for discussion. The reports from each group and notes taken during the large-group discussion were analysed for themes, which are summarised below.

System barriers

The most commonly cited system barrier to effective referral was the lack of psychosocial professionals, especially in rural settings. Even in better resourced urban settings, hospital staff were often uninformed about appropriate referral sources, or could not access the right

person at the right time. Sometimes psychosocial professionals in private practices were utilised, but only a proportion of patients could afford these services. Insufficient access to interpreters was identified as another system barrier to effective referrals by workshop participants.

Strategies to overcome system barriers

To overcome system barriers, participants identified the following strategies:

- identify patients' current resources. For example, a friend, member of the family, family physician or priest may be already providing good psychosocial care. Informing and supporting this person may be less time-consuming and more effective than trying to find a scarce psychosocial professional
- develop a service directory of local community resources, including support groups, the relevant State or Territory Cancer Council, peer support networks and private practitioners. Familiarise staff with the contents and location of the directory
- lobby to get more cancer-specific psychosocial positions
- explore the possibility of sharing psychosocial positions with other departments
- if insufficient psychosocial staff are available, introduce a consultative role, where the psychosocial professional provides support, ideas and debriefing to existing staff, rather than directly providing patient care.

Professional barriers

Participants thought that effective referral was much more difficult in a work culture that emphasised physical, rather than emotional patient needs. If the oncology treatment team as a whole did not agree on criteria for referral, and did not endorse time spent discussing emotional issues and arranging a referral, individual staff members were less likely to give this priority. Nurses felt they sometimes lacked control over the referral process if a formal medical referral was required and the doctor disagreed with their assessment that a referral was needed.

Participants felt that assessment of emotional distress might not be undertaken if staff felt unskilled to deal with emotions or had insufficient time. Raising psychosocial issues was seen as potentially 'opening the Pandora's box'. Participants also felt they could become 'hardened' to patients' cancer experiences, and fail to recognise significant emotional distress.

Another problem identified by participants was that many health professionals are confused about when and how to make a referral, and also knowing who should refer to whom. General ignorance about psychosocial care was also noted as a problem. Staff may fear losing a special bond they have built up with the patient if they refer on. They may feel that they are the most qualified to help the patient because of that bond, even if they do not have specialist psychosocial skills. They might also fear loss of control over the patient's management plan.

Personal preferences and prejudices about psychosocial professionals might reduce willingness to refer, as might concern about stigmatising the patient. Non-integration of psychosocial professionals into the oncology team was thought to contribute to confusion about differing psychosocial, nursing and doctor roles, and mistrust of psychosocial professionals. Further referrals were also discouraged by a lack of feedback following a referral, or feedback from the patient about a poor experience with the psychosocial professional.

Strategies to overcome professional barriers

To overcome professional barriers, participants identified the following strategies:

- talk through team disagreements about priorities and responses to psychosocial concerns
- get the team involved in some psychosocial research and/or have experts present psychosocial findings at staff meetings
- introduce psychosocial issues as part of regular case management
- educate and up-skill all staff to elicit patients' emotional concerns and to respond to these, with referrals as appropriate
- have an additional, separate psychosocial meeting if there are enough staff to focus specifically on psychosocial issues
- define team roles, recognising overlap and team-member's particular expertise
- develop formal and informal assessment procedures for psychosocial distress (eg questionnaires and clinical strategies such as asking a psychosocial question in the first 3 minutes of every consultation/interview)
- develop critical pathways for psychosocial care
- develop feedback mechanisms between psychosocial professionals and referring staff, such as a copy of the letter sent to the consultant
- allow all staff to refer, providing the referral is documented
- introduce a psychosocial clinic for half a day or a full day, to which all staff can refer patients for an initial assessment
- coach the patient to ask the consultant for a referral, if they want one; and
- introduce performance management and clinical supervision.

Patient barriers

Patients were thought to refuse a referral if they were 'in denial', and did not want to acknowledge psychosocial difficulties. This might especially apply to older patients, who believed in the 'stiff upper lip' and that psychosocial referral reflected their own failure to cope as they should. Such attitudes might also come from patients' families who feel they can look after their own, and who fear loss of face in their community if psychosocial referral became known.

Patients might also resist referral if they did not want to disclose concerns to another person, or want to stay with a trusted staff member with whom they are already comfortable.

Strategies to overcome patient barriers

To overcome patient barriers, participants identified the following strategies:

Denial

- explore 'allowed' issues like pain, and then move to emotional issues
- find the 'crack' in the denial and negotiate, eg *'You say you are fine, but you also say you are not sleeping at night. That is an important problem. Perhaps we could help you with that'*

- try at another time. This may not have been the ‘right’ time. Research suggests that many people focus on emotional issues after the treatment has concluded.

Stigma and resistance

- provide patients with written and verbal material (in appropriate language) about likely emotions and help available. Normalise emotions and psychosocial referral: i.e. people with cancer are normal people undergoing an extraordinary experience, and should receive help. Encourage discussion of emotional issues
- use analogies, eg ‘*you wouldn’t hide a broken leg, or use a band-aid to fix it up – why respect emotional needs less?*’ and ‘*You are more than just your cancer*’
- introduce psychosocial professionals early as part of the oncology team, and if possible, face-to-face. Display a poster showing names and photos of the whole team, to emphasise the multidisciplinary nature of the team. Explain special areas of expertise of each person in the team, rather than using their titles and discipline
- separate (openly negotiated in front of all concerned) patient and family and explore their separate needs if necessary
- if you believe a referral to be appropriate, discuss the person’s strengths, before the issues underlying the need for referral
- suggest you are struggling with the issues they have raised, and would like some extra support and expertise
- note that psychosocial professionals can provide an additional way of looking at things, not necessary the solution. Present the referral as adding to the stock of tools they and you are using – not as a failure of yourself or them. Suggest that the new person will make a team of three working on the problem (you, the patient and the new person), rather than changing from you to them
- re-frame asking for help as a strength
- initially, ask a psychosocial professional for advice, and bring back their ideas to the patient, eg ‘*Mary suggested this – she had some other ideas too, and would be happy to talk with you herself at any time*’
- offer to tell the patient’s story to the new health professional, so they don’t have to go over it all again and facilitate the first contact, perhaps accompanying them
- positively promote the psychosocial service as evidence-based
- offer to communicate with family members who may see the referral as negative, and work with the patient on how they will respond to negative feedback
- acknowledge that not all people get on, and ask the person to come back to you if they are uncomfortable with the referral. This can reassure them that you are not abandoning them
- note that referral often involves only one visit, that the length of contact will be negotiated, that there is no commitment to continue and that confidentiality is assured
- openly discuss financial issues, if they are relevant
- write a formal referral letter, to ensure both you and the patient are clear about why you are referring, and why to that particular person

- match the patient with an individual staff member (eg men may be better off seeing men, even if the profession is not perfect)
- obtain advice about culturally appropriate care.

APPENDIX H: SERVICES FOR PEOPLE FROM CULTURALLY AND LINGUISTICALLY DIVERSE BACKGROUNDS

THE TRANSLATING AND INTERPRETING SERVICE (TIS)

The Translating and Interpreting Service (TIS) is a national service with offices in each State and Territory. The service offers both telephone and face-to-face interpreting. If an interpreter is needed to attend an appointment, this will need to be booked a few days in advance. TIS is available 24 hours a day, 7 days a week. The TIS can be contacted from anywhere in Australia, for the cost of a local telephone call, on 13 14 50.

Some states and territories also have other interpreter services available in a range of community languages. Some have health interpreters who are specially trained to interpret medical terms and procedures. The service is usually free of charge in public hospitals (some services do charge a fee). In addition to the interpreter services listed below, the patient's GP or local Departments of Social Security may be able to provide information about additional services in their area.

National (Australia Wide)

Translating and Interpreting Service (TIS) 13 14 50 (local call cost, 24 hour). To book an on-site interpreter call 1300 655 081

ACT:	ACT Health Care Interpreters	(02) 6205 3333
NSW:	Health Care Interpreter Service	
	Central & South Eastern Sydney	(02) 9515 3222
	Northern Sydney	(02) 9926 7560; (02) 9962 5772 (A/H)
	South Western Sydney	(02) 9828 6088; (02) 9616 8111 (A/H)
	Western Sydney & Wentworth	(02) 9840 3456; (02) 9840 3456 (A/H)
	Hunter	(02) 4924 6285; (02) 4921 3000 (A/H)
	Illawarra	(02) 4274 4211
	Greater Murray and Southern	1800 247 272
	All other country areas	1800 674 994
NT:	Northern Territory Interpreter and Translator Service	
	Darwin	1800 676 254

	Alice Springs	(08) 8951 5389
	Aboriginal translator services	
	Darwin	(08) 8924 4300; (08) 8924 4223
	Alice Springs	(08) 8951 5576; (09) 8924 3400
QLD:	No other accredited interpreter services call TIS	13 14 50
SA:	Interpreting and Translating Centre (ITC), Multicultural and Ethnic Affairs Commission	(08) 8226 1990
TAS:	AMIGOS Translate	(03) 6288 5480
VIC:	Central Health Interpreting Service (CHIS) Victorian Interpreting and Translating Service	(03) 9370 1222 (03) 9280 1955
WA:	No other accredited interpreter services call TIS	13 14 50

AUSTRALIAN TRANSCULTURAL MENTAL HEALTH NETWORK

The Australian Transcultural Mental Health Network is a national body that links State and Territory transcultural mental health centres and networks with the goal of improving mental health outcomes for Australia's diverse communities. The service provides information about and access to:

- Australian transcultural mental health organisations
 - Transcultural mental health centres
 - National and peak bodies
 - Linkage, advocacy and consumer groups
- Library and information services
- Research and policies
- Consumers and carers services - access to information about relevant national, state and local agencies that cover issues for carers and consumers within a culturally and linguistically diverse society.

Ph: (02) 9840 3333

Fax: (02) 9840 3388

Locked Bag 7118

Parramatta BC NSW 2150

Email: atmhn@wsahs.nsw.gov.au

MULTICULTURAL CANCER INFORMATION SERVICE

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

What does the service provide?

- information about cancer in Arabic, Cantonese, Mandarin, Greek and Italian to those diagnosed with cancer and their families
- a confidential telephone service
- information workers who speak Arabic, Cantonese, Mandarin, Greek and Italian. Each information worker also speaks English
- emotional support for people diagnosed with cancer and their families and friends
- information about referral to other services related to cancer
- information about cancer including investigations and treatment options
- information about attitudes and beliefs related to cancer in people from non-English speaking backgrounds for health care providers and community workers
- feedback to doctors and other health care providers about the person's concerns (at the person's request)
- information for the media about cancer
- information sessions to language specific community groups
- some assistance to bilingual cancer support groups
- bilingual brochures about cancer.

About the Information Workers

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

For further details, contact the Cancer Helpline on 13 11 20.

Contact details for the Bilingual Information Workers:

These numbers may be called from NSW and anywhere in Australia for the cost of a local call. The days listed are the 'usual' days of operation, but they may vary.

Arabic	Monday, Tuesday & Thursday	1300 301 625
Cantonese and Mandarin	Monday to Friday	1300 300 935
Greek	Tuesday, Thursday & Friday	1300 301 449
Italian	Monday, Thursday & Friday	1300 301 431

APPENDIX I: SERVICES AND CONTACTS FOR PEOPLE FROM ABORIGINAL AND TORRES STRAIT ISLANDER BACKGROUNDS

The following organisations can offer information to people from Aboriginal and Islander Strait backgrounds about how to access Aboriginal or Torres Strait Islander health workers, liaison officers, health education officers, social workers, community care workers, doctors and nurses:

- Office for Aboriginal and Torres Strait Islander Health (OATSIH)
- Aboriginal Health Branches in each State and Territory Department of Health
- Aboriginal Health Coordinators in each State and Territory area or regional health service
- Aboriginal Liaison Officers at major hospitals
- National Aboriginal Community-Controlled Health Organisations (NACCHO) and State and Territory equivalents
- Aboriginal Medical Services (AMS)
- Aboriginal Land Councils in each State and Territory
- Torres Strait Regional Authority (TSRA)
- Australian Indigenous Doctors Association (AIDA)
- Coalition of Aboriginal and Torres Strait Islander Social Workers Association (CATSISWA)
- Home and Community Care Workers (HACC).

APPENDIX J: RECOMMENDED INTERNET SITES

This is not an exhaustive list but gives some indication as to what is available. Readers are also directed to sites that have been included in Appendix E: Resources and Contacts for Patients and the Treatment Team.

American Cancer Society

<http://www.cancer.org>

Useful site providing information about cancer including information about the American Cancer Society, its publications, programs and local offices.

CancerBACUP

<http://www.cancerbacup.org.uk>

The UK's leading cancer information service.

National Cancer Institute

<http://www.cancer.gov>

Information developed by the US National Cancer Institute for health professionals, the general public, and cancer researchers from a variety of sources. Also offers links to Cancer Trials.

OncoLink

<http://cancer.med.upenn.edu>

Sponsored by the University of Pennsylvania Cancer Centre. Directed towards physicians, health professionals, social workers, and cancer patients including their family and friends.

Clinical Trials Centre (NHMRC)

<http://www.ctc.usyd.edu.au>

Details of clinical trials and other research conducted in Australia.

Institute of Cancer Research

<http://www.icr.ac.uk>

Information about the Institute plus information for patients and families

International Agency for Research on Cancer

<http://www.iarc.fr>

Part of the World Health Organisation and responsible for coordinating and conducting research about the causes of human cancer.

International Union Against Cancer

<http://www.uicc.ch>

Global non-government cancer organisation with more than 285 cancer control organisations in 86 countries.

National Comprehensive Cancer Network (NCCN) and American Cancer Society (ACS) Cancer Treatment Guidelines for patients

<http://www.nccn.org>

The NCCN and ACS have translated the NCCN Oncology Practice Guidelines into easy-to-understand information that can assist patients and families in making medical decisions. Four guidelines provide information about breast, colon and rectal, lung, and prostate cancer, the others provide information about cancer related physical symptoms such as fatigue, pain, and nausea and vomiting. Access is available by clicking on the 'NCCN/ACN treatment guidelines' link in the above website.

PubMed

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi>

US National Library of Medicine's search service. Provides access to citations in MEDLINE and other databases

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GLOSSARY

Adjuvant therapy

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

Allogeneic bone marrow transplant

The procedure in which bone marrow collected from another person is transplanted to the patient after their own bone marrow has been eradicated, for example by large doses of anticancer medication.

Alopecia

Hair loss. The extent depends on the type of treatment. Although hair loss following chemotherapy is usually temporary, new hair is often a different texture and colour from previously.

Alternative therapy

The term 'alternative therapies' is used loosely to describe any type of therapy that is outside the orthodox circle of surgery, radiation and chemotherapy. Alternative therapies have not been tested in randomised controlled trials to determine their safety and efficacy, and in some cases may interact adversely with conventional treatments, or exacerbate side-effects. See also Complementary Therapies.

Anterior resection

Transperitoneal resection of the sigmoid colon.

Anti-emetic treatment

Used to prevent or relieve nausea and vomiting.

Anxiety

The apprehensive anticipation of future danger or misfortune accompanied by a feeling of dysphoria or somatic symptoms of tension. The focus of anticipated danger may be internal or external.

Atrophic vaginitis

Drying of the vaginal mucosa, resulting in a watery discharge, yellow and usually not odourous. Caused by either natural menopause, radiation induced menopause or following surgical removal of ovaries.

Autologous bone marrow transplant

The procedure of collecting a cancer patient's own bone marrow, storing it (by freezing), giving treatment with high doses of anticancer medication, and then returning the stored marrow to the patient.

Azoospermia

The absence of spermatozoa in the semen.

Body image

The individual's conception of and feelings about their body – its overall integrity, its physical characteristics such as form, size and shape, and its conformity to societal values and norms. Self-esteem, psychosocial functioning and sexuality are intimately linked with body image.

Breast conserving surgery

Surgery where the breast cancer is excised together with a margin of normal breast tissue. The whole breast is not removed.

Chemotherapy induced nausea

Nausea that arises as a consequence of the drugs used in chemotherapy treatments.

Chronic disease

Diseases that have one or more of the following characteristics: they are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation, or care.

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 behavioural intervention

Interventions that use methods focused on modifying specific thoughts or behaviours, or on learning specific coping skills or problem-solving skills. Included in this category are progressive muscle relaxation training, meditation, hypnotherapy, systematic desensitization, biofeedback, behaviour modification or reinforcement.

Complementary therapies

A range of approaches to care provision aimed at enhancement of quality of life, including relaxation therapy, music, art, prayer, visualisation, guided imagery, massage, aroma, and dietary therapies, and other wellness or socialisation programmes. Complementary therapies such as relaxation and meditation are considered effective components of the care of many patients with cancer, and can be employed in conjunction with conventional therapies.

Conflict resolution

A technique of resolving conflict between two or more people that involves all parties expressing their needs and wants, and negotiating possible solutions to which the parties can agree.

Continuity of care

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

Coping

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

Coping skills training

Training, strategies or behaviours employed to maximise functioning and reduce or eliminate psychological distress in response to stressful situations.

Counselling

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

Couples therapy

Therapy that targets problems and issues within the couple relationship. Specific issues that might be addressed include communication, the sexual relationship, or parenting issues.

Cryopreservation

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

Deep fascia removal

Removal of a lesion together with the fascia deep to it.

Depression

A pervasive and sustained lowering of mood or the loss of interest or pleasure in nearly all activities. When used clinically, it is a cluster of symptoms, or syndrome, whose other features may include: changes in appetite or weight, sleep and psychomotor activity; decreased energy; feelings of worthlessness or guilt; difficulty thinking, concentrating or making decisions; or recurrent thoughts of death or suicidal ideation, plans or attempts.

Dyspareunia

Difficult or painful sexual intercourse.

Dysphagia

Difficulty in swallowing.

Dyspnoea

Shortness of breath, difficult or laboured breathing.

Educational and informational intervention

Interventions primarily providing sensory, procedural, medical information, or coping information.

Ejaculation dysfunction

Condition in which the sudden forcible expulsion of semen from the male urethra is disrupted. Premature – ejaculation immediately after the beginning of the sex act; retrograde – ejaculation with discharge of the semen into the bladder rather than through the urethra; dry – ejaculation that does not include spermatic fluid.

Emotional adjustment

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

Empathy

The ability to recognise and to some extent share the emotions and states of mind of another, and to understand the meaning and significance of that person's behaviour. It is fundamental to the clinical care of the patient with cancer, and their family.

Enteral nutrition

Nutrition directly delivered into the small intestine via a tube.

Erectile dysfunction

The inability to achieve an erection sufficient for penetration. Formerly known as impotence.

Existential therapy

Therapy that aims to enhance the capacity of the person to live life as fully as possible, and in the present moment. Rather than help patients to overcome or avoid distress, it attempts to acknowledge suffering and explore more fully the basis of this. In existential therapy, illness is often seen as an opportunity for personal growth.

Family therapy

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

Fascia

A fibrous structure giving strength to tissues under the skin.

Fistulae

An abnormal passage between one hollow organ and another or between a hollow organ and the surface of the skin.

Framing

The way in which, or perspective from which, information is given. For example positive framing describes the chances of survival, while negative framing describes the chances of dying.

Generic evidence

In the context of cancer studies, evidence that is applicable to or referring to all cancers.

Gonadal damage

Damage to the sex glands. For women the ovary, in men the testes

Grief

The normal emotional responses to loss which may include a complex range of painful feelings such as sadness, anger, helplessness, guilt and despair.

Group therapy

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

Guided imagery

A technique where a person is guided to use their imagination to picture a desired state with the goal of achieving relaxation and relief from symptoms such as anxiety, nausea or pain.

Hemoptysis

Coughing up blood or blood stained sputum from the respiratory tract.

Hormone therapy

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

Informed consent

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

Inguinal lymphadenectomy

Excision of one or more lymph nodes in the groin.

Keloid scars

An overactive scar that extends well beyond the original wound.

Ligation

Tying off, as in tying off blood vessels at surgery to stop bleeding, or tubal ligation to prevent sperm reaching the egg.

Lymphoedema

Swelling of the subcutaneous tissues caused by obstruction of the lymphatic drainage. Results from fluid accumulation and may arise from surgery, radiation or the presence of a tumour in the area of the lymph nodes.

Meta-analysis

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

Metastatic disease

Cancer that has spread to a site distant from the original site.

Mood

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

Morbidity

The outcome or consequence of a process or treatment.

Multidisciplinary care

Multidisciplinary care is recommended as a means of achieving best practice in that through their combined understanding, all members of the team liaise and co-operate together with the patient to diagnose, treat and manage the condition, to the highest possible standard of care.

Multidisciplinary team

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

Music therapy

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

Oesophageal speech

Speech utilising tracheo-oesophageal fistula in laryngectomised patients.

Oncologist

A doctor who specialises in the study and treatment of neoplastic diseases, particularly 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.

Oncology nurse

A nurse who specialises in the nursing of cancer patients.

Oocytes

An incompletely developed ovum.

Oophorectomy

Surgery to remove the ovary.

Organogenesis

The formation and differentiation of organs, and organ systems during embryonic development. This extends from approximately the end of the second week through the eighth week of gestation.

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 achievement of the best quality of life for patients and their families.

Pastoral care

The provision of care and support for a person's spiritual and existential needs provided by a member of the clergy or lay clergy.

Patient or peer support groups

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

Peer support

Support provided by people with similar problems or illnesses rather than by a trained health professional; based on the premise that mutual sharing of experiences and information is beneficial for participants.

Pharmacological treatments

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

Probabilistic

Likelihood of something happening.

Problem solving

A technique of assisting the patient to identify and clarify problems, consider potential strategies for responding, and evaluate the outcome.

Professionally-led groups

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

Progressive disease or advanced cancer

Cancer that has spread beyond the original site.

Progressive muscle relaxation

Therapy in which the individual learns how to relax muscle groups one at a time, and focus on regular deep breathing, with the aim of reducing anxiety, and helping control symptoms such as pain.

Prosthesis

An artificial substitute for a missing body part, such as an arm, leg or breast, used for functional or cosmetic reasons or both.

Psychiatric disorders

Illnesses classified within the discipline of mental disorders.

Psychodynamic

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

Psycho-educational program

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

Psychosocial intervention

Treatment that is intended to address psychological, social and some spiritual needs.

Psychosocial support

The culturally-sensitive provision of psychological, social and spiritual care.

Quality of life

An individuals' overall appraisal of their situation and subjective sense of well-being. 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, and which compares an experimental group with another group of subjects, equal in all respects, who do not undergo the treatment being trialled.

Recurrence

Reappearance of the cancer after a period of remission.

Referral network

Health professionals to whom the treating practitioner may refer the patient for the provision of specific treatments or support throughout the different stages of treatment and follow-up.

Reframing

Describing or thinking about something from a different perspective to assist in adjustment and reduce distress.

Relaxation therapy

A form of therapy where 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.

Retroperitoneal lymph node dissection

Lymph nodes that drain the diseased organ, usually in the pelvis or para-aortic region.

Retroperitoneal surgery

Any surgery that dissects behind the posterior peritoneum of the abdomen, either in the pelvis or para-aortic region.

Self-esteem

One's personal evaluation or view of self, generally thought to influence feelings and behaviours.

Self-help groups

Groups in which volunteers or fellow patients provide support to each other. See also patient or peer support groups.

Social functioning

Patient's ability to function in a social environment.

Specialised services

Psychological and or other supportive interventions or services that specialise in a particular aspect of treatment.

Specialist breast nurse

A specially trained nurse who works as a member of the multidisciplinary team, giving specialist advice, education and support to women with breast cancer and their families.

Specialist providers

In the context of the 'overall psychosocial care' of the cancer patient this includes: providers of specialised psychological interventions aimed at improving the psychological well-being of the patient eg psycho-oncology units, professional counsellors (including psychologists and psychiatrists) and cancer support services; and providers of other specialised services or therapies that can markedly improve the physical well-being of a patient, with clear implication for emotional well-being eg speech therapists, physiotherapists, nutritionists etc.

Spermatogenesis

The process of development of spermatozoa.

Stenosis

The constriction or narrowing of an opening or passageway in a body structure.

Stoma

An artificial opening of an internal organ on the surface of the body, created surgically.

Support network

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

Supportive psychotherapy

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

Survivor

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

Systematic desensitisation

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

Therapeutic relationships

Relationships between patients and health professionals in which the needs of the patient are paramount, conducted within defined professional codes of conduct.

Treatment modality

A specific type of treatment. Examples of different treatment modalities include radiation therapy, chemotherapy, and psychological therapy.

Treatment team

Generic health professionals who are directly involved in the provision of medical treatment to the patient. This includes general practitioners, surgeons, medical and radiation oncologists, and the specialist nursing and allied health staff involved in surgery, radiotherapy, and chemotherapy. It also includes the medical staff directly involved in the less common treatments such as blood transfusions, reconstructive surgery, treatment for lymphoedema, etc.

Trophoblastic disease

Disease of the placental tissues; may be potentially malignant as in molar pregnancy, or malignant as in choriocarcinoma. Treated, usually successfully, with chemotherapy. Fertility is preserved.

Tumour

Also called neoplasm. A new growth of tissue in which cell multiplication is uncontrolled and progressive. Tumours are classified in a number of ways, the simplest being their origin and whether they are malignant or benign.

Ultralow anastomosis

Resection of the distal sigmoid colon where anastomosis is technically difficult.

Volunteer programs

Many cancer organisations train volunteers, who are often former cancer patients, to provide support for patients. This might involve telephone contact, hospital or home visits, and include advice giving, sharing of resources, and general support.

LIST OF ABBREVIATIONS

ACN:	Australian Cancer Network
ACS:	American Cancer Society
ACSA:	Australian Council of Stoma Associations
AIDA:	Australian Indigenous Doctors Association
AMS:	Aboriginal Medical Services
BCNA:	Breast Cancer Network Australia
BCSS:	Breast Cancer Support Service
CATSISWA:	Coalition of Aboriginal and Torres Strait Islander Social Workers Association
CHIS:	Central Health Interpreting Service
CT:	computerised tomography
ECT:	electroconvulsive therapy
GHQ28/12:	General Health Questionnaire
GP:	general practitioner
HACC:	Home and Community Care Workers
HADS:	Hospital Anxiety and Depression Scale
HON:	Health on the Net
IPTAAS:	Isolated Patients' Travel and Accommodation Assistance Scheme (NSW)
IPTAS:	Interstate Patient Travel Assistance Scheme (ACT)
ITC:	Interpreting and Translating Centre
MCIS:	Multicultural Cancer Information Service
MRI:	magnetic resonance imaging
NAATI:	National Accreditation Authority for Translators and Interpreters
NACCHO:	National Aboriginal Community-Controlled Health Organisations
NBCC:	National Breast Cancer Centre
NCCI:	National Cancer Control Initiative
NCCN:	National Comprehensive Cancer Network
NESB:	non English speaking background
NHMRC:	National Health and Medical Research Council
OATSIH:	Office for Aboriginal and Torres Strait Islander Health
OvCa Australia:	the National Ovarian Cancer Network

PATS:	Patient Assistance Travel Scheme (NT)/ Patient Assistance Transport Scheme (SA)/ Patient Assisted Travel Scheme (WA)
PBS:	Pharmaceutical Benefits Scheme
PTAS:	Patient Travel Assistance Scheme (TAS)
PTSC:	Patient Travel Subsidy Scheme (QLD)
PTSD:	post-traumatic stress disorder
QCHOC:	NHMRC Standing Committee on Quality of Care and Health Outcomes
RSCL:	Rotterdam Symptom Check List
SNRIs:	selective noradrenergic reuptake inhibitors
SSRIs:	selective serotonin reuptake inhibitors
TIS:	Translating and Interpreting Service
TSRA:	Torres Strait Regional Authority
VPTAS:	Victorian Patient Transport Assistance Scheme

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