

WA Cancer & Palliative Care Network

Psycho-Oncology Model of Care



Government of **Western Australia**
Department of **Health**



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Introduction

1.1 Defining Psycho-Oncology

Psycho-Oncology is concerned with the psychological, social, behavioural, and ethical aspects of cancer. This sub-speciality addresses the two major psychological dimensions of cancer: the psychological responses of patients to cancer at all stages of the disease (and that of their families and caretakers); and the psychological, behavioural and social factors that may influence the disease process. (Holland JC, 1992).

Psycho-oncology is an area of multi-disciplinary interest and has shared boundaries with the major specialities in oncology including medical oncology, haematology and radiation oncology : the clinical disciplines (surgery, medicine, paediatrics, and radiotherapy), epidemiology, immunology, endocrinology, biology, pathology, bioethics, palliative care, rehabilitation medicine, clinical trials research and decision making, as well as psychiatry and psychology (Adapted from Holland JC).

The domain of psycho-oncology includes the formal study, understanding and treatment of the social, psychological, emotional, spiritual, quality of life and functional aspects of cancer; as applied across the cancer trajectory from prevention through to bereavement. It seeks to develop and integrate new knowledge and techniques of the psychosocial and biomedical sciences as it relates to cancer care (Canadian Association of Psychosocial Oncology, 1999).

1.2 Rationale for Developing a Psycho-Oncology Model of Care

People with cancer suffer significant emotional morbidity. In addition to the distress, fear and grief consequent upon diagnosis, the National Breast Cancer Centre and National Cancer Control Initiative (NBCC & NCCI), *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer* (2003) report that up to 66% of people with cancer experience long term distress. Furthermore, up to 30% experience clinically significant anxiety disorders and prevalence rates for depression range from 20% to 35%.

This psychosocial distress has 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 distress adversely impacts on capacity to cope with disease burden, and may reduce patient adherence to recommended treatments (NBCC & NCCI, 2003).

The NBCC & NCCI Guidelines report that 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. 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 NBCC & NCCI guidelines were developed for use by all health professionals who care for people during the course of cancer diagnosis and treatment. These guidelines, which are based on predominantly Level I and II evidence, provide clear recommendations to promote well-being and reduce the distress of patients and their families as they cope with cancer, with the view that these should be incorporated into routine clinical practice.



This Psycho-Oncology Model of Care draws heavily upon the recommendations of the NBCC & NCCI Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (2003), and seeks to apply the evidence highlighted by this landmark document, to the provision of psychosocial care to cancer patients and their carers / families in Western Australia.

In response to the clinical practice guidelines, the *WA Health Cancer Services Framework* by the WA Cancer Services Taskforce (2005) has previously identified a number of initiatives geared toward improving the psychosocial care of patients with cancer;

- (Initiative 12) Increase the number of and access to clinical psychologists and counselling psychologists for public patients. Increase public, specialist and GP awareness of these systems.
- (Initiative 13) Each Tumour collaborative should have links to a specialist clinical psychology service. The Breast Cancer Clinical Psychology Service could be expanded with additional resources to include all cancer patients.

In addition, the WA Cancer Services Taskforce has made provision to increase the level of psychosocial support to all cancer patients, through a variety of mechanisms including;

- Inclusion of supportive care as an integral component of cancer care. (Initiative 6)
- Active management of referral to psychosocial support services (Initiative 11, 43)
- Up-skilling of the cancer workforce (Initiative 14, 29, 42)
- Increased consumer awareness of options for accessing psychosocial support. (Initiative 16 – “A Directory of Cancer Services is developed and published”)

The Taskforce also recommended a plan be developed to improve access to psychosocial support services and a referral pathway to the CPS through cancer nurse coordinators:

Initiative 11 – The Director of the Cancer Network will audit current services and develop a plan ensuring patients have access to a range of supports such as allied health, psychosocial, and complementary supportive care. Cancer nurse coordinators have a referral role to clinical psychology and other psychosocial support services, liaising closely with the Cancer helpline and other non-government sources of psychosocial support.

In the past three years, while some of these recommendations have been acted upon to improve services providing care for patients with cancer in Western Australia, such as the inception of the WA Psycho-Oncology Service and provision of cancer nurse coordinators, significant concerns remain regarding the detection and management of psychosocial distress across the state. Furthermore, there is inconsistency across services with respect to attention to psychosocial care.

It is with this in mind, that the Psycho-Oncology Collaborative of the W.A. Cancer and Palliative Care Network has produced this model of care document. We propose that this document be used to guide government and service initiatives in the improvement of the psychosocial care of cancer patients and their families in W.A.

1.3 Current Quality of Psychosocial Care of Cancer Patients in Western Australia

It is difficult to clearly quantify the quality and extent of psychosocial care of cancer patients in W.A., because to date, there have been no comprehensive statewide



studies to measure the extent of psychosocial distress across care settings and sites, patient knowledge of services and the frequency of accessing these, or outcome measures for efficacy and patient satisfaction with available services.

However, if it can be assumed that the W.A. Cancer population shares similar psychosocial characteristics and needs to cancer populations in the Western World, it is likely that a significant amount of distress is unidentified and therefore untreated as has been demonstrated elsewhere (McDaniel et al. 1995).

The psycho-oncology executive collaborative of the W.A. Cancer and Palliative Care Network remains concerned that whilst there are a number of important initiatives underway, the approach to the psychosocial care of cancer patients in Western Australia has tended historically to be reactive rather than proactive, without a systematized approach.

Likely Under-Detection of Psychosocial Distress

At present, there is no routine process of screening all patients in the Western Australian cancer setting, for the presence of psychosocial distress. Whilst a focused discussion assessing psychosocial needs should ideally be an integral part of all clinician-patient consultations, time pressures and lack of interest/knowledge of psychosocial needs often result in physical symptom issues and discussions regarding treatment options taking priority.

Thus, there is scope for the introduction of a brief systematized screening tool, to be used routinely by cancer clinicians, nurses and specialized allied health staff across cancer care settings, with the aim of ensuring identification of psychosocial distress early in the cancer journey.

It may also be helpful to raise awareness amongst health professionals of the incidence and impact of psychosocial distress on cancer patients and their families and to assist health professionals to detect and respond to patient's emotional cues, as reported by Ryan et al.

Inadequate Provision of Information Regarding the Psychosocial Impact of Cancer

There is currently no statewide approach to the routine delivery of information regarding the likely emotional impact of cancer diagnosis and treatment.

There is anecdotal evidence that many patients are unaware of “normal” processes of psychological adjustment to cancer diagnosis, and are unaware of strategies to manage their anxiety and distress. Likewise patients and their families are often unaware of the sort of symptoms that indicate serious distress warranting more formal psychological or psychiatric input, while others may perceive stigma associated with reporting psychological distress.

Furthermore, it is likely that many clinicians and patients are unaware of the free or subsidized counselling provided by organizations such as The Cancer Council of W.A. and Silver Chain Hospice Care Service, or of government funded initiatives such as the W.A. Psycho-Oncology service.

Lack of Consistency Across Services

Whilst some patients are routinely referred at the time of diagnosis to a clinical cancer nurse, who can provide general education about the anticipated cancer journey, provide a point of contact for concerns and ensure continuity of care, this



is not routine for all cancers and is not consistent across private and public settings or between metropolitan and rural settings.

There is anecdotal evidence to suggest that the routine presence of clinical cancer nurses in outpatient consultations between patients and medical staff, facilitates the assessment and triaging of patient's physical and psychosocial needs in a timely manner. In addition, clinical cancer nurses are able to contact patients and/or their family members in the days following consultations and throughout their treatment to ensure that information has been appropriately understood.

CNC's are often able to address many patient concerns and ensure that patients are receiving the psychosocial support they require. Research on the value of CNCs in reducing patient distress and anxiety is warranted to obtain Level 1 Evidence and demonstrate that WA is leading the way in providing clinical cancer nurse support.

There would appear to be significant scope for expanding this program to ensure that all patients diagnosed with cancer have the opportunity to benefit from this comprehensive care.

Lack of Awareness of available Resources

Clinicians across many disciplines report that their knowledge of available psychosocial support resources and referral pathways is limited. Clinicians are therefore often dependent on "local knowledge" of individuals, with an interest in psychosocial care (particularly for specialized areas such as supporting children of parents with cancer or managing sexuality issues post cancer treatment), rather than information that is easily accessible across health services.

In addition, there are a number of highly skilled professionals with extensive specialised experience in the psychosocial care of patients and their families working in the private sector. However, many cancer clinicians are unaware of the availability or referral pathways to these individual practitioners.

Whilst there have been attempts to develop a directory of specialized psychosocial resources for cancer patients and their families that is widely accessible for clinicians, these have been hampered by issues of currency of data and responsibility for maintaining and updating this, and adequate credentialing of practitioners for endorsement by the health department.

This is particularly challenging in the area of psychosocial care, as techniques ranging from emotional and practical support, counselling, supportive psychotherapy and psychodynamic psychotherapy may be administered by individuals from a range of disciplines, many of which have limited formal registration requirements or verification of competency standards for these skills.

Furthermore, the issue of determining what constitutes "specialized experience in cancer care" remains an issue for many cancer care disciplines. However, these are important questions warranting further consideration in order to ensure that all cancer patients and their families have access to optimal psychosocial care.

Lack of Continuity and Communication Across Care Settings

At present, the responsibility for monitoring the emotional well-being of patients and their families is often delegated to General Practitioners, despite the fact that GP's are often not made aware of patient's diagnoses or treatments in a timely fashion, and are often not informed of significant changes in the management plan, such as transition to palliative care.



Furthermore, many patients do not necessarily have a consistent relationship with a single GP or practice. This lack of continuity may impact significantly on the ability of primary care practitioners to provide holistic care for patients within the context of their wider family system.

At present, there is a range of service providers representing primary, secondary, tertiary health care sectors, and non-government organizations that provide psychosocial care for patients with cancer and their families within Western Australia. This breadth of service is appropriate given the potential complexity of patient's psychosocial needs throughout the cancer journey.

Unfortunately, there are few formalized mechanisms of communication or networking between these services. More importantly, many clinicians working within the field of cancer care are not aware of the availability of these services, and the means by which patients can access these, which may result in under-utilisation of some services, and lack of appropriate referral for many patients and families in need.

Appendix 1 shows a map of current psychosocial service providers in Western Australia, with an outline of their main fields of psychosocial care and main contact telephone numbers. This document was produced (with the assistance of funding by the W.A. Cancer and Palliative Care Network) by the Psycho-Oncology Collaborative, with the aim of developing an easily accessible resource for clinicians working within the cancer field. This resource is now in its final stages of development and is ready to be trialed in the clinical setting. It is hoped that this will assist with the timely referral of patients to appropriate services within the state.

Recognising the Needs of Family and Carers of Cancer Patients

At present there is no systematic approach to identifying whether carers and families are experiencing high levels of anxiety and distress, and limited services available to provide support to these individuals. Partners of patients with cancer experience similar levels of psychological stress to the patient, with some studies revealing higher levels of distress in the partner (Hamilton, Peters, Round & Sharp, 2005; and Corbin & Strauss, 1985). Many couples confront cancer as a team and adjustment to cancer by one partner affects the other (Northouse, Templin & Mood, 2001). The diagnosis of cancer may also have an impact on communication between partners' and their intimate relationships. Although spouse's needs are often high, spouses receive minimal support from the medical team, particularly if they are not forthcoming in discussing their distress.

In addition, there is a current gap in service provision relating to children. At the present time, cancer patients in Western Australia are not routinely asked whether they have dependent children, and whether these children require psychosocial support. Thus it is difficult to appropriately plan for psychosocial support provision for these families, as the magnitude of the need is unknown. This omission reflects a lack of consideration of the potential for distress in children and their parents and should be identified as a priority for service planning and provision.

In addition, Children of older adult patients with cancer are often at a loss to know how to respect their parent's privacy, but to be involved in the treatment plan and to understand the impact of the illness on their own and their parent's psychological health. Often, there are supportive friends also wish to be involved in caring for the patients and take a role in providing assistance in day-to-day care. Mechanisms are required to ensure appropriate communication of important information regarding patients to those caring for them, while respecting the



privacy and confidentiality of the patient. Effective communication in this area will assist in better informing discharge planning following treatment.

Inequality of Access for Rural and Remote Patients

Patients in rural and remote areas not only experience inequality with respect to provision of local cancer services, including psychosocial support, they also face potentially obstructive financial outlays in order to access basic services. As was identified by the recent senate enquiry (2007), The Commonwealth Funded Patient-Assisted Transport Scheme (PATS) can be inflexible to the complex and changing needs of cancer patients and their families, with resulting additional psychosocial burden associated with isolation from family and cultural networks (particularly for patients from Aboriginal and Torres Strait Island backgrounds).

Regional Cancer Nurses provide an invaluable source of support for some patients and their families in rural and regional areas. However, the burden of providing intensive psychosocial support isolated from peers can be significant, and there is a need to ensure that staff working in situations such as these have access to appropriate clinical supervision and support.

The Cancer Council of Western Australia has attempted to improve equity of access to psychosocial support by funding a telephone counselling service for patients in rural and remote areas, and offers subsidized access to accredited counsellors with cancer experience in most regional centres. In addition, the newly developed W.A. Psycho-oncology Service has endeavored to offer telephone based clinical psychology services to isolated patients following an initial face to face meeting. However, many treating clinicians remain, unfortunately, unaware of these services or do not routinely advise patients about these services.

Indigenous and CALD patients

There is a need to adapt programs to meet the needs of minority and vulnerable groups. Surprisingly, little is understood about the experiences of Culturally and Linguistically Diverse (CALD) groups diagnosed with cancer.

Indigenous Australians experience later cancer diagnosis, lower five-year survival, higher mortality rates than non-Indigenous Australians and lower participation in screening programs (Cunningham et al. 2008). While there has been a 30 per cent reduction in cancer mortality rates in Australia over the last two decades, there has been little change in Indigenous cancer mortality. Therefore, there is a need to reconsider how all aspects of cancer control are managed for this group (Lowenthal, Grogan & Kerrins, 2005).

At present, there is no single contact service that a clinician caring for a patient from ATSI or CALD backgrounds can make contact with, to identify culturally appropriate support services that might be available to the individual in their local area, or to direct them to culturally appropriate resources regarding cancer diagnosis and treatment. As a result, cancer patients who are most in need are often least able to access specialised information and supports due to language and technology barriers.

Workforce Development

To date, many clinicians working in the cancer field have had limited formal training in communication skills for talking to patients about their cancer, particularly regarding points of increased emotional distress such as diagnosis of recurrence, poor prognosis and transition to palliative care. Furthermore, many clinicians feel



they have limited skills in managing emotional distress if it arises in the consultation, and find managing angry or demanding patients and families particularly stressful. (Delvaux, Razavi & Farvacques, 1988). Horowitz et al. (1994) noted that it is important for those who work in oncology to draw on the expertise of the multidisciplinary team to assist them to deal with complex clinical problems.

The National Breast and Ovarian Cancer Centre (NBOCC – previously NBCC) has developed communication skills training modules to assist with development of these skills, and a number of senior clinicians and trainees of multiple disciplines have had the opportunity to take part in these programs with excellent feedback. These workshops now need to be provided to more clinicians and allied health professionals in WA and further plans made regarding development and testing of new modules.

At present, there is no formal process of clinical supervision or self-reflective practice regarding the emotional impact of treating cancer patients on clinicians, which may contribute to high rates of burn out and workplace stress. This issue warrants further research and consideration, to ensure the cancer care workforce remains healthy.

Systemic Pressures

At the present time, there are systemic barriers to the provision of appropriate psychosocial care in the cancer setting. High patient numbers and workforce shortages often result in clinicians having limited time to address the psychosocial needs of their patients in the consultation setting.

Patients have often had to wait weeks or even months to be seen or to commence treatment, with resultant anxiety regarding the potential for their disease to worsen in the intervening time.

The physical environment in which cancer care is administered is not particularly patient-centred or family friendly, with patients often waiting for long periods in cramped waiting rooms. There are often limited rooms for nursing staff and allied health professionals to see patients privately to discuss psychosocial concerns.

Hospitals are rarely designed with spaces for children of parents with cancer to play or spend time together as a family, and there are few (if any) services which are able to provide onsite child care for patients attending outpatient appointments and treatment.

There is a significant lack of access to social work support in the ambulatory care settings in both the public and private sectors, with these services tending to be swamped by the needs of inpatients, with little time to attend to the comparatively larger outpatient population.

Given their skill mix, social workers experienced in the cancer field, are well placed to assess and triage psychosocial and practical needs, and to guide patients to mobilize their individual coping strategies and resources. It would seem that routine social work assessment of all patients in the outpatient setting may help to address psychosocial distress in its early stages, with the aim of preventing the development of serious psychological morbidity.



Concerns Regarding Access to “Best Practice” Multidisciplinary Psychosocial Care in the Private Sector

A significant proportion of patients diagnosed and treated for cancer in Western Australia, are managed wholly or partially in the private sector. Patients often presume that they will be offered the “best” care as a result of their financial outlay. However, particularly in the outpatient setting, they may be cared for by only one or two individual clinicians, without the benefit of multidisciplinary input or attention to their psychosocial needs, as would be considered appropriate for “best practice” cancer care (The National Breast Cancer Centre, 2005).

Furthermore, clinicians and patients in the private sector may have concerns about the additional costs of accessing psychosocial support, particularly when these services may not be funded by Medicare and may add to the additional financial burden of their cancer treatment.

It is therefore important to ensure that the development of a model of care for the psychosocial care of patients with cancer (and their families) is applicable across both public and private settings and takes into account the significant proportion of patients who will receive the majority of their care in the busy ambulatory setting.

It is also essential to ensure patients cared for in the private setting have equitable access to government funded specialist clinical Cancer Nurses and social workers, to assist with information provision, continuity of care, screening for psychosocial distress and triaging and referral for psychosocial support.

Survivorship

As treatment regimes advance, many patients are now living with cancer as a chronic illness and facing the significant psychosocial burden of survivorship without formalized support. Cancer survivors may face significant physical, financial and occupational hardship in the years following cancer treatment, with resultant high rates of psychological morbidity (Dow, Ferrell, Haberman & Eaton, 1999).

Whilst services such as the Cancer Council of Western Australia (TCCWA) and Solaris Care have identified this as an area of unmet need and are now offering survivors limited access to programs which discuss these issues, there is no formalized approach to screening for this morbidity and assisting patients to regain their sense of well-being.

Summary

In summary, there is currently no adequate consistent statewide process of systematic assessment and follow up of patients and families’ psychosocial needs and well-being in the setting of cancer care, despite the recognition that these experiences carry a high risk of significant psychological morbidity and impact adversely on quality of life.

Primary, secondary and tertiary healthcare centres and Non Government Organisations have services that provide psychosocial support to cancer patients. However, many cancer clinicians are not aware of these services or the relevant referral pathways. Furthermore, there are few formalized mechanisms of communication between these psychosocial service providers, with resultant potential for loss of continuity of care and loss to follow-up.



There are significant systemic pressures and workforce issues which contribute to under-diagnosis of psychosocial distress, and to increased levels of workplace stress for clinicians working in the field of cancer care.

However, there are a number of recent initiatives that aim to improve the psychosocial care of cancer patients in W.A., and it is hoped that this model of care will assist with the identification of strategies that can be incorporated into routine care to identify and care for patients in need of psychosocial support.

1.4 Guiding Principles for a Psycho-Oncology Model of Care

- 1.** All people affected by cancer should have the right, and are likely to benefit from, having their social, psychological, emotional, spiritual and functional needs treated as an integral part of their overall cancer care.
- 2.** All patients with cancer and their families and carers, should have equitable access to psycho-social care, regardless of their geographic location or cultural or linguistic background.
- 3.** Care of cancer patients should be patient centred and responsive to each individual patient / carer / family's needs and priorities.
- 4.** Attention to psychosocial wellbeing should remain a priority across the cancer journey from screening through diagnosis and treatment, recurrence or transition to palliative care and cancer survivorship.
- 5.** Cancer care should be provided in settings that are family friendly and that recognise the special needs of families with young children or specific cultural background. The physical environment should recognise the right of individuals to privacy and confidentiality when discussing personal issues
- 6.** Psychosocial care should be a shared responsibility of all clinicians working with the person affected by cancer; with each clinician able to make a valued contribution to care (within the limits of their role and expertise).
- 7.** All patients undergoing cancer care should have access to multidisciplinary input in order to optimize patient care. Clinicians should relate as an interdisciplinary team, including regular case discussion and contribution to the patient's integrated medical record.
- 8.** All clinicians working in the field of cancer care should be encouraged to develop and practice effective communication skills and assessment for psycho-social issues. Staff should be aware of risk factors for psychosocial distress and points of vulnerability for distress within the cancer journey.
- 9.** Clinicians providing specialized psycho-social support should have experience working within the cancer field, or should have access to guidance by other professionals with such experience.
- 10.** Evidence-based assessment and intervention strategies should be utilized in the provision of psychosocial care to patients and their families.
- 11.** A culture of reflective practice should envelope all cancer services, particularly in the realm of psychosocial care provision – this should include clinical supervision, quality improvement processes assessing the effectiveness of interventions and service performance/achievement of core aims and objectives, and benchmarking service performance.
- 12.** Consumers of cancer services should be given meaningful opportunities to participate in service development and quality improvement activities



1.5 Defining Psychosocial Distress

The U.S. based National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines in Oncology (Holland & Anderson et al. 2007) define “Distress” as:

“a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears, to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crises.” (Holland & Anderson et al, 2007, pg DIS-2)

The NCCN Guidelines indicate that the overriding goal of their “Standards of Care for Distress Management” (Holland & Anderson et al, 2007, pg MS-2) is to ensure that no patient with distress goes unrecognized and untreated. They further report that their first principle of care is that “distress, like pain, should be recognized, monitored, documented, and promptly treated at all stages” (Breitbart, 1995).

A balance of risk and protective factors for the level of distress and quality of life of the person with cancer and their family can be inferred from the research reviewed in The NBCC & NCCI Clinical Practice Guidelines (2003, See Table 3.7D pg 98).

Examples of protective factors identified include:

- hopefulness,
- access to a social support network,
- active and problem-solving focused coping which includes emotional expression,
- flexibly adaptive coping responses, and
- identification with others who are seen to be improving/de-identification with others who are not doing well in their cancer treatment.

Alternatively, examples of psychosocial factors that increase people’s risk of distress include those who:

- are of a younger age,
- prefer to use coping strategies which include avoidance of emotions and stressors
- desire to maintain a high degree of control.
- experience loss of hopefulness (often related to clinical uncertainty)
- experience restriction in access to social and leisure activities

The Need for Psychosocial Care

Psychosocial health services are psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological / behavioural and social aspects of illness and its consequences so as to promote better physical health and quality of life. (Institute of Medicine of the National Academies (IOM), 2007) The Institute of Medicine Guidelines state that “Attending to psychosocial needs should be an integral part of quality cancer care... It is not possible to deliver good-quality cancer care without addressing patient’s psychosocial health needs.”



The IOM committee identified a common framework for the effective delivery of psychosocial health services; (IOM, 2007):

1. Identify psychosocial needs
2. Link patients and families to services
3. Support patients and families in managing illness
4. Coordinate psychosocial and biomedical health care
5. Follow up on care delivery to monitor the effectiveness of services

Furthermore, they identify a number of psychosocial needs common to cancer patients and their families and identify relevant programs and services to assist in managing these needs;

- **Understanding of illness, treatments and services** – strategies to improve patient-provider education eg. Written information, cancer nurse coordinators etc.
- **Coping with emotions surrounding illness and treatment** – peer support groups, counselling / psychotherapy, pharmacological management of symptoms
- **Managing illness and health** – comprehensive self-management / self-care programs
- **Behavioural change to minimise disease impact** – behavioural / health promotion interventions such as smoking cessation assistance, patient education etc.
- **Managing disruptions in work, school and family life** – family and caregiver education, assistance with Activities of Daily Living.
- **Financial assistance** – Financial planning, info re: wills, eligibility and assistance with applications for disability pension, carer's allowance etc.

Evidence is accumulating to suggest that psychological therapies improve emotional adjustment and social functioning, and reduce both treatment and disease-related distress in patients with cancer. Recent meta-analyses of randomized controlled trials conducted on psychological therapies demonstrated the efficacy of both supportive and cognitive behavioural therapies in the treatment of depressive disorders in patients with cancer (Devine & Westlake, 1995; Sheard & Maguire, 1996) and the efficacy of both individual and group therapies. (Sheard & Maguire, 1996)

The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (NBCC & NCCI, 2003), report a meta-analysis of 116 intervention studies which 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. (Devine & Westlake, 1995)

Thus, there is good evidence to support the need for psychosocial support for cancer patients in Western Australia and an existing framework of services in place to provide this support. However, challenges remain regarding strategies to identify psychosocial distress in its early stages, and to direct patients and their carers / families to the appropriate resources in a timely manner.

With this in mind, the Psycho Oncology collaborative has developed a proposed patient pathway, with suggestions regarding elements of best practice psychosocial care that should be incorporated within the cancer journey for all patients and their carers / families.



Figure 1. Patient Pathway

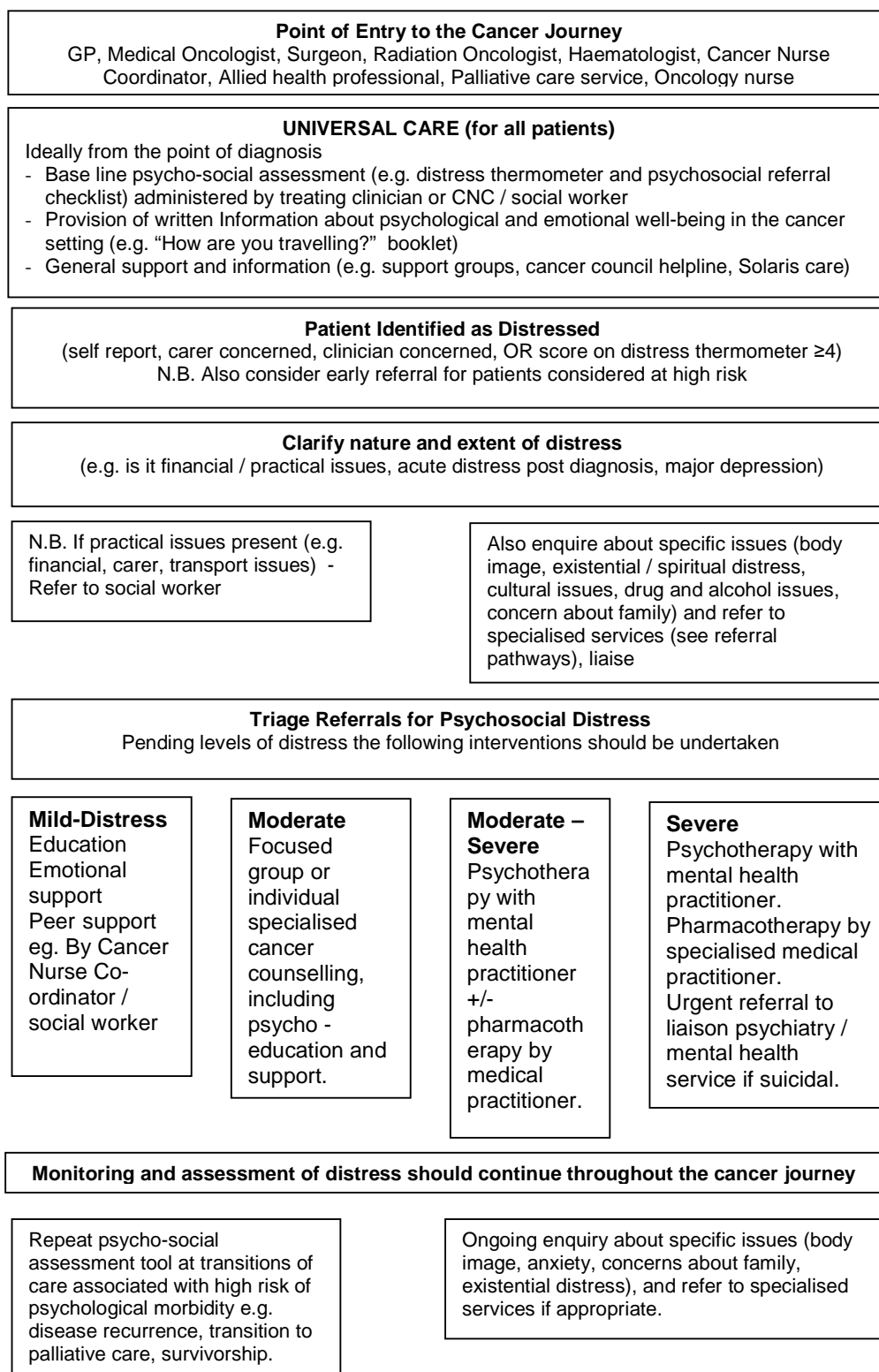


Figure 1 Adapted from:
 (Hutchinson, Suzanne, & Dunn, 2006; and NBCC & NCCI, 2003)



2. Model of Care

2.1 Point of Entry

This section refers to the point of entry into the health care system at which all patients should have the opportunity to be screened for psychological distress. The point of entry varies for each patient and may begin in the community with a GP or may occur in the public or private setting following referral to medical specialists and allied health professionals.

2.2 Universal care

These processes should be provided for all patients with a cancer diagnosis, and should be performed at the point of entry into the cancer journey; in both private and public sectors and in both inpatient and outpatient settings.

Screening and Assessment for Psychosocial Distress

a) Psychometric tools

The NCCN standards for managing distress suggest that “all patients should be screened to ascertain their level of distress at the initial visit, at appropriate intervals, and as clinically indicated, especially when changes occur in disease status (remission, recurrence or progression)” (NCCN Guidelines - Holland & Anderson et al, 2007 pg MS-2). They go on to assert that “systematic screening may prove to be essential for the early evaluation and effective management of psychological distress in cancer patients” (NCCN, 2007 pg MS-1) as supported by the research of Carlson and Bultz (2003) and Zabora (1998). Furthermore, during screening, the overall nature of distress, as well as the sources of distress, should be identified.

The National Breast and Ovarian Cancer Centre (NBOCC) published in August 2007, a “Psychosocial Care Referral Checklist” (National Breast and Ovarian Cancer Centre (NBOCC), 2007) and recommended that this should be administered at initial presentation, in conjunction with the National Comprehensive Cancer Network (NCCN) Distress Thermometer Screening tool. (NCCN Guidelines Holland & Anderson et al, 2007, DIS-A)

Explanation of the Distress Thermometer

Several “ultra short” methods have been developed to screen for distress in cancer patients. The most well known is the Distress Thermometer, which is similar to the rating scale used to measure pain: 0 (no distress) to 10 (extreme distress). This method has been validated by several studies. (Roth, Kornblith & Batel-Copel et al, 1998; Ransom, Jacobsen & Booth-Jones, 2006; Patrick-Miller, Broccoli, Much & Levine, 2004; Jacobsen, Donovan & Trask et al, 2005; and Hoffman, Zevon, D’Arrigo & Cecchini, 2004).

The distress thermometer serves as a rough single-item question screen. The patient places a mark on the scale answering “How distressed have you been during the past week on a scale of 0 to 10?” (See Appendix 2).

Scores of 4 or more indicate a significant level of distress that should be further evaluated. The distress thermometer has been validated based on comparisons of these scores with the previously validated Hospital Anxiety and Depression Scale (HADS).



In addition, a “Problem List” which is on the same page as the Distress Thermometer, asks patients to identify their problems: physical, practical (eg. transportation, financial), psychological, social or spiritual.

To ensure that distress in cancer patients is recognized, the NCCN panel recommends that all patients be assessed in the waiting room using the “Distress Thermometer” to assess the level of distress and the accompanying “Problem List” to identify the causes of distress (NCCN Guidelines Holland & Anderson et al, 2007, MS-4).

Psychosocial Care Referral Checklist

The items listed on the checklist are those identified in the Clinical Practice Guidelines for the psychosocial care of adults with cancer (NBCC & NCCI, 2003) as being important indicators of psychosocial distress for a patient with cancer, and particularly those at increased risk for distress. (see Appendix 3 for NBCC Psychosocial Care Referral Checklist & Appendix 4 for the NBCC Explanatory Notes to the Checklist).

Risk Factors for Psychosocial Distress:

- Younger than 55 years
- Single / separated / divorced / widowed
- Lives alone / relationship or family problems / lack of social support
- Children Younger than 21 years
- Financial Concerns / issues
- Previous episodes of depression / psychiatric illness / mental health problems
- History of stressful life events
- Problems related to drugs or alcohol
- Female gender

The results of the above screening tools should be reviewed by the oncologist, cancer nurse and/or social worker and clarifying questions asked. Concerns expressed by carers / family members and other health professionals involved in the care of an individual regarding observed (but perhaps unreported) distress should also be taken in to account.

The recommended action to be taken following detection of significant psychosocial distress will depend on the nature and extent of that distress. This is further outlined on page 17 of this document.

N.B. It should be noted that the both the NCCN “Distress Thermometer” and the NBOCC Psychosocial Referral Checklist are protected by copyright and cannot be published or distributed without obtaining the permission of the NCCN / NBOCC respectively. This will be of relevance with respect to publishing this Model of Care Document, and with commencing widespread screening using these tools.

It should also be noted that whilst the above recommendations regarding screening protocols are based on high quality peer reviewed evidence based research. Application of these tools to a West Australian cancer population should be trialed initially in a pilot setting, with opportunities for consumer and clinician feedback, and tracking of impact on downstream services to ensure that adequate provisions are made to meet any additional demand generated by screening.



b) Psycho-Educational Materials

Education of patients and their families regarding normal emotional responses to cancer diagnosis and treatment can contribute significantly to reducing the perceived stigma of psychosocial distress.

In addition education can aid in identifying signs and symptoms suggestive of more severe distress which would warrant further input. With this in mind, all patients should have the opportunity to discuss “normal” emotional reactions to the cancer journey and should be provided with a copy of the NBOCC-produced booklet “Cancer, How are you travelling?” (National Breast Cancer Centre (NBCC), 2007). (see appendix 5)

c) General Information Provision

Where available, patients should be routinely provided with specific language-appropriate written information regarding their tumour type and likely treatments as have been produced by the health department of Western Australia for a number of cancers such as bowel and prostate.

All patients (and their carers / families), should be routinely advised at their point of entry to the cancer journey, of the contact details for relevant community and institution based organizations such as the Cancer Council of Western Australia, which provides a frequently updated telephone and web-based resource for comprehensive information regarding a wide range of supports. In addition, the SolarisCare Foundation Cancer Support Centres are hospital based information resource centres that are also able to provide links to many other support networks in Western Australia.

Where appropriate, patients and their families / carers should be notified of specific government-sponsored organizations providing high quality information for tumour-specific groups, such as the Leukaemia Foundation, the Prostate Cancer Association and the National Breast and Ovarian Cancer Centre.

2.3 Clarify Nature and Extent of Distress

The Psycho-Oncology Collaborative proposes that, identification of the type of distress and relevant psychosocial needs should be clarified by the treating clinician, clinical cancer nurse or social worker, via an in-depth assessment with the patient which incorporates;

- Development of an empathic rapport with the patient via use of strategies outlined in the NBCC & NCCI Clinical Guidelines tables 3.1 and 3.3A (see appendices 6 and 7) (NBCC & NCCI, 2003, p. 42, 70).
- Identified needs from the Distress Thermometer and psycho-social checklist.
- Sensitively asking the patient about the presence of vulnerability factors
- Identifying family and carer's concerns.

The combination of these components allows for the type of distress to be clarified so that it can be addressed comprehensively.

It should be noted that the effectiveness of any intervention is predicated on the capacity of the intervention to be tailored to the individual patient/family's range of psychosocial needs, the balance of risk and protective factors and their psychosocial history.

This is challenging as the group of people affected by cancer is as diverse as the general population, taking in people across the lifespan, from different socio-



cultural, socio-economic and spiritual backgrounds, of both genders and different sexualities, with varying familial, health and educational histories. The array of types of cancer and stages in the disease trajectory being experienced further compound the degree of diversity among the population.

Not only is the cancer population diverse but the myriad of psycho-social services and the variety of settings from which these are administered is also complex. Hutchison, Steginga and Dunn (2006), writing from a Queensland perspective, acknowledge an emerging diversity of psychosocial services being offered to people affected by cancer in both government acute care settings and non-government and/or community based services. They propose a “stepped care approach” where screening and “triage or treatment matching” activities are used to educate people affected by cancer about service options and link them with appropriate levels of psychosocial care.

It should be noted that this tiered model of psychosocial interventions does not utilise numerical scores such as those generated by the “Distress Thermometer”, but instead relies on the health professional performing the assessment, to determine the severity of needs. It would be envisaged that whilst the proposed screening tool would utilise the validated numerical value of 4 or greater as indicative of significant distress, the specific numerical value beyond this would be interpreted in light of further clarification and identification of distress via the above mentioned methods and thus identify appropriate levels of intervention.



Figure 2. Tiered Intervention Model for Psychosocial Interventions

Adapted from Hutchison, Steginga & Dunn (2006, p. 534).

Level of Distress /Complexity of Need	Methods	Relevant Services	Example of Psychosocial Issue
Minimal-mild	General Information Sharing	Primary Care Team Telephone help-lines Printed & audiovisual productions	Side-effects of medications/treatments. Practical concerns
Mild-moderate	Psychoeducation & emotional support Peer support	Hospital or community based support programs, eg. cancer social worker, clinical nurse co-ordinator, Telephone help-lines	Treatment decision making Problem solving and coping strategies
Moderate	Focused individual, couple, family or group counselling including psychoeducation and support	Cancer specific hospital and / or community based counselling services	Adjustment to cancer, grief Stress management Coping skills
Moderate to severe	Psychotherapy , Couple & Relationship Therapy, or Family therapy with mental health practitioner	Hospital/community based psychotherapy services specialized in the needs of cancer patients and their carers / families.	Mood & anxiety disorders, Trauma, relationship and sexuality problems
Severe	Psychotherapy with mental health practitioner Pharmacotherapy by medical practitioner	Specialist Community and hospital based mental health or psycho-oncology teams; Psychiatric Inpatient facilities	Multiple, complex psychiatric difficulties Risk issues Severe personality and relationship functioning

This concept of a **tiered model of psychosocial care** individualises level and type of psychosocial support according to individual patient need and preference. In addition, this model promotes integration of services across multiple tiers, allowing health professionals to provide care within their scope of practice, and to refer to other resources when appropriate. (Hutchison, Steginga & Dunn, 2006).

It should be noted that the proposed formalised application of such a tiered model of psychosocial care to Western Australia would warrant further research regarding the impact of such a framework on the provision of care within our local setting.



2.4 Who Should Provide Psychosocial Support?

Each person a patient encounters in their cancer journey should reasonably represent an opportunity to address psychosocial needs and/or facilitated linkage with indicated services. This would require that all health professionals, and support workers affiliated with the care of the patient across the cancer journey:

- Acknowledge a shared responsibility for, and can make a valuable contribution to the holistic psychosocial care of people affected by cancer
- Maintain fundamental levels of knowledge and competency around psychosocial issues, assessment and counselling, and knowledge of referral/resource options
- Have efficient access to specialized information and intervention services when their expertise or resources cannot match the person's need.

However, it is important to emphasise that some members of the treating team should have specialized experience in managing the psychosocial needs of patients with cancer and their carers / families. These individuals may represent a number of disciplines as outlined below, but should ideally meet as a multidisciplinary team in conjunction with nursing and medical staff on a regular basis, to in order to improve interdisciplinary communication and optimize patient care.

2.5 Management of Mild Distress

Mild distress (i.e. a score of less than 4 on the distress thermometer) may represent what the NCCN panel terms “expected distress” (NCCN Guidelines Holland & Anderson et al, 2007 MS-5) symptoms as part of the “normal” response to cancer diagnosis and treatment, for example:

- Fears, worry and uncertainty about the future
- Concerns about the illness and treatment effects and side effects
- Sadness about loss of good health
- Anger and the feeling that life is out of control
- Poor sleep, poor appetite and poor concentration
- Preoccupation with thoughts of illness and death.

It should be noted that these symptoms are particularly troublesome during the times of greatest uncertainty in the cancer journey eg:

- during a workup for a suspicious symptom
- at a time of diagnosis; when awaiting treatment
- during arduous treatment cycles
- at the end of treatment when paradoxical anxiety and distress occur
- before follow-up visits with the oncologist
- with minor symptoms that could reflect recurrence
- with major symptoms that impact upon quality of life, such as poorly controlled pain and nausea
- actual recurrence
- progression of disease
- transition to palliative or hospice care
- awareness of end of life.



If these symptoms are not particularly distressing or prolonged, they can be routinely managed by the treating clinician / team. However, the quality of the physician's communication with the patient is paramount, and this should occur in the context of a mutually respectful relationship in which enough time is set aside for asking questions and for putting the patient at ease (Ryan, Scholfield, Cockburn et al, 2005).

The NCCN guidelines also emphasise that it is important for the treating clinician / oncology team to acknowledge that this is a difficult experience for the patient and that distress is normal and expected. "Being able to express distress to the staff relieves it somewhat and builds trust." (NCCN Guidelines Holland & Anderson et al, 2007).

Patients may benefit from specific written information regarding the emotional impact of cancer. The "Cancer – How are you travelling?" booklet produced by the NBOCC (2007) offers some strategies for managing these symptoms.

The treating clinician / team is also responsible for ensuring that social supports are in place for the patient and that the patient is informed about community resources such as the Cancer Council of W.A. telephone helpline and website, and relevant support groups.

2.6 Management of Significant Psychosocial Distress

If the patient's distress is moderate or severe (score on distress thermometer of 4 or above), this should be used as a trigger to prompt referral for a more in depth assessment by the clinician or by the social worker or clinical cancer nurse.

Social Workers

Social workers in the cancer setting have an ideal mix of skills to enable them to undertake both initial and comprehensive psychosocial assessments and to triage patients and refer accordingly for other psychosocial services.

In addition to specialized skills for identification of psychosocial distress (including an ability to perform a mental health risk assessment), and awareness of available psychosocial resources and practical supports; social workers are trained to approach management of psychosocial distress from a systemic approach which considers the needs of the individual patient within the context of their carer and family functioning and wider cultural or community network.

Social workers may provide support for mild psychosocial distress by using patient and family education, support groups, grief counselling and by suggesting local resources. For moderate to severe psychosocial distress, counselling and supportive psychotherapeutic techniques may be used, community resources are mobilized, problem-solving is taught; and advocacy, education and protective services are made available.

As the "medical model" tends to be patient focused, the important role of provision of support for carers and families is often undertaken by social workers. For example, specialized Palliative Care social workers may assist families (and patients) by addressing end of life issues, providing support and counselling in relation to grief and loss and providing bereavement follow-up even after an individual patient has died.

It should be emphasized that concerns about costs and availability of and access to services may add significantly 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. In some settings, Welfare assistants are able to assist social workers to address the welfare needs of patients and their families such as arranging financial assistance, transport etc.

The NCCN Guidelines outline a number of areas of practical and psychosocial distress in which social workers can provide important input. (Holland & Anderson, 2007, pg MS-7).

Practical problems include:

- illness related concerns
- concrete needs eg. Housing, food, financial assistance, help with activities of daily living, transportation
- employment, school or career concerns
- cultural or language issues and caregiver availability

Psychosocial problems include:

- adjustment to illness
- family conflicts and isolation
- issues regarding discussion of illness with partner and family, particularly dependent children
- difficulties in decision-making
- quality of life issues
- domestic abuse and neglect
- coping or communication skills
- functional changes eg. Body image, sexuality)
- issues pertaining to end of life and bereavement (including cultural and caregiver concerns)

It should be noted that at the present time in Western Australia social work services are significantly under resourced in both inpatient and outpatient cancer settings, and as a result, referral for social work input tends to occur in response to crises or as a component of discharge planning, in a reactive rather than a proactive way. The incorporation of a routine screening tool and assessment process such as that outlined above for all patients, would necessarily require a significant increase in access to social work service for both public and private facilities in both inpatient and outpatient settings.

However, it is hoped that the process of screening in itself may assist to validate the presence of psychosocial distress for many patients and identify available resources, and may therefore be therapeutic in itself. In addition, it is proposed that early detection of psychosocial distress may allow for early intervention, thus reducing the severity and duration of distress experienced by patients and their carers / families and potentially reducing unwarranted emergency department and outpatient visits due to anxiety and inpatient crisis admissions.



Cancer Nurses

Cancer Nurse Coordinators (also referred to as Clinical Cancer Nurses) are well placed to assist with reducing the psychosocial impact of cancer on the patient and their families.

1. By assessing patients and family members.
2. Identification of unmet needs
3. Providing a point of contact across and between services at any time in the trajectory of a patient's cancer journey.
4. Anticipation of supportive needs in the immediate and longer term.
5. Referral to services for psychological and relational (couple and family counselling) support

The CNC acts as a point of contact for both cancer patients and health professionals. They are able to provide support including psycho social support for patients and their families throughout the cancer journey as well as assisting patients to navigate the health care system and to signpost and refer patients to available oncology services. The CNC is also able to provide disease specific information for patients and help them to understand what their treatment involves and what the possible side effects are.

Cancer nurses are well placed to identify patients and families / carers at risk during transition points of the cancer journey, particularly relapse and recurrence, or moving from curative to palliative intent of treatment. Cancer Nurses often work closely with social workers, to whom they refer for more comprehensive psychosocial assessments.

In addition, the CNC role is working towards improving communication between health service providers in the metropolitan area and aiming to ensure a streamlined approach to communication between services throughout metropolitan and rural Western Australia.

2.7 The Role of General Practitioners

General Practitioners play an important role in the cancer journey for many patients. G.Ps are often involved in the initial diagnosis of cancer, but are all too often "lost" off the list of addressees for correspondence as patients are referred between departments and practitioners across multiple sites and settings, or receive letters months after the date of consultation due to administrative delays.

As a result, G.P.s are often not informed in a timely fashion of changes in their patient's wellbeing or of significant transitions in care eg. from curative to palliative intent. This can significantly impact on the psychosocial care of their patient and their carers / families, as G.Ps often have extensive knowledge of a patient's background such as family circumstances and social history, comorbid physical and mental health issues, and response to previous treatments etc., and are ideally placed to provide monitoring of psychosocial well-being in the longer term for cancer survivors, those living with cancer as a chronic illness and providing follow-up of carers and family members in the setting of grief and bereavement.

G.P.s should have the opportunity to take an increasing role in the provision of multidisciplinary cancer care, with improved communication via fax ,phone, mail and email and potentially for particularly complex patients, with attendance at multidisciplinary meetings either face to face or via teleconferencing (utilising the



appropriate medicare provider numbers for case conferences). In addition, GP's should have the opportunity to engage in shared-care arrangements with the W.A. Psycho-Oncology Service and Consultation Liaison Psychiatry services.

The Psycho-oncology Collaborative recommends that GP Divisions should include educational programs highlighting the psychosocial impact of the cancer journey with further training offered in techniques to assist patients, carers and families in the negotiation of this journey.

2.8 Management of Moderate to Severe Distress

It is important to note that the treating clinician or team should also be aware of a number of concerning symptoms that would warrant further evaluation. These include:

- Excessive worries and fears
- Excessive sadness
- Unclear thinking
- Despair and hopelessness
- Severe family problems
- Spiritual crises
- Suicidal ideation
- Psychotic phenomena

Depending on the problems identified in the "Problem List" and issues identified in the psychosocial referral checklist, this may assist with triaging the patient for more specific psychosocial interventions.

The NBCC & NCCI Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (NBCC & NCCI, 2003) alert us to a proportion of people affected by cancer who experience clinically significant levels of distress, who may require more intensive and specialized psychological interventions.

For this group of patients referral on to additional services / clinicians for specialized interventions may be appropriate, as outlined below, in the comprehensive table included in the NBCC & NCCI Guidelines.



3. Referral for Specialised Interventions

A Guide to appropriate referral and specialized interventions for specific problems
(Adapted from NBCC & NCCI Guidelines, 2003, Table 4.1A p. 103)

Figure 3. Appropriate Referral and Specialized interventions for specific problems.

Problem	Discipline to refer	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; alone or in combination
Depression	Clinical psychologist/ Psychiatrist	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.
	Social worker*	
Suicidal ideation	Psychiatrist	Thorough assessment, identification and treatment of any specific stressors including pain, other physical symptoms, delirium. Treatment of identified depression, anxiety
PTSD	Clinical psychologist/ Psychiatrist	Cognitive behavioural therapy; supportive psychotherapy (including existential therapy), often in combination with antidepressants such as SSRIs
Body image concerns	Clinical psychologist/ Psychiatrist	Cognitive behavioural therapy; supportive psychotherapy; crisis interventions; complementary therapies, eg exercise. Treatment of depression or anxiety with can compound the body image distress
	Social worker*	
Sexuality concerns	Clinical psychologist/ Psychiatrist	Personal and or couples counselling
	Social worker *	Endocrine assessment and or therapy if hormonal basis for the problem appears likely
	Endocrinologist	
Interpersonal problems	Clinical psychologist/ Psychiatrist	Couples counselling; family counselling
	Social worker *	



Problem	Discipline to refer	Specialised interventions with demonstrated effectiveness
Severe emotional problems	Clinical psychologist/ Psychiatrist	Cognitive behavioural therapy; supportive psychotherapy
Physical symptoms	Clinical psychologist/ Psychiatrist Social worker *	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 specialties listed above, there may be other local practitioners trained in the interventions listed eg occupational therapists, cancer counselors / psychotherapists / specialist nurses. Many GPs will also have trained in the above interventions.

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



3.1 Referral to Other Disciplines

Any approach to optimising psychosocial well-being of cancer patients (and their carers / families) from a holistic perspective, must include attention to spiritual well-being also. This is particularly important given the existential nature of many questions raised by a diagnosis of cancer and the “meaning” of this for an individual and their carer / family.

Pastoral Care Services

The importance of spiritual issues contributing to psychospiritual suffering and impacting upon health should not be underestimated. Issues of meaning may become important for many patients and their families following a cancer diagnosis, and this is particularly relevant during the transition to end of life care.

In a crisis many people prefer to talk with a person from their own spiritual or religious community. Today, most chaplains in WA have training in pastoral counselling and are available to provide support to any patient who may benefit from their assistance.

The inclusion of pastoral services/chaplaincy as a referral resource is important as the diagnosis of cancer can lead to a crisis of faith or belief. Some patients may question their life up to this moment, or wonder why they have cancer. Others, may feel that a higher power is punishing them, or has abandoned them for now. Some may use their religious and spiritual resources as a means to cope with their illness, using prayer as a major source of help.

The chaplain may address any of the following symptoms or concerns:

- Grief
- Concerns about death, and the afterlife.
- Conflicts or challenged belief systems.
- Loss of faith
- Concerns about the relationship with a deity/God
- Isolation from the religious community
- Guilt
- Hopelessness
- Conflict between beliefs and recommended treatment
- Ritual needs.

(Adapted from NCC Guidelines, Holland & Anderson et al, 2007, pg DIS-19)

In many of the above cases the patient may find it easier to talk to a chaplain, rather than to a representative of their own faith. Chaplaincy services are available onsite through each of the main teaching and religiously-based private hospitals. In reach services are available in rural and regional areas via liaison with local hospitals and in community settings via local religious groups and by home-based palliative care organisation such as Silver Chain Hospice Care Service.

Furthermore, there is a growing trend toward increasing undergraduate medical exposure to pastoral care issues (for example the University of Western Australia optional 5th year training in “Spirituality, suffering and Healing”). In light of this trend and the importance of improving access for health professionals of all disciplines to training in this field, the recent suspension of the Clinical Pastoral Education (CPE) training programme at Royal Perth Hospital is of significant concern. It will be



important to ensure that the new cancer centres include adequate space and resources to ensure that patients are able to access pastoral support and CPE training is maintained.

Counselling for Patients, Carers and Families

Counselling is a collaborative process that involves the development of a unique, confidential helping relationship. The counsellor acts as a facilitator in helping clients to understand feelings, behaviours, relationships with others, situations, choices and decisions. Further, the counsellor offers a safe, confidential and non-judgmental context in which patients and their carers / family members can:

- Gain clarity and perspective on a particular issue;
- Receive the support they need to resolve issues and make decisions;
- Deal with negative feelings and emotions;
- Explore personal resources and develop new skills.

Counselling has broad applications in the cancer setting, as patients and their families face multiple practical and emotional challenges throughout their cancer journey, and must adjust to multiple and varied losses, such as the loss of good health, financial and occupational losses, loss of usual roles in families and relationships etc.

It should be noted that the level of training and experience can vary significantly between individuals identifying with the term “counsellor”, particularly with respect to specific experience assisting patients with cancer and their carers / families. It is therefore imperative that services providing counselling support in the cancer setting have mechanisms by which they can accredit the skills of those working within their organization and provide opportunities for clinical supervision and reflection.

The Psycho-Oncology Collaborative proposes that counsellors working in the cancer field must be university qualified, with significant post graduate experience including specialist training in grief, loss and bereavement and must possess membership of a professional association such as PACFA (Psychotherapy and Counselling Federation of Australia.)

Counselling Services Provided by Non-Government Organisations in W.A.

There are a number of non-government organizations that provide free or subsidized counselling to cancer patients and their carers / families in W.A. These make up an essential component of the network of psychosocial support resources for the state, as health department funded resources alone are insufficient to meet demand and many patients prefer to receive psychosocial care outside of the hospital setting, closer to their home environments.

The first of these organizations is the Cancer Council of W.A., which has its own service of specialized counsellors experienced in issues related to managing cancer. TCCWA offers subsidized counselling for individuals, couples, families, children and adolescents, both face to face at their location in Shenton Park and by telephone in limited circumstances in which individuals are unable for health or practical reasons to attend in person.

In addition, TCCWA offers subsidized counselling for rural and remote patients and families, via a network of accredited private counsellors around the state, who have specialized cancer experience. Patients and carers / families can self refer to



these services after contacting the Cancer Council, or can be referred by health practitioners.

TCCWA is also the major telephone based information resource for the state, maintaining up to date contact information for a number of cancer-related services such as wig libraries and peer support groups, in addition to general information regarding cancer screening, diagnosis and treatment, and are often a starting point for many patients and family members following diagnosis.

Silver Chain Hospice Care Service (SCHCS) is another important Non-government organisation providing specialized counselling services to cancer patients and their carers / families, both from their bases located throughout the metropolitan area and in the home setting for patients who are receiving palliative care from the service, particularly those who are terminally ill. This access to home-based support and the opportunity to die at home supported by palliative care services, may also have significant benefits for the psychosocial well-being of many cancer patients and their families.

The SCHCS counselling service participates in multidisciplinary meetings with the treating hospice team where appropriate, to ensure psychosocial needs of patients and their carers / families are maintained as a focus of care. Representative nursing staff from SCHCS regularly attend multidisciplinary team meetings for oncology and palliative care services, to optimize communication between the hospital inpatient, hospice and home-based care settings.

SCHCS also provides time-limited free grief and bereavement counselling and support prior to and following the death of a family member, and is one of the few resources in the state to provide grief and bereavement support to children.

Other specialized non-government organizations such as the Leukaemia Foundation and CANTEEN are also able to offer limited access to specialized counselling, in addition to peer support programs not only for patients and carers, but also for children and siblings affected by a cancer diagnosis within the family.

Organisations such as The Cancer Council of W.A. and the Leukaemia Foundation are also able to offer limited financial and practical assistance for patients and families under significant strain, particularly with respect to subsidizing transport and accommodation costs.

An additional psychosocial support resource for cancer patients and their carers is the SolarisCare Foundation (currently at Sir Charles Gairdner Hospital and the St John of God Cancer Centre), which provides information about cancer, accommodation and transport options, links with local and national cancer support groups, and access to an onsite lounge, library and kitchen facilities for cancer patients and their carers attending the hospital, with a 'listening ear' from dedicated volunteers. The Foundation also provides inpatient and outpatient integrative (complementary) touch-based therapies and encourages rigorous scientific research into the use of these in the cancer setting.

3.2 Specialist Clinical Psychology Services

Clinical psychologists seek to understand the nature of an individual's psychological distress and work collaboratively toward reducing this via an approach which involves:

- Assessing the emotional, intellectual and behavioural functioning of the patient



- Exploring the thoughts, emotions and behaviour of the patient and tracing their origins
- Helping the patient develop effective ways of controlling and coping with these difficulties
- Helping the patient to implement changes that enhance wellbeing and awareness, and alleviate the presenting problems.

Typical referrals seen by clinical psychologists working in the cancer setting include:

- Depression.
- Needle phobia or other phobias that interfere with treatment and recovery eg. anticipatory nausea and vomiting.
- Anxiety (e.g., about treatment, recurrence, the future).
- Adjustment difficulties (including complicated grief).
- Body image disturbance.
- Relationship or sexuality issues
- Unmanageable distress related to mortality and life threatening illness.

Treatments utilized include a number of evidence-based formalized therapies such as cognitive behavioural therapy and interpersonal therapy, in addition to supportive and psychodynamic psychotherapeutic techniques.

The NBCC & NCCI Clinical Guidelines for the Psychosocial care of Adults with Cancer, include a “Summary of Interventions” for managing significant psychological distress in the cancer setting, which outlines a number of these therapies (many of which are offered by clinical psychologists).



(Adapted from NBCC and NCCI Clinical Guidelines for the Psychosocial Care of Adults With Cancer (2003) Table 4.1B Pg. 105):

Figure 4. “Types of intervention and their impact on patients with cancer”

Type	Description/Benefits
Cognitive behavioural therapy	<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 a psychiatric morbidity; Decrease in nausea, vomiting and insomnia; Increase in control over illness.</p>
Supportive psychotherapy	<p>Encourages the expression of emotions, validates the experiences of the individual, and offers support through empathetic 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>
Group therapy	<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>
Family therapy	<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>
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. Beneficial in increasing sexual satisfaction.</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>



Type	Description/Benefits
Other therapies	Other therapies may include art therapies, eg music, painting, reading and poetry, wellness programs, medication, hypnosis, acupuncture, relaxation, exercise, prayer, laughter etc. Improvement in mood, coping, anxiety, depression, breathing; Reduction in nausea, pain.
Other specialist services	Includes speech therapy, physiotherapy, occupational therapy, dentistry, endocrine therapy, plastic surgery, reconstructive surgery, nutritionist, fertility services, specialised pain services. Target specific physical symptoms or impairments resulting from the disease or treatment. Assist in reducing pain, restoring or improving physical functioning or appearance.

W.A. Psycho-Oncology Service

The W.A. Psycho-Oncology Service is an initiative of the Department of Health to improve patient care in this state. It is a state-wide service that provides free evidence-based psychological services to both private and public health system patients and their families who have been affected by cancer within 5 years of diagnosis. Patients can be referred by health professionals, including nursing and allied health staff, or can self refer.

The Service provides comprehensive psychological assessment and individual, couple, family and group psychotherapy treatments that are tailored to the particular problems identified. Clinical psychologists do not offer psychiatric medications for the treatment of psychological distress but can identify where these are indicated and make appropriate referral. Nor does the service manage patients with comorbid substance dependence or longstanding complex mental health problems, however, these patients can be linked with other available resources in the community.

At present the W.A. Psycho oncology Service, and other related clinical psychology services, do not respond to acute crises, such as psychiatric emergencies in which a person is in acute danger of harm to self or others (these patients are currently referred to consultation-liaison psychiatry or to the emergency department of major hospitals). However, the duty officer is able to provide phone based support for individuals in acute emotional distress that is not life-threatening, and refer for further assessment or support as appropriate.

At the present time, the W.A. Psycho-Oncology Service is limited to providing service in the outpatient setting from its base in Shenton Park. However, with additional funding, there would be scope to expand this service to the inpatient setting also, to ensure that patients requiring specialized psychological therapies during prolonged inpatient admissions can access these appropriately and to ensure continuity of care for patients who may be intermittently receiving cancer treatments in both the inpatient and outpatient settings.

Expansion of the service to the inpatient setting, with attendance of clinical psychologists at major medical oncology, radiation oncology and haematology multidisciplinary meetings, may increase clinician awareness of the service and



prompt referral of appropriate patients in a setting which fosters interdisciplinary communication.

In addition, there may be scope to expand the current service to include outreach opportunities to outer metropolitan areas, provided that the opportunity for formal and informal supervision with peers at a centralized base remains.

Other Psychology Resources for Cancer Patients and their Carers / Families

The W.A. Psycho-Oncology Service operates in addition to other specialized clinical and counselling psychology services based at major teaching hospitals, such as the Breast cancer Psychology Service at Royal Perth Hospital, and the Department of Psychological Medicine at King Edward Memorial Hospital.

It should be noted also that some cancer patients and their families will access private clinical psychology input in the community, and that some private clinical psychologists have extensive experience in the cancer setting.

However, as Medicare-subsidized access to clinical psychology input becomes more widespread as a result of the General Practitioner based “Better Outcomes in Mental Health” funding, it may become increasingly important to ensure patients and clinicians alike are aware of the potential benefits of referral to a practitioner with specialized cancer experience, with a means of identifying these individuals within the community.

3.3 Psychiatric Care in the Cancer Setting

Although emotional distress in people with cancer is normally occasional and time-limited, some people experience more severe emotional reactions. “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.” (NBCC & NCCL, 2003, pg 19)

Liaison psychiatry services offered by each of the main teaching hospitals, and by specific individuals in the private sector, tend to utilize a “BioPsychoSocial” approach to the differential diagnosis and management of significant psychological / psychiatric distress. This approach emphasises the need for a comprehensive assessment of factors that may contribute to psychosocial distress and psychological morbidity, including biological factors related to disease or treatment effects which may precipitate or exacerbate mood symptoms.

Comprehensive psychiatric care encompasses psychotherapeutic strategies in addition to pharmacotherapeutic strategies. Liaison Psychiatrists are often well placed to co-ordinate multidisciplinary psychosocial supports, particularly for more complex patients, and to liaise with the treating medical teams..

Anxiety

Anxiety is a common symptom in the cancer setting, particularly at times of waiting for results of diagnostic tests or transitions of care from curative to palliative intent etc. The majority of this anxiety will respond to relaxation strategies, reassurance and support. Some will require use of specific interventions such as desensitization techniques or cognitive behavioural therapy.

However, the treatment of moderate / severe acute anxiety states resulting in significant functional impairment may require 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 effects (Massie & Lesko, 1990).

Depression

A diagnosis of a major depressive episode in cancer 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. (Massie, 1989). 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." (NBCC & NCCI, 2003, pg 21).

The treatment of moderate to severe depression should incorporate psychotherapeutic interventions and the use of medication. There is clear evidence of the efficacy of antidepressant medication in treating depression in the medically unwell, including patients with cancer. (Gill & Hatcher, 2000; and Goodnick & Hernandez, 2000).

There is no evidence that any particular antidepressant is superior to any other. Starting with a low dose of the drug and increasing the dose slowly is likely to minimize the occurrence of side-effects. (NBCC & NCCI, 2003).

Suicide

Sensitive exploration of suicidal thoughts, plans and access to means is crucial for any patient who acknowledges severe low mood and feelings of hopelessness. Risk factors for suicide include severely depressed mood, a family history of completed suicide, past history of self-harm and a history of alcohol and 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 (Chochinov, Wilson, Enns & Lander, 1998). Urgent psychiatric consultation should be considered for any patient who appears at risk of suicide. This can be arranged via teaching hospital liaison psychiatry services (or emergency department services after hours) or via community mental health triage services in rural areas.

Complex Mental Health Needs

Mental health service / psychiatric liaison service input should also be routinely considered for patients with complex past psychiatric history, behaviours that are difficult to manage in the inpatient / outpatient setting, co-morbid substance abuse and those for whom issues of capacity to consent to treatment are of concern.

At present the most significant limitation on patient access to psychiatric support in the cancer setting, is a workforce shortage of psychiatrists, training registrars and mental health nurses in the in consultation liaison psychiatry services. This shortage has resulted in many services being able to provide only initial assessment and follow-up in the inpatient medical setting, with limited scope for providing assessment or follow-up for outpatients within many services. This situation is similar in the private setting, where the number of psychiatrists with specific experience in the cancer setting is limited.



Patients with cancer in the community care or outpatient settings experiencing acute severe distress are often referred to busy hospital emergency departments to await assessment by a duty psychiatry liaison nurse or registrar, often with significant delays. This situation is less than ideal, and highlights the need for improved staffing and training of consultation liaison psychiatry services and emergency psychiatric response teams to allow timely and comprehensive response, with appropriate follow-up for patients with complex mental health needs.

3.4 The Need for Co-operation Between Psychosocial Support Services

Appendix 1 outlines the referral pathways for the major health department and NGO funded services providing support for adult cancer patients and their families in Western Australia.

Whilst there is some overlap between services, this is warranted given the potentially complex care needs of cancer patients, who may transition through care in numerous settings during the course of their cancer journey, for example a single patient may potentially undergo:

- Diagnosis in the primary care setting with initial emotional support from their GP
- Referral to the cancer council of W.A. Counselling service for family support regarding adjustment to diagnosis
- Ambulatory outpatient assessment at a medical oncologists's private rooms
- Referral to a teaching hospital for specialized chemo or radiotherapy
- Tertiary hospital assessment by a social worker to assist with practical needs
- Assessment by a tumour specific or rural cancer nurse co-ordinator
- In-patient admission in the setting of a disease-related complication
- Referral to hospital liaison psychiatry services for management of depression / anxiety
- Referral to W.A. Psycho-Oncology Service for specialized techniques for management of anticipatory nausea and vomiting
- Referral to a teaching hospital palliative care service for assistance with management of physical symptoms contributing to anxiety
- Silver Chain Hospice Care Counselling Service follow-up in the home, for support regarding adjustment to change in treatment focus to palliative care
- Referral for chaplaincy input to assist with existential issues in the context of terminal care
- Hospice admission for respite or terminal care
- Bereavement counselling for family post patient-death through silver chain hospice care service.

During their cancer journey, a patient and/or their family may also access support from numerous non-government organizations such as information regarding cancer and access to financial support via the Cancer Council of Western Australia or on site emotional support via the SolarisCare Complementary Cancer Care Centres at Sir Charles Gairdner Hospital and St John of God Hospital, Subiaco.

Thus, there may be a number of services providing psychosocial support in different forms to a patient and / or their carer / family at any one time. Whilst maintenance of patient privacy and confidentiality should remain a priority, it would be helpful to improve communication between services, (perhaps in a manner



similar to the attendance of Silver chain Hospice Care Staff at teaching hospital Oncology and palliative care multidisciplinary meetings) to ensure that patients with significant psychosocial distress are not lost to follow-up simply due to a change in setting of care.

This issue requires further consideration and may benefit from a focused discussion with relevant stakeholders at a future date, to determine ways in which communication between services may be improved.

Existing community services that would need to be considered in fostering cooperative links should include (but would not necessarily be limited to):

- The Cancer Council of WA – various services, the most pertinent being their Counselling Services (metro and rural) and Helpline
- The Cancer Support Association
- SolarisCare Foundation Cancer Support Centres (SCGH and Subiaco SJOGH)
- Leukaemia Foundation nurse counsellors and counselling psychologist
- Silver Chain Hospice Care Service
- Carers W.A.

In addition, there are a number of existing department of health services that would need to be considered in fostering cooperative links. These include:

- WA Psycho-Oncology Service (WAPOS)
- Statewide Clinical Psychology Service for Breast Cancer (based at RPH)
- Consultation-Liaison Psychiatry (RPH, SCGH, Fremantle)
- Palliative Care Services (RPH, SCGH, Fremantle, HPH, SJOGH Murdoch, Bethesda)
- Social Work Services (RPH, SCGH, Fremantle, KEMH, SJOGH Subiaco and Murdoch, Hollywood Private Hospital, Mount Hospital, Bethesda, Joondalup etc.)
- Clinical Psychology and Liaison Psychiatry Service (KEMH)
- Haematology Counselling Psychology Service (SCGH)
- Nurse Counsellors as part of in-patient services (RPH)
- Cancer Nurse Coordinators (CNC's)
- Rural Cancer Nurses



4. Specific Areas for Consideration of Psychosocial Care Needs

4.1 Children of parents with cancer

At the present time, there is no standard mechanism by which patients with cancer in Western Australia are asked if they have dependent children. This is of concern because patients with children must cope not only with the effects of cancer, but also with concerns about the emotional impact on their family. In addition, parents with cancer have practical demands on their time and concerns about issues of child care which can have a major impact on their health and ability to attend appointments and complete treatments.

There is a current gap in service provision relating to children. Children are not routinely included when parents are offered psychosocial support in adult treatment centres and in current treatment models of cancer care (Osborne, 2007). This omission reflects a lack of consideration of the potential for distress in children and the impact this has upon their parents that needs to be addressed in services planning and provision at all levels.

Routine assessment of the psychosocial needs of families including the children of a parent with cancer need to be a standard part of service provision starting from the point of initial diagnosis and offered at significant points of transition throughout the cancer journey. Early intervention can encourage families to improve links with primary care providers and provision of information can empower parents and children to cope more effectively and to seek help more readily when needed (Hoke, 2001).

Clinical findings from research show that parents as a natural response, attempt to protect their children by omitting the information that their disease is cancer, not realising that the omission can increase their children's anxiety. Children's levels of understanding of illness have been reported by Rushforth, (1999), as being greater than initially believed. Children are able to sense when they are being excluded from information and may respond with changes in behaviour. Osborne (2007) reported that:

“Factors related to school aged children experiencing emotional or behavioural change seem to be related to maternal depression and poor family communication rather than the treatment status of the parent or time since diagnosis. Family variables, especially family communication/expressiveness, are consistently associated with psychosocial functioning”.

In terms of direct service provision, parents should routinely be offered strategies to help them talk to their children about cancer and to educate them about the amount and type of information that children of differing developmental stages can understand.

Information about illness, normal reactions to illness effective coping strategies preventative support and genetic counselling for children should be routinely offered during initial assessments. As part of this assessment families can be routinely screened for high risk factors identified from the literature such as low socio economic status, maternal depression and poor communication styles and offered targeted interventions via the multidisciplinary team.



In addition, parents should be offered practical and financial assistance to manage child care arrangements whilst attending for treatment and during inpatient stays.

Referral and linkages with the primary sector such as school psychologists can be made, to facilitate awareness of schools regarding the additional stressors on children and their families. Specialised support groups such as CANTEEN are able to offer support to teenagers and young adults who have a parent or other carer with a cancer diagnosis. At present there are limited services for young children of parents with cancer. The developmental needs of this group are particularly important, and subsidised access to specialised play therapy services for these children and their parents may be appropriate. Family-centred help should be available and accessible to all families throughout the cancer journey.

As the patient's illness progresses the need for information practical support and adjustment counselling for the person with cancer and their family may increase, and may need to be provided by practitioners experienced in this field in the tertiary sector.

Romer et al. (2007) reported that interventions for children of parents with cancer are beneficial in preventing future mental health problems. These services may need to continue over some years at different developmental stages.

Further research into the needs of dependent children of parents with cancer is currently underway by staff at the Western Australia Centre for Cancer and Palliative Care (Curtin University of Technology). It is hoped that this research will help to identify areas of unmet need with the aim of informing future service development for these families.

4.2 Psychosocial care of the child and adolescent with cancer and their families

Whilst rare, a diagnosis of cancer in children and adolescents is a devastating event that has far reaching effects on the individual and on their immediate and extended family. Every effort should be undertaken to maintain a child or adolescent's normal psychosocial development and activities, to reduce the long term impact and potential for psychosocial morbidity later in life.

The National Institute for Health and Clinical Excellence (2005) acknowledge that the evidence for the best model of psychosocial care of children and young people with cancer is poor. However, they recommend comprehensive and coordinated psychosocial care is provided by appropriately skilled and trained clinical professionals in a centralised, age-appropriate specialist cancer treatment centre. This is supported by the Children's Oncology Group/SIOP/ guidelines for psychosocial care of the child with cancer (Armstrong & Reaman, 2005).

Comprehensive psychosocial multi-disciplinary care and support should be provided to children and young people with cancer in WA, in accordance with the Paediatric and Adolescent Cancer Model of Care. Assessment should be undertaken at key time points in the disease and treatment by a skilled multi-disciplinary team.

At the present time, Princess Margaret Hospital, the major service provider for children's cancer care in Western Australia, has a comprehensive multidisciplinary dedicated to identifying and meeting the psychosocial needs of children with cancer and their families. This team is funded with a combination of state and non-government organisation contributions.



The unique nature of children's cancer care, and the need to take into account differing developmental stages and information needs, usually precludes application of the same screening techniques outlined above in the adult setting. However, ongoing attention to needs assessment and screening of children and their families in accordance with "best practice" guidelines remains a strong focus for both the Psycho-Oncology and Paediatric and Adolescent tumour collaborative of the WACPCN.

Cancer-related medical sequelae are only one of many factors contributing to childhood cancer survivors' health status. The childhood cancer experience also may produce chronic psychological and cognitive impairments that hinder posttreatment adjustment and adversely affect quality of life, with 10% to 20% of individuals showing signs of psychological maladjustment, manifested as mood disturbances, behavioral problems, and somatic distress. (Zeltzer et al 1997), (Zebrack et al 2002), (Elkin et al 1997) and (Chen, E, 1998)

As the new adult cancer centres are designed and developed, it will be important to ensure that adequate resources are allocated for adolescent survivors of childhood cancers as they transition to adult services.

4.3 Services for Rural and Remote Patients

It is recognised that patients from rural and remote areas, (especially those in WA), have a range of poorer outcomes in cancer, including mortality, morbidity, access and completion of appropriate treatments and access to information. Other aspects of care such as multidisciplinary care, patients support, and access to psychosocial intervention are also less than optimal for those living outside metropolitan Perth.

Formalised mental health services are limited in many areas of rural and remote Western Australia, and those that do exist are often overwhelmed by high acuity mental illness or have limited experience in supporting patients facing psychosocial distress as a result of cancer diagnosis and treatment.

At the present time, Rural Cancer Nurses, palliative care services and subsidised counsellors accredited by the Cancer Council of WA would appear to provide the bulk of psychosocial support to patients in rural and remote Western Australia. The Cancer Council of Western Australia has recognised a need for increasing patient support activity and will continue to subsidise psychosocial support in the country although it was noted in 2005 that this is not as widely used as may be needed.

Further support by the Area Health Services is vital, in particular provision of local psychology and other support services and improved training of existing clinical staff in recognition and management of psychosocial distress, in keeping with the goals outlined by the WA Health Cancer Services Taskforce, (2005, pg. 21, 23).

The W.A. Psycho-Oncology Service has recently commenced offering telephone-based follow-up of patients from rural and regional areas (ideally following an initial face to face meeting). Clinicians and cancer health professionals of all disciplines should be encouraged to notify their patients and their carers / families of these available services and initiate referral when appropriate.

4.4 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. A study conducted in three major Australian oncology clinics found that 22% of patients reported using alternative therapies, and of these patients, 40% had not told their



clinician about this. (Begbie, Kerestes & Bell, 1996) In this study, the reasons given for using alternative therapies included; the need for a new source of hope, a preference for “natural” therapies, a desire to try something different and achieving a greater sense of personal involvement. “For many patients, feeling they can assume some control of their disease is psychologically empowering”. (NBCC & NCCI, 2003, pg. 58).

The NBCC & NCCI Guidelines (2003) assert that “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 should be explored with all patients who use alternative therapies. It should be noted that the majority of alternative therapies have not been assessed for safety and efficacy in randomised clinical trials.

Complementary Therapies

Those therapies that do not replace or preclude concurrent conventional medical therapies are termed “complementary therapies”. These include many different approaches often with the promotion of a mind-body connection.

However there is building evidence for the efficacy of “touch-based” complementary therapies for both patients and carers as a component of psychosocial care in the cancer setting. The growing use of integrative care (including Integrative Oncology) in major hospitals throughout the Western world is becoming widely accepted as having a place in mainstream care (Cassileth, 2005).

The main focus of these therapies is to improve the quality of life and symptom control of cancer patients as they journey through their diagnosis, treatment and recovery from cancer (Joske, Rao & Kristjanson, 2006). Modalities such as physical exercise (Samad, Taylor, Marshall & Chapman, 2004), reiki, acupuncture (Cassileth, 2005; and Richardson et al, 2005), mind-body medicine, massage and music therapy are safe and effective. Acceptance of complementary therapies by the general public is quite high (Cassileth, 2005).

An example of a hospital based patient-centred drop-in centre offering complementary therapies in Australia is the SolarisCare Foundation based at Sir Charles Gairdner Hospital and St John Of God Hospital. Anecdotally, patients to these services have reported benefits of the co-location of the service on site with medical treatments, including the informal “drop-in” nature of facilities providing support such as a cup of tea and a sympathetic ear after receiving bad news or whilst awaiting medical treatments and appointments.

Given the reported benefits to patients with respect to well-being and quality of life (Joske, Rao, Kristjanson 2006), consideration should be given to funding expansion of the SolarisCare Foundation services to other hospital sites.

Health Professionals should be given opportunities for education regarding the potential benefits of complementary therapies to cancer patients and their carers / families and the mechanisms of referral to these services, and further funding should be provided to enable evidence-based recommendations regarding the use of complementary therapies.



4.5 Psychosocial Care of Families and Carers of People with Cancer

Relatives and other unpaid caregivers who provide informal care in the home, providing assistance with transport to and from appointments and assisting with activities of daily living are major sources of support for people with cancer.

The nature of the care-giver burden may change throughout the cancer journey, and carers may spend many years meeting the complex care needs for their loved ones, often at the expense of their own physical, social and emotional health (Aoun et al *The Social Impact of Caring for Terminally Ill People in Australia*, Palliative Care Australia, 2004).

The contribution of carers to the economy and sustainability of the health system is enormous. With this in mind, there should be policy developments in the taxation, social security and income / pension benefit domains to ease the financial hardship of carers (Aoun et al, Palliative Care Australia, 2004).

Carers should have access to coordinated service funding and service provision across all levels of government (federal, state and local) to ensure equitable social and geographical distribution of services. Education at a community level should be encouraged, to promote the social value of caring and an awareness of the demands and impact of the caring role.

There should be education of health professionals at both the undergraduate and post graduate level, regarding the specific needs of carers, and to improve communication and awareness of and timely access to support services. Staff should be encouraged to take the time to elicit and address carer concerns and questions regarding cancer diagnosis and management, and to keep them abreast of changes in disease status and management plans.

Oncology and Palliative Care Services can assist by providing educational materials and courses that are geared specifically to caregivers, regarding information about specific skills and tasks such as safe manual handling techniques, dispensing medications, assisting with personal hygiene etc., in addition to self care strategies and support services. Currently there are some carers courses offered through TCCWA and the Solaris Foundation Cancer Care services. Awareness of these programs should be increased.

Specialized strategies should be developed which address the needs of special groups such as younger and older carers, those from indigenous and CALD backgrounds, those living in rural areas and those with chronically disabling cancers where access to medium stay palliative care is limited (Aoun et al, Palliative Care Australia, 2004). All carers of patients with cancer should have ready access to in-home and specialized respite care services.

Partnerships and collaborations should be developed between government, service providers, GPs and families to ensure an adequate support network for carers and to enable early detection and assistance for psychosocial distress within this group.

4.6 The Psychosocial Care of People From Culturally and Linguistically Diverse Backgrounds (CALD)

Patient and their families from CALD backgrounds may have specific needs which have not been understood or systematically addressed by policy makers, the health care sector and the general population. At present it is not possible to



clearly identify the number of patients diagnosed and treated for cancer in Western Australia who are of CALD backgrounds.

Endeavours should therefore be made to identify and engage patients of cancer services from CALD backgrounds and to explore and document specific issues of cultural sensitivity in the cancer care setting for major CALD groups, with this information made readily available to health care professionals.

Service providers should be given training to address specific issues of concern to CALD patients and their families, such as; the cultural meaning of a cancer diagnosis, preferences regarding cross-gender communication and examination, issues associated with faith and those surrounding dying and handling of the body after death.

Cancer patients (and their carers / families) of CALD background, should have ready access to free on-site and telephone interpreting when accessing medical and psychosocial services to enable appropriate communication of medical information and provision of informed consent. The use of experienced professional interpreters should be routine in the cancer care setting across all stages of the cancer journey, to ensure unnecessary stress is not placed on family members to convey complex medical or emotionally sensitive information.

CALD patients and their families may have additional psychological stressors related to the possibility of death away from their culture, their homeland and their ancestors. Attempts should be made to be sensitive to these concerns and to accommodate culturally sensitive rituals and practices where possible.

Aoun et al. (2004) noted that “CALD patients and their families may only seek help for psychosocial distress when they are at crisis point and not before. For carers particularly, asking for help may be seen as a failing not only in one’s caring role, but also in failing the family, the community and most importantly, the person with the illness.”

A high level of surveillance should therefore be maintained for psychosocial distress appearing in patients of CALD backgrounds and their carers / families, with appropriate supports offered pro-actively in a culturally sensitive way. Links should be developed and maintained between cancer service providers and transcultural mental health providers to ensure psychosocial support can be provided to patients, carers and their families in a culturally sensitive manner.

4.7 Sexuality, Body Image and Cancer

Sexual Health is the experience of the ongoing process of physical, psychological, and socio-cultural well-being related to sexuality. (WHO, 2000). Body image is developed in childhood and reinforced by societal attitudes, values and the media. It is intensely personal, tied to our relationships with others and linked with self-concept, sexuality, sexual expression, self esteem and emotions. Our body image and sexuality are shaped by the social, economic, political, religious and cultural climates in which we live.

Cancer has in recent years been described as a ‘chronic’ rather than fatal disease, with a shift and increased emphasis on quality of life issues of which sexuality is a leading aspect (Graziottin, 2001). A diagnosis of cancer, followed by surgery, chemotherapy, radiotherapy or endocrine therapy can have a profound effect both physically and emotionally on body image and sexuality (NBCC & NCCI C, 2003).



It is with this in mind that a 'whole of person' approach to cancer and palliative care cannot exclude the effect this may have on a person's body image and sexuality (see Table 6). The extent of these effects is not governed by age or extent of treatment, but rather by the effect that has on the individual and significant others (Yee & Sundquist, 2003).

Figure 5. Type and prevalence of sexual problems reported by patients with different types of cancer

(NBCC & NCCI Guidelines, 2003.)

Sexual Problem	Cancer Type	Prevalence
Loss of libido, change in sexual activity, decreased satisfaction/orgasm	Breast cancer	10-50%
	Head and neck	39-74%
	Laryngeal	60%
	Prostate	43-51%
	Lung	48%
	Gynaecological	No% given
Sexual dysfunction (vaginal dryness, vaginal bleeding, stenosis, dyspareunia, atrophic vaginitis, pain)	Gynaecological	66% No% given
	Colorectal	20%
Erectile dysfunction and ejaculation dysfunction (premature, retrograde or dry ejaculation)	Colorectal (with stoma)	62-88%
	Prostate	41-91%
	Testicular	25-70%
	Hodgkins Disease	

The Literature shows (Sundquist & Yee, 2003):

- Sexuality concerns of cancer patients are not being adequately addressed
- Clinicians find sexuality a difficult topic to discuss with patients
- Clinicians report a lack of knowledge and skills in this area
- Clinicians think that it is someone else's job to talk about it with the patient.

Barriers for Health Professionals include (Sundquist & Yee, 2003):

- Find it a difficult topic to discuss
- Report a lack of training, knowledge and skills
- Think that it is someone else's job to talk about it
- Lack the time
- Lack a private space to talk to patients
- Fear intruding into deeply personal matters
- Are embarrassed (age, gender, behavioural and cultural differences)

WHO suggests clinicians take the lead in addressing sexual health concerns of patients (Kingsberg, 2006), but communication about sexuality and intimacy without adequate resources and training leads to mismatched expectations and unmet needs (Hordern & Street, 2007).

Several models have been developed to initiate discussions with patients about their body changes, their intimate relationships and their sexuality regardless of



their age or situation. Clinicians working in the cancer field should be encouraged to consider the impact of cancer diagnosis and treatment on the sexual well-being of their patients, and should be equipped with the appropriate skills and knowledge to do enquire about this for all patients in a sensitive manner.

There is anecdotal evidence to suggest that health professionals do not discuss these issues with patients and their carers. Therefore, research needs to be conducted to determine whether this is the case, and to develop resources to assist health professionals to adequately address these issues throughout the patient's cancer experience.

Further sources of information are available and include;

- Cancer Helpline 13 11 20
- Clinical practice guidelines for the psychosocial care of adults with cancer
- PLISSIT Model
- The C.A.R.E. Approach
- National training programs such as "Talking about Sexuality, Body Image and Cancer" (TCCWA).

Based on the above information, the Psycho-Oncology Collaborative proposes the following recommendations for the incorporation of Body Image and Sexuality Issues into routine cancer care:

- A whole of person approach to cancer and palliative care must include recognition of the effects on an individual's body image and sexuality.
- Clinicians & health providers should be offered education opportunities to be aware of the prevalence of sexual problems reported by cancer patients.
- Clinicians & health providers should be offered training to develop the knowledge and skills to discuss sexuality and body image with patients.
- Assessment of sexuality and intimacy should be part of a holistic patient assessment at each consultation.
- Clinicians & health providers need to be aware of services available to refer patients to for supportive care related to sexuality and intimacy.

4.8 Aboriginal and Torres Strait Islander Cancer Patients

'Health is not just the physical wellbeing of the individual but the social, emotional and cultural well being of the whole community. This is a whole of life view and it also includes the cyclical concept of life-death-life' (The National Aboriginal Health Strategy, 1989).

Cancer Services in ATSI communities has not been a priority throughout Australia for many years as the incidence of Cancer has not had such an impact as Diabetes, Heart Disease and Renal failure. However more Aboriginal patients diagnosed with Cancer die from the disease than in the non Aboriginal population (Thomson & Irvine, 2001). Cancer is mainly a disease of older adults. Life expectancy for ATSI peoples is some 17 years below that of other Australians. So as life expectancy increases, the diagnosis of Cancer would be expected to increase in this population.

Numerous National and state Government reports and documents state that in order for the health of Aboriginal people to improve, it is imperative to take a holistic approach in order to achieve better health outcomes (The National Aboriginal Health Strategy, 1989).



An example of the necessity to take a holistic approach is that of Cancer survivorship of country and remote area patients. There is clear evidence that country patient's survivorship is less than in the city. The most disadvantaged are the ATSI population. Many, for family and cultural reasons, may only attend or do not attend for prolonged appointments or choose not to commence treatment.

In order to address these issues a Model of Care for Cancer should adopt the principles of the (AHMAC, 2004). These principles should be applied throughout the Cancer Journey for ATSI patients.

Recommendations arising from these principles would include:

- Mandatory cross-cultural awareness training for all staff which includes components on culture, language, spiritual beliefs and individual diversity. There are many common issues among Aboriginal cancer patients - late presentation; increasing incidence; high mortality; reluctance to access, comply or complete treatments; lack of appropriate, sensitive support systems and spiritual beliefs into the causes of cancer. Health professionals should be sensitive to these cultural differences.

Use of specific strategies to ensure clear communication throughout the patient's journey, should also be incorporated, such as:

- Endeavouring to obtain an interpreter who speaks the same language and dialect as the patient, and who themselves has a sufficient level of English to understand and accurately interpret information regarding medical terminology, consequences of cancer, treatment outcomes or side-effects to enable informed consent.
- Use of clear simple words without being condescending; use of non-threatening language with awareness of potential differing interpretations of the meaning of words. Comprehension should be reassessed frequently during the consultation.
- Awareness of the importance of non verbal communication – for example, nodding does not necessarily imply agreement or comprehension - it may be an effort to obtain a period of silence to enable further contemplation of the information provided. Direct eye contact may make people uncomfortable – and can be considered rude in some Aboriginal communities.
- ATSI patients may have particular concerns regarding issues of privacy – and may not comfortable talking about 'personal' things in front of strangers (including student doctors etc) They may misinterpret communication between health professionals that is out of context as pertaining to them.
- Respect is a crucial element of establishing rapport. Asking about practical considerations / support is important in order to understand potential barriers to completing the recommended treatment regimen – eg. Availability of transport to and from appointments, financial constraints (may be supporting two households), cultural and family issues such as the need to attend funerals of family members etc.

At the present time, it is difficult for an individual clinician in many consultation settings, to identify any specific culturally appropriate resources to support patients of Aboriginal and Torres Strait Islander background. Endeavours should be made to develop an information line or similar resource that can assist clinicians to access appropriate psychosocial support for their patients in both metropolitan and rural and remote areas.



4.9 Education and training

Care for Cancer Clinicians

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.

The clinical care of patients with severe, disabling or life-threatening conditions such as cancer, poses special burdens for staff, and this issue is often neglected. (NBCC & NCCI Guidelines, 2003) High levels of stress are reported among oncologists (Wippen & Canellos, 1991) and oncology nursing staff. Levels are higher among staff who are younger, feel less supported in the ward (Yasko, 1983; and Jenkins & Ostchega, 1986) and more recent graduates (Wilkinson, 1994).

Treating the dying is recognised as a potent source of stress (Kent, Willis, Faulkner et al, 1994). Staff may feel immersed in suffering with little respite from the demands of displaying warmth and empathy towards others (Abeloff, 1991)

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 (NBCC & NCCI, 2003).

Strategies for coping must include attention to training of health professionals that traditionally has offered little preparation for the intensity of grief, anger frustration and resentment that may be displayed by families facing a devastating diagnosis (Davaux, Razavi & Farvacques, 1988).

Specialist medical colleges are increasingly endorsing the need for enhanced communication skills for members, to improve the provision of information and emotional support for patients and their families as those who feel insufficiently trained in communication and management skills have higher levels of stress (Ramirez, Graham, Richards et al, 1995; and NBCC & NCCI, 2003).

In addition, all clinicians involved in the care of cancer patients may benefit from the opportunity to attend clinical supervision with a senior clinician experienced in psycho-oncology, to reflect upon occupational challenges and debrief regarding particular cases. This should be funded within cancer services.

In addition, there is a role for developing the skills and knowledge of the existing workforce, with specialised undergraduate and postgraduate training programs for counsellors, social workers, psychologists and psychiatrists, in the management of specific psychological morbidity in cancer patients and their families.

The Role of Allied Health Professionals

For the majority of cancer patients and their carers / families, the cancer journey often involves contact with a number of allied health professionals who, due to the nature of their care, may well see the patient on a more frequent basis than the medical and nursing staff.

The important contribution of these individuals to the psychosocial support of cancer patients and their carers / families should not be underestimated.



Landmark qualitative research on living with a chronic condition also highlights three aspects that the patient must manage:

- the disease/symptoms
- the emotional consequences
- the impact on daily function/life roles (Corbin & Strauss, 1985).

Occupational therapists, physiotherapists, community nurses and nutritionists have a valued role to play in assisting patients to manage symptoms and impact on daily life roles. Examples include rehabilitation to better maintain or regain independence in self care; modifications to homes; self-management programmes for common cancer symptoms (e.g. fatigue), pain management techniques, lymphoedema care; graded exercise programs; carer education; and nutritional advice. In addition there is evidence to support the involvement of specially trained art and music therapists to enable non-verbal expansion of psychosocial distress and aid relaxation (Meyer & Mark, 1995; and Zimmerman, Pozehl Duncan et al, 1989).

While these interventions are included in algorithms for best practice (such as the NCCN Practice Guidelines in Oncology: Cancer-Related Fatigue), the mechanisms to ensure patients' access to such services do not yet exist (NCCN, 2007; and Cancer WA, 2007) nor do mechanisms to allow multiple professionals to communicate with each other or the patient.

The continuity of care provided by these individuals often makes them ideal candidates for identifying psychosocial distress in its early stages and encouraging patients and carers / families with whom they have already developed a rapport, to seek further input regarding their psychosocial needs.

With this in mind, we should be ensuring that allied health professionals receive appropriate training in the identification of psychosocial distress in the cancer setting and are made aware of available resources and appropriate referral mechanisms to these.

Furthermore, the high emotional burden of caring for cancer patients and their families should be taken into account for these disciplines also, with provision made for opportunities to debrief and reflect in a supportive environment.

4.10 Grief and bereavement services

The NBCC & NCCI Guidelines (2003) note that while historically, "grieving has been facilitated through families, church, funeral rituals and other social customs, the reduced emphasis on such formalities may make it more difficult for some people to deal with the thoughts and feelings of grief" (pg 83).

Parkes (1998) notes that 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, and that in these instances, the bereaved person is at high risk of ongoing stress. The 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 (Raphael, 1984). With this in mind, formalised approaches to grief and bereavement follow up are becoming more commonplace across cancer service providers, particularly hospice facilities and palliative care services. However, this is an area that warrants further review to ensure that all



cancer care providers have some means of acknowledging patient deaths and providing families and carers with the opportunity of further contact.

Furthermore, carers and families should be routinely advised of opportunities for accessing free and subsidised grief and bereavement counselling through services such as Silver Chain Hospice Service, particularly for young children who may be grieving the loss of a parent or grandparent.



5. Research

The importance of empirical research to guide practice has been clearly established by the development and implementation of the NBCC & NCCI Clinical Practice Guidelines for the Psycho-social Care of Adults with Cancer (2003). Current research, Australia wide and in WA, spans a large range of topics across the illness trajectory, including bereavement support, for patients, families and carers. This research also adopts a diverse variety of approaches and methodologies.

However, more research in this area is required and more funding is needed to address these priorities. The WA Psycho-Oncology collaborative has worked towards establishing research goals and priorities over the past two years. The key areas that have been articulated are:

- Identifying the specific needs of cancer patients from Culturally and Linguistically Diverse groups (CALD)
- Improving the sensitivity of cancer services to the needs of patients from Aboriginal and Torres Strait (ATSI) backgrounds, particularly those from remote Western Australia.
- Development of Programs to address the psychosocial wellbeing of carers of people living with cancer
- Developing psychosocial services for patients and carers living in rural and remote areas
- Identifying strategies to meet the needs of children of parents with cancer
- Improving the psychological wellbeing of adolescents and young adults with cancer, with identification of strategies to reduce the risk of long term psychological morbidity
- Exploring the psychosocial impact of cancer on people with increased risk such as young people and people with chronic debilitating disease, with development of appropriate resources
- Improving allied health professionals' understandings of psychological, social and spiritual support in the oncology domain and pathways for appropriate referral
- Use of systematized screening tools for psycho-social assessment
- Incorporating principles of "best practice" multidisciplinary cancer care across inpatient and outpatient settings in both public and private settings.
- Optimising the role of health professionals in discussing sexual and interpersonal issues with patients
- Exploring the needs of cancer survivors, and those living with cancer as a chronic debilitating illness

The following organisations are recognised as setting the benchmarks for national and international research into the psychosocial needs of cancer patients and their carers / families.

- National Breast and Ovarian Cancer Centre (NBOCC), www.nbcc.org.au
- Psycho-Oncology Cooperative Research Group (PoCoG), www.pocog.org.au
- International Psycho-Oncology Society (IPOS), www.ipos-society.org
- American Psychosocial Oncology Society (APOS), www.apos-society.org
- National Cancer Institute, www.cancer.gov



Clinicians, together with researchers based at the Universities located in Western Australia are well equipped to conduct further research and improve services in the areas identified, provided they have access to appropriate funding and resources.



6. Conclusion and Final Recommendations

The psychosocial care of patients with cancer and their family and carers should be recognised as an essential component cancer care, having a significant impact on quality of life throughout all stages of the cancer journey, from screening and prevention, to survivorship or palliative care and grief and bereavement. This principle should inform cancer service development across all levels including:

Education of Patients

- Increasing the awareness of cancer patients (and their carers / families) of the emotional impact of cancer and the resources that can be utilised to manage this, via written and verbal information from health professionals provided at the point of entry to the cancer journey

Education and Training of Health Professionals

- Education and up-skilling of the cancer care workforce regarding identification of psychosocial distress and improving communication skills to optimise patient-health professional interactions via expansion of the NBOCC “Communication Skills Workshops” and use of professional development forums

Formalising Attention to Psychosocial Needs Within All Models of Care

- Formalising incorporation of attention to psychosocial needs of patients (and their carers / families) within Models of Care and clinical pathways of care for all tumour groups

Systematised Psychosocial Screening

- Adoption of evidence-based screening techniques to identify psychosocial distress, with provision of sufficient time within consultations and appropriate physical environments with respect to privacy to enable screening to be done sensitively

Improving Clinician and Patient Awareness of Psychosocial Resources

- Pro active strategies to increase clinician and patient awareness of specific government and non-government resources providing psychosocial support
- Formal Distribution of the WACPCN “Referral Pathways” document outlining psychosocial service providers and their contact details, to all clinicians involved in providing cancer care

Improve Communication and Continuity Between Psychosocial Service Providers

- The complex array of commonwealth, state and privately funded organisations providing psychosocial care for cancer patients and their families should be identified and recognised as providing essential components of psychosocial care in settings beyond the confines of public teaching hospitals. Endeavours should be made to improve communication and continuity of care between psychosocial service providers across inpatient, outpatient, hospice and home-based settings



Audit of Current Quality of Psychosocial Care

- A formal audit should be undertaken to assess the current quality of psychosocial care received by cancer patients and their carers / families in Western Australia, with identification of barriers to optimising psychosocial care and gaps in service provision

Access to “Best Practice” Multidisciplinary Care

- “Best Practice” principles of psychosocial care, including formalised assessment processes, should be adopted across all sites and practitioners providing cancer care including the primary care and private sectors
- All patients should have access to multidisciplinary care regardless of the setting of their care, with at least one member of the team identified to bring attention to individual patient / carer / family psychosocial needs

Recognising the role of General Practitioners

- General Practitioners should have the opportunity to take an increasing role in the provision of multidisciplinary cancer care, particularly in the setting of survivorship and cancer as a chronic disease.
- Increasing emphasis should be placed on the identification of patient’s correct GP details at the point of entry into cancer care settings. Information regarding significant transitions in care e.g. from curative to palliative intent, should be prioritised in its transmission to GPs, so that GPs can be made aware of periods of increased vulnerability to psychosocial distress.
- GP Divisions should provide educational programs outlining the psychosocial impact of the cancer journey and management techniques to assist patients, carers and families in the negotiation of this journey. GP’s should have the opportunity to engage in shared-care arrangements with the W.A. Psycho-Oncology Service and Consultation Liaison Psychiatry services.

Accreditation of Private Psychosocial Practitioners

- Provided that issues of accreditation regarding “specialised cancer experience” can be resolved, developing networks with private psychology and counselling practitioners with specialised skills in the cancer setting via the Medicare funded “Better Outcomes” initiative may assist with meeting the demand for providing specialised psychological care

Expanding Provision of Social Work Services

- Social work services in both inpatient and outpatient cancer settings across public and private sites should be significantly expanded to enable holistic assessment of psychosocial needs of patients, carers and families, and skilled triaging with referral on to appropriate resources in the primary, secondary, tertiary and non-government sectors

Improving Resources for Carers and Families

- The psychosocial impact of cancer on carers and families should be formally recognised, with increased awareness of the physical, financial and emotional demands of caring for a patient with cancer, and increased funding for assistance with these needs
- Increased funding should be provided for in home and hospice or residential respite care for cancer patients who are being cared for at home



- New facilities should be developed for the provision of medium-stay hospice care, to reduce the distress of pursuing nursing home placement for patients whose prognosis is in terms of months

Services for Rural and Remote Patients

- Increased funding should be provided to assist cancer patients from outer metropolitan, rural and remote areas with meeting the costs of transport and accommodation, given the geographic inequity of service provision
- An awareness campaign should be held to inform patients (and their carers and families) and cancer care providers regarding the free and subsidised psychosocial support services available in rural and regional areas

Services for Patients of ATSI and CALD Background

- All cancer care health professionals should be provided with formal training in the provision of culturally sensitive care to patients and carers / families of Aboriginal and Torres Strait Islander (ATSI) and Culturally and Linguistically Diverse (CALD) backgrounds

Family Friendly Cancer Services

- Given the increased risk of psychosocial distress and potential long term psychological impact of parental cancer diagnosis, urgent endeavours should be made to routinely identify patients with young children and adolescents, and offer information and supports regarding developmentally sensitive techniques to discuss cancer impact on families
- Attention should be given to the design of hospitals and cancer centres to ensure that these physical environments are family-friendly, with provision of appropriate children's play areas and indoor and outdoor spaces for families to spend time together

Advocacy for Design of Cancer Centres

- Urgent discussion should be held with the designers of the Sir Charles Gairdner Hospital and Fiona Stanley Hospital Cancer Centres, to ensure that these facilities provide appropriate and sufficient spaces for; recognising patient's needs for privacy when undertaking psychosocial assessment, providing multidisciplinary input, providing emotional support to patients and their carers / families in acute distress, conducting family and teams meetings, provision of group educational activities and for families to spend time together both indoors and outdoors

Expansion of Access to Clinical Cancer Nurse Co-ordinators

- The current Clinical Cancer Nurse Program should be expanded to enable all patients, regardless of care setting, to have access to care coordination and tumour-specific resources

Caring for Health Professionals

- Increased attention should be provided for the well-being of health professionals providing cancer care. Systemic factors contributing to stress such as high patient loads and unrealistic time pressures should be managed to reduce staff burn out. Options such as mentorship and clinical supervision to enable self-reflection on the emotional impact of providing cancer care should be explored



Impact of Cancer on Body image and Sexuality

- Strategies should be implemented to increase clinician awareness regarding the impact of cancer diagnosis and treatment on body image and sexuality and training in techniques to explore these issues sensitively with awareness of available resources for further support

Holistic Care Provision

- Increased funding should be provided to expand services such as the SolarisCare Foundation providing touch-based complementary therapies and “drop-in” resources to cancer patients and their carers / families, to other hospital sites

Expansion of the W.A. Psycho-Oncology Service and Liaison Psychiatry Services to Improve Inpatient / Outpatient Continuity of Care

- The W.A. Psycho-Oncology Service should be expanded to enable continuity of clinical psychology input between inpatient and outpatient settings
- Consultation Liaison Psychiatry Services should be expanded to enable both inpatient and outpatient assessment and follow up of patients (and carers / families) with complex mental health needs

Development of an Online Directory of Psychosocial Services

- An on-line directory of psychosocial resources for cancer patients and their carers / families should be developed, which is regularly maintained and updated, and is easily negotiated by patients and health professionals alike

Grief and Bereavement Services

- Formalised protocols for Grief and Bereavement follow-up should be maintained by all sites and organisations providing cancer care. Carers / family members identified as being at risk of complicated grief should be referred for specialised support via hospital social work departments or the Silver Chain Hospice Care Service Counselling Service

Research Priorities

- There should be specific statewide research endeavours to explore strategies to improve the provision of psychosocial care for cancer patients (and their carers, families) of ATSI and CALD backgrounds, in rural and remote areas, who are parents of young children, are young adults and adolescents, and for those dealing with issues of cancer survivorship and living with cancer as a chronic disease

Developing a Culture of Continuous Quality Improvement and Consumer Input

- There is a need to ensure that psychosocial care programs and providers are regularly reviewed for quality assurance and subject to consumer feedback. In addition, there should be encouragement of consumer representation on service development committees.



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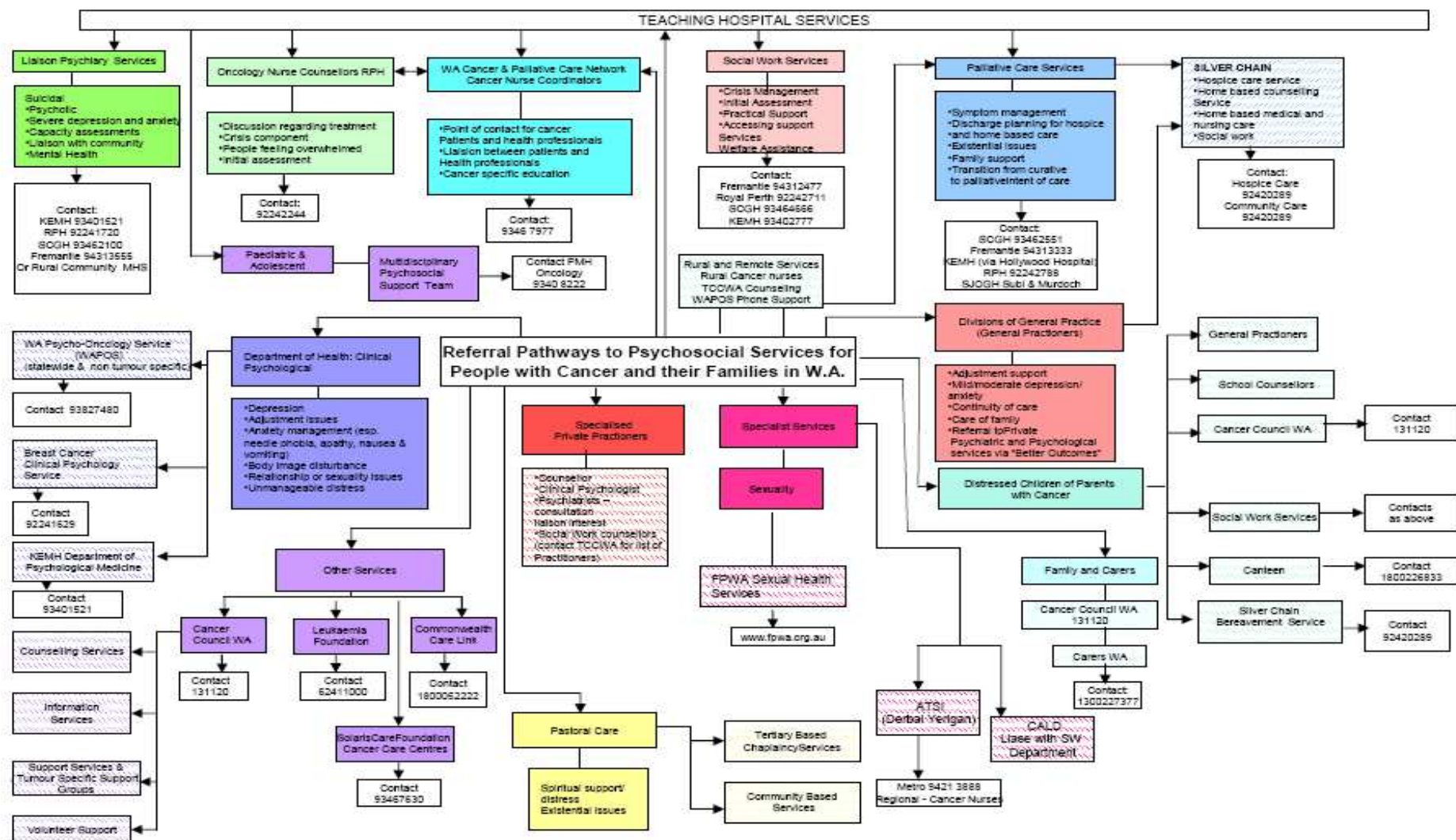


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Appendices

Appendix 1: WACPCN "Referral Pathways Document for Psychosocial Care Providers for Cancer Patients and Carers / Families in Western Australia"





Appendix 2: NCCN Distress Thermometer and "Problem List"



Distress Thermometer

DIS-A

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress

10

9

8

7

6

5

4

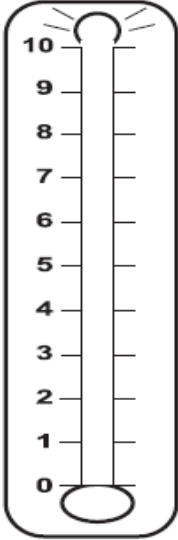
3

2

1

0

No distress



Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

<p>YES NO Practical Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Child care</p> <p><input type="checkbox"/> <input type="checkbox"/> Housing</p> <p><input type="checkbox"/> <input type="checkbox"/> Insurance/financial</p> <p><input type="checkbox"/> <input type="checkbox"/> Transportation</p> <p><input type="checkbox"/> <input type="checkbox"/> Work/school</p> <p>Family Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with children</p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with partner</p> <p>Emotional Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Depression</p> <p><input type="checkbox"/> <input type="checkbox"/> Fears</p> <p><input type="checkbox"/> <input type="checkbox"/> Nervousness</p> <p><input type="checkbox"/> <input type="checkbox"/> Sadness</p> <p><input type="checkbox"/> <input type="checkbox"/> Worry</p> <p><input type="checkbox"/> <input type="checkbox"/> Loss of interest in usual activities</p> <p><input type="checkbox"/> <input type="checkbox"/> Spiritual/religious concerns</p>	<p>YES NO Physical Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Appearance</p> <p><input type="checkbox"/> <input type="checkbox"/> Bathing/dressing</p> <p><input type="checkbox"/> <input type="checkbox"/> Breathing</p> <p><input type="checkbox"/> <input type="checkbox"/> Changes in urination</p> <p><input type="checkbox"/> <input type="checkbox"/> Constipation</p> <p><input type="checkbox"/> <input type="checkbox"/> Diarrhea</p> <p><input type="checkbox"/> <input type="checkbox"/> Eating</p> <p><input type="checkbox"/> <input type="checkbox"/> Fatigue</p> <p><input type="checkbox"/> <input type="checkbox"/> Feeling Swollen</p> <p><input type="checkbox"/> <input type="checkbox"/> Fevers</p> <p><input type="checkbox"/> <input type="checkbox"/> Getting around</p> <p><input type="checkbox"/> <input type="checkbox"/> Indigestion</p> <p><input type="checkbox"/> <input type="checkbox"/> Memory/concentration</p> <p><input type="checkbox"/> <input type="checkbox"/> Mouth sores</p> <p><input type="checkbox"/> <input type="checkbox"/> Nausea</p> <p><input type="checkbox"/> <input type="checkbox"/> Nose dry/congested</p> <p><input type="checkbox"/> <input type="checkbox"/> Pain</p> <p><input type="checkbox"/> <input type="checkbox"/> Sexual</p> <p><input type="checkbox"/> <input type="checkbox"/> Skin dry/itchy</p> <p><input type="checkbox"/> <input type="checkbox"/> Sleep</p> <p><input type="checkbox"/> <input type="checkbox"/> Tingling in hands/feet</p>
---	--

Other Problems: _____

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Appendix 3: NBCC Psychosocial Care Referral Checklist



Psychosocial Care Referral Checklist

FOR PATIENTS WITH CANCER

AIM

National Breast and Ovarian Cancer Centre's *Psychosocial care referral checklist* provides a simple way for health professionals to identify patients at higher risk of psychosocial distress who may benefit from additional assessment and appropriate referral for psychosocial care.

The purpose of the *Psychosocial care referral checklist* is not to diagnose psychiatric disorders.

Explanatory notes

National Breast and Ovarian Cancer Centre has developed explanatory notes to assist health professionals in completing the *Psychosocial care referral checklist*.

How to use the checklist

The *Psychosocial care referral checklist* is divided into two sections. The first section is to be completed at initial presentation and the second at follow-up. Any information identified after initial presentation can be recorded at follow-up.

Ideally the *Psychosocial care referral checklist* is to be completed in consultation with the patient, but can be completed post-consultation.

Patient supportive care needs can change with time. It is important to monitor each patient and make appropriate referrals for further assessment and support as necessary.

National Comprehensive Cancer Network (NCCN) Distress thermometer screening tool

It is recommended that the NCCN *Distress thermometer screening tool* be used in conjunction with the *Psychosocial care referral checklist*.

The NCCN *Distress thermometer screening tool* is designed to be completed by the patient to support the information recorded on the checklist. By completing the screening tool patients will be able to identify their present level of distress and any concerns they have that may be impacting on their distress.



EXPLANATORY NOTES

The *Psychosocial care referral checklist* is divided into two sections. The first section is to be completed at initial presentation and the second at follow-up. Disease and treatment factors will change with time. Information may not be available during the initial treatment planning meeting – known or anticipated factors should be recorded. Any information identified after initial presentation can be recorded at follow-up. Ideally the *Psychosocial care referral checklist* is to be completed in consultation with the patient, but can be completed post-consultation.

The items listed on the checklist are those identified in the *Clinical practice guidelines for the psychosocial care of adults with cancer*¹ as being important indicators of psychosocial distress for a patient with cancer. When considering the psychosocial or support needs of a patient it is important to include an appraisal of individual patient circumstances, including past experiences of bereavement or loss and family history of cancer or mental health problems, which can impact on a patient's coping mechanisms.

The following information and prompts have been provided to assist you in completing the *Psychosocial care referral checklist*.

PATIENT CHARACTERISTICS

Younger than 55 years?

Research shows that younger patients are more vulnerable to emotional distress and are more likely to experience poorer adjustment and show more symptoms of depression. 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. There is an accepted definition of 'young' as it applies to cancer patients. For the purpose of this checklist younger patients are defined as those younger than 55 years. In general, the younger the age of the patient, the higher the risk of distress.

Single/separated/divorced/widowed?

Being single has been associated with an increased risk of psychosocial problems. Single patients may be more likely to experience emotional distress associated with establishing new relationships, a sense of isolation and inadequate support, and fears about disclosing their cancer.

Lives alone/marital/family problems/lack of social support?

Patients who perceive they have poor social support are more likely to experience greater psychosocial distress. The following open-ended questions may be helpful in eliciting the extent to which social support issues are relevant for the patient:

"Who do you feel you have helping you at the moment?"

"Are you getting the emotional support you feel you need?"

"Are family and friends giving the sort of help that you would like?"

"Do you ever feel that you are having to cope with the emotional side of things pretty much on your own?"

¹ National Breast Cancer Centre and National Cancer Control Initiative. 2003, *Clinical practice guidelines for the psychosocial care of adults with cancer*. National Breast Cancer Centre, Camperdown, NSW.



Children younger than 21 years?

Patients with children must cope not only with the effects of cancer, but also with concerns about the emotional impact on their family. In addition parents with children have practical demands on their time and concerns about issues of childcare, which can have a major impact on their health. There is evidence that having children younger than 21 years places the person with cancer at increased risk of psychosocial distress, and this is especially so if the parent feels guilty or worried about the impact of the cancer on their family. These issues can be explored using questions such as:

"What sort of impact do you think cancer has had on your family?"

"Do you have any concerns about the emotional impact on your children?"

"Are there any practical issues affecting how your family is coping?"

Financial concerns/issues?

Patients with cancer may incur considerable costs as a result of cancer treatments, as well as the financial burden resulting from loss of income. Financial concerns may affect their treatment and well-being. Health professionals can explore financial concerns by asking questions like:

"Cancer treatment and care can be expensive for you and your family. Is finance a concern for you?"

"Do you feel that the cancer has put pressure on you financially? How much do you worry about that?"

Previous episodes of depression/psychiatric illness/mental health problems?

Any person who has experienced depression is at risk of experiencing further episodes. Experiences of loss, such as becoming unemployed, can precipitate further episodes and the diagnosis of cancer is also a common precipitant for episodes of depression. In general, if a person has an extensive history of depression or psychiatric illness they are at increased risk of psychosocial distress following the diagnosis and treatment of cancer.

These issues can be explored using questions such as:

"It is important to ensure that we have all of the information for us to provide the best possible care. One of the areas we need to be aware of is any emotional issues you have faced in the past."

"Have you ever had counselling or seen a psychologist or psychiatrist? Can you tell me some more about that?"

"Problems like anxiety and depression are common in the community. Have you ever been affected by problems like that?"

History of stressful life events?

Stressful life events and patient's coping styles can impact on their current psychosocial distress. How patients have coped in the past during stressful times in their life can predict their ability/inability to cope with their current diagnosis and the potential stress associated with cancer and treatments. In addition, there is evidence that multiple current stressors can add to pose a cumulative burden and undermine coping. Because the individual events are not enormous, patients may not reveal the extent of the life events with which they are coping, and specific questions about this are necessary.

Explore the patient's coping mechanisms by asking open-ended questions, such as:

"Can you tell me about past stressful experiences in your life and how they have affected you?"

"People cope with stressful situations in different ways. Some people seek out information to help them handle the situation; whilst some people avoid thinking about it. What strategies have you used in the past?"



Explore current life stressors by general questions such as:

"Even though individual problems might be small, if there are enough of them they can add up to have a large effect on anyone. Can you tell me if there are a lot of things happening in your life apart from the cancer at present?"

"Are there things happening in your life that complicate how you are able to deal with the cancer?"

"Do you feel that there are issues other than the cancer that are weighing you down?"

Problems related to drugs or alcohol?

Health professionals commonly omit to elicit a history of alcohol ingestion, and this represents a significant lost opportunity for preventive health interventions, particularly in patients with cancer. Previous or current high alcohol intake or drug use is associated with increased psychosocial distress in patients with cancer. It is important to approach this topic sensitively, and to explain to your patient that the questions you are asking are to help you provide the best possible care. In general, patients will underestimate their alcohol consumption. Asking about the amount of alcohol intake by giving 'top-down' examples is a useful technique. Some suggested approaches include:

"Do you ever drink alcohol?"

"On average, how many times a week would you drink alcohol? Are there any days in the week when you don't have a drink?"

"On average, how many drinks would you have most days?" If the patient is not specific, could ask: *"How often would you have more than 10 glasses of wine per day?"* or similar and adjust according to patient response.

"Can you tell me if you have taken drugs in a larger dose than prescribed?"

"There are certain drugs that are commonly used for anxiety or stress such as benzodiazepines, diazepam, or paroxetine hydrochloride. These drugs can affect people's health. Have you ever taken one of these drugs for more than a few weeks at a time?"

"Can you tell me if you have ever used any drugs other than prescribed?" Most patients who have used illicit substances will respond openly if the question is asked directly.

"Are there times when you think that alcohol (or drugs) might have affected your health?"

"Have you ever worried about drinking (or taking drugs) and tried to cut down?"

"Have any drugs or medications ever been a problem for you?"

Female?

A number of studies have examined the incidence of psychosocial distress for women with cancer. They have shown that women are at higher risk of experiencing anxiety and/or depression, sexual difficulties, and other problems related to body image.



DISEASE/TREATMENT FACTORS

The nature and severity of psychosocial distress can vary over time; hence it is worthwhile to elicit and record emotional concerns regularly during treatment. Each patient will experience a range of practical, psychosocial, and emotional challenges as a result of their cancer diagnosis and treatment-related adverse effects.

Initial diagnosis and diagnosis of recurrence are times of increased psychosocial vulnerability and active assessment of coping is important at these times.

Patients who are diagnosed with cancer with a poor prognosis are especially vulnerable to psychosocial distress. Coping with grief and concerns associated with disease progression may be very difficult for patients. Many patients report that distress increases as the cancer progresses.

Distress caused by physical symptoms?

People with cancer can experience distress caused by a number of physical symptoms. Research shows that when physical symptoms are less well controlled, psychosocial distress increases and physical and social functioning decreases. Patients may not reveal symptoms if they feel that they are to be expected, or they feel that nothing can be done to help.

The following prompts may be useful:

"Sometimes the treatment can be hard going and side effects can be tough. How would you say the treatment is going for you?"

"How have physical symptoms impacted on your life and ability to do the things that matter to you?"

"Are there any physical symptoms you have experienced that have been particularly worrying or upsetting?"

Distress caused by disease burden?

It is important to monitor the emotional and psychosocial impact of the cancer on patients. Many patients, although not experiencing severe difficulties with one specific aspect of their cancer, may experience minor difficulties across a number of areas. While each problem in itself may not be severe, the cumulative effect may significantly affect their psychosocial well-being. The following questions can be used to frame questions which elicit the patient's concerns:

"How are things going overall?"

"Many people who have been treated for cancer feel that their outlook on life has changed. Changes to your body and how it functions mean having to make some adjustments. Are there any particular issues that concern you?"

"Even though symptoms might be small themselves, having a number of symptoms from the cancer can make life difficult. Would you say that your life is affected by ongoing symptoms?"

Impaired ability to perform daily activities?

Cancer symptoms and side effects of treatment can impact on a patient's ability to perform everyday tasks. The following questions can be used to determine the emotional impact of cancer on the patient's everyday life.

"Experiencing cancer symptoms can affect the way we feel emotionally. It is important to have a sense of whether symptoms are troubling you, and whether they are affecting your day-to-day life."

"How do you think cancer is affecting your ability to perform everyday activities?"

"Is the cancer making doing things much more of an effort for you?"



Lymphoedema?

Lymphoedema can be debilitating, impairing a patient's ability to perform ordinary tasks and resulting in increased psychosocial distress. It is important to enquire about the presence of limb or other swelling. The degree to which lymphoedema causes limitation in function is a more important determinant of psychosocial risk than the extent of the lymphoedema.

Chronic pain?

Enquiring about pain is part of routine clinical care. Pain has an emotional dimension and for patients with cancer, the interpretation of the meaning of pain may influence the way the patient deals with it. It is important to assess the degree of psychosocial distress resulting from physical symptoms. Try an approach such as:

"Having pain can affect how we feel mentally and emotionally. Can you tell me how your pain is affecting you?"

Fatigue?

Many patients fail to discuss fatigue with their treating team because of the belief that nothing can be done to help. Signs of fatigue may include tired eyes, whole body tiredness, inability to concentrate, weakness, boredom or lack of motivation, sleepiness, and increased irritability. When discussing fatigue with your patient the following comments may be helpful:

"Fatigue is a common complaint of patients with cancer and it can sometimes interfere with everyday life. Since being diagnosed with cancer, how have your energy levels been?"

"How have your energy levels been affecting you?"

"We know that fatigue can last well after treatment has been completed. Is fatigue having an impact on your life?"

THE NATIONAL COMPREHENSIVE CANCER NETWORK (NCCN) DISTRESS THERMOMETER SCREENING TOOL²

The NCCN *Distress thermometer screening tool* is designed to be filled out by the patient to support the information recorded on the *Psychosocial care referral checklist*. By completing the screening tool patients will be able to identify their present level of distress and any concerns they have which may be impacting on their distress. Patients should be screened for distress at initial presentation, at follow-up and at other times of significant change to their disease and/or treatment status.

REFERRAL INFORMATION AND OPTIONS

This *Psychosocial care referral checklist* is intended to highlight the extent of psychosocial and supportive care needed by patients being treated for cancer in your centre or unit. In some circumstances, there may be a need to think flexibly about who can provide such care.

Before using this checklist it is important to consider:

- What specialist expertise in psychological and/or supportive interventions are available at your local cancer centre or unit? If specialist services are not available at your local centre, who else could you refer to? It may be useful to discuss the patient's needs with their GP.
- Are there local cancer support groups that could help?

Before making a referral it is important to consider:

- Does this patient want to be referred to specialist services at this time?
- Does this patient prefer individual or group-based psychosocial intervention?

² The NCCN 1. 2005 *Distress Management Guidelines*. The Complete Library of NCCN Clinical Practice Guidelines in Oncology (CD-Rom) Jenkintown, Pennsylvania.



The following table outlines possible service providers with demonstrated effectiveness for specific problems experienced by people with cancer. It will be useful for services to establish a referral network and develop a contact list for possible psychosocial care referrals.

Table 1: A guide to appropriate referral for specific problems

Problem	Discipline to refer to
Depression/psychiatric illness/mental health problems	Clinical psychologist/Psychiatrist
Interpersonal problems	Clinical psychologist/Psychiatrist/Social worker
Financial concerns	Social worker/Welfare worker
High alcohol intake/drug use	Clinical psychologist/Psychiatrist/Drug & alcohol counsellor
Distress caused by physical symptoms	Clinical psychologist/Psychiatrist/Social worker
Distress caused by disease burden	Clinical psychologist/Psychiatrist
Impaired ability to perform daily tasks	Occupational therapist/Support services/Physiotherapist
Lymphoedema	Physiotherapist/Occupational therapist
Chronic pain	Specialist pain services/Clinical psychologist/Psychiatrist
Fatigue	Occupational therapist/Dietitian

Adapted from National Breast Cancer Centre and National Cancer Control Initiative, 2003. *Clinical practice guidelines for the psychosocial care of adults with cancer*. National Breast Cancer Centre, Camperdown, NSW: Pg. 103.



Appendix 4: Explanatory Notes to the NBCC Psychosocial Care Referral Checklist



PSYCHOSOCIAL CARE REFERRAL CHECKLIST for patients with cancer

EXPLANATORY NOTES

The *Psychosocial care referral checklist* provides a simple way for health professionals to identify patients with cancer who may be at increased risk of psychosocial distress. These patients may benefit from additional assessment and appropriate referral for supportive/psychosocial care. The purpose of the *Psychosocial care referral checklist* is not to diagnose psychiatric disorders.

The *Psychosocial care referral checklist* is divided into two sections. The first section is to be completed at initial presentation and the second at follow-up. Disease and treatment factors will change with time. Information may not be available during the initial treatment planning meeting – known or anticipated factors should be recorded. Any information identified after initial presentation can be recorded at follow-up. Ideally the *Psychosocial care referral checklist* is to be completed in consultation with the patient, but can be completed post-consultation.

The items listed on the checklist are those identified in the *Clinical practice guidelines for the psychosocial care of adults with cancer*¹ as being important indicators of psychosocial distress for a patient with cancer. When considering the psychosocial or support needs of a patient it is important to include an appraisal of individual patient circumstances, including past experiences of bereavement or loss and family history of cancer or mental health problems, which can impact on a patient's coping mechanisms.

The following information and prompts have been provided to assist you in completing the *Psychosocial care referral checklist*.

PATIENT CHARACTERISTICS

Younger than 55 years?

Research shows that younger patients are more vulnerable to emotional distress and are more likely to experience poorer adjustment and show more symptoms of depression. 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. There is an accepted definition of 'young' as it applies to cancer patients. For the purpose of this checklist younger patients are defined as those younger than 55 years. In general, the younger the age of the patient, the higher the risk of distress.

Single/separated/divorced/widowed?

Being single has been associated with an increased risk of psychosocial problems. Single patients may be more likely to experience emotional distress associated with establishing new relationships, a sense of isolation and inadequate support, and fears about disclosing their cancer.

¹ National Breast Cancer Centre and National Cancer Control Initiative. 2003. *Clinical practice guidelines for the psychosocial care of adults with cancer*. National Breast Cancer Centre, Camperdown, NSW.



Lives alone/marital/family problems/lack of social support?

Patients who perceive they have poor social support are more likely to experience greater psychosocial distress. The following open-ended questions may be helpful in eliciting the extent to which social support issues are relevant for the patient:

"Who do you feel you have helping you at the moment?"

"Are you getting the emotional support you feel you need?"

"Are family and friends giving the sort of help that you would like?"

"Do you ever feel that you are having to cope with the emotional side of things pretty much on your own?"

Children younger than 21 years?

Patients with children must cope not only with the effects of cancer, but also with concerns about the emotional impact on their family. In addition parents with children have practical demands on their time and concerns about issues of childcare, which can have a major impact on their health. There is evidence that having children younger than 21 years places the person with cancer at increased risk of psychosocial distress, and this is especially so if the parent feels guilty or worried about the impact of the cancer on their family. These issues can be explored using questions such as:

"What sort of impact do you think cancer has had on your family?"

"Do you have any concerns about the emotional impact on your children?"

"Are there any practical issues affecting how your family is coping?"

Financial concerns/issues?

Patients with cancer may incur considerable costs as a result of cancer treatments, as well as the financial burden resulting from loss of income. Financial concerns may affect their treatment and well-being. Clinicians can explore financial concerns by asking questions like:

"Cancer treatment and care can be expensive for you and your family. Is finance a concern for you?"

"Do you feel that the cancer has put pressure on you financially? How much do you worry about that?"

Previous episodes of depression/psychiatric illness/mental health problems?

Any person who has experienced depression is at risk of experiencing further episodes. Experiences of loss, such as becoming unemployed, can precipitate further episodes and the diagnosis of cancer is also a common precipitant for episodes of depression. In general, if a person has an extensive history of depression or psychiatric illness they are at increased risk of psychosocial distress following the diagnosis and treatment of cancer.

These issues can be explored using questions such as:

"It is important to ensure that we have all of the information for us to provide the best possible care. One of the areas we need to be aware of is any emotional issues you have faced in the past."



"Have you ever had counselling or seen a psychologist or psychiatrist? Can you tell me some more about that?"

"Problems like anxiety and depression are common in the community. Have you ever been affected by problems like that?"

History of stressful life events?

Stressful life events and patient's coping styles can impact on their current psychosocial distress. How patients have coped in the past during stressful times in their life can predict their ability/inability to cope with their current diagnosis and the potential stress associated with cancer and treatments. In addition, there is evidence that multiple current stressors can add to pose a cumulative burden and undermine coping. Because the individual events are not enormous, patients may not reveal the extent of the life events with which they are coping, and specific questions about this are necessary.

Explore the patient's coping mechanisms by asking open-ended questions, such as:

"Can you tell me about past stressful experiences in your life and how they have affected you?"

"People cope with stressful situations in different ways. Some people seek out information to help them handle the situation; whilst some people avoid thinking about it. What strategies have you used in the past?"

Explore current life stressors by general questions such as:

"Even though individual problems might be small, if there are enough of them they can add up to have a large effect on anyone. Can you tell me if there are a lot of things happening in your life apart from the cancer at present?"

"Are there things happening in your life that complicate how you are able to deal with the cancer?"

"Do you feel that there are issues other than the cancer that are weighing you down?"

Problems related to drugs or alcohol?

Health professionals commonly fail to elicit a history of alcohol ingestion, and this represents a significant lost opportunity for preventive health interventions, particularly in patients with cancer. Previous or current high alcohol intake or drug use is associated with increased psychosocial distress in patients with cancer. It is important to approach this topic sensitively, and to explain to your patient that the questions you are asking are to help you provide the best possible care. In general, patients will underestimate their alcohol consumption. Asking about the amount of alcohol intake by giving 'top-down' examples is a useful technique. Some suggested approaches include:

"Do you ever drink alcohol?"

"On average, how many times a week would you drink alcohol? Are there any days in the week when you don't have a drink?"

"On average, how many drinks would you have most days?" If the patient is not specific, could ask: *"How often would you have more than 10 glasses of wine per day?"* or similar and adjust according to patient response.



"Can you tell me if you have taken drugs in a larger dose than prescribed?"

"There are certain drugs that are commonly used for anxiety or stress such as benzodiazepines, diazepam, or paroxetine hydrochloride. These drugs can affect people's health. Have you ever taken one of these drugs for more than a few weeks at a time?"

"Can you tell me if you have ever used any drugs other than prescribed?" Most patients who have used illicit substances will respond openly if the question is asked directly.

"Are there times when you think that alcohol (or drugs) might have affected your health?"

"Have you ever worried about drinking (or taking drugs) and tried to cut down?"

"Have any drugs or medications ever been a problem for you?"

Female?

A number of studies have examined the incidence of psychosocial distress for women with cancer. They have shown that women are at higher risk of experiencing anxiety and/or depression, sexual difficulties, and other problems related to body image.

DISEASE/TREATMENT FACTORS

The nature and severity of psychosocial distress can vary over time; hence it is worthwhile to elicit and record emotional concerns regularly during treatment. Each patient will experience a range of practical, psychosocial, and emotional challenges as a result of their cancer diagnosis and treatment-related adverse effects.

Initial diagnosis and diagnosis of recurrence are times of increased psychosocial vulnerability and active assessment of coping is important at these times.

Patients who are diagnosed with cancer with a poor prognosis are especially vulnerable to psychosocial distress. Coping with grief and concerns associated with disease progression may be very difficult for patients. Many patients report that distress increases as the cancer progresses.

Distress caused by physical symptoms?

People with cancer can experience distress caused by a number of physical symptoms. Research shows that when physical symptoms are less well controlled, psychosocial distress increases and physical and social functioning decreases. Patients may not reveal symptoms if they feel that they are to be expected, or they feel that nothing can be done to help.

The following prompts may be useful:

"Sometimes the treatment can be hard going and side effects can be tough. How would you say the treatment is going for you?"

"How have physical symptoms impacted on your life and ability to do the things that matter to you?"

"Are there any physical symptoms you have experienced that have been particularly worrying or upsetting?"



Distress caused by disease burden?

It is important to monitor the emotional and psychosocial impact of the cancer on patients. Many patients, although not experiencing severe difficulties with one specific aspect of their cancer, may experience minor difficulties across a number of areas. While each problem in itself may not be severe, the cumulative effect may significantly affect their psychosocial well-being. The following questions can be used to frame questions which elicit the patient's concerns:

"How are things going overall?"

"Many people who have been treated for cancer feel that their outlook on life has changed. Changes to your body and how it functions mean having to make some adjustments. Are there any particular issues that concern you?"

"Even though symptoms might be small themselves, having a number of symptoms from the cancer can make life difficult. Would you say that your life is affected by ongoing symptoms?"

Impaired ability to perform daily activities?

Cancer symptoms and side effects of treatment can impact on a patient's ability to perform everyday tasks. The following questions can be used to determine the emotional impact of cancer on the patient's everyday life.

"Experiencing cancer symptoms can affect the way we feel emotionally. It is important to have a sense of whether symptoms are troubling you, and whether they are affecting your day-to-day life."

"How do you think cancer is affecting your ability to perform everyday activities?"

"Is the cancer making doing things much more of an effort for you?"

Lymphoedema?

Lymphoedema can be debilitating, impairing a patient's ability to perform ordinary tasks and resulting in increased psychosocial distress. It is important to enquire about the presence of limb or other swelling. The degree to which lymphoedema causes limitation in function is a more important determinant of psychosocial risk than the extent of the lymphoedema.

Chronic pain?

Enquiring about pain is part of routine clinical care. Pain has an emotional dimension and for patients with cancer, the interpretation of the meaning of pain may influence the way the patient deals with it. It is important to assess the degree of psychosocial distress resulting from physical symptoms. Try an approach such as:

"Having pain can affect how we feel mentally and emotionally. Can you tell me how your pain is affecting you?"



Fatigue?

Many patients fail to discuss fatigue with their treating team because of the belief that nothing can be done to help. Signs of fatigue may include tired eyes, whole body tiredness, inability to concentrate, weakness, boredom or lack of motivation, sleepiness, and increased irritability. When discussing fatigue with your patient the following comments may be helpful:

"Fatigue is a common complaint of patients with cancer and it can sometimes interfere with everyday life. Since being diagnosed with cancer, how have your energy levels been?"

"How have your energy levels been affecting you?"

"We know that fatigue can last well after treatment has been completed. Is fatigue having an impact on your life?"

THE NATIONAL COMPREHENSIVE CANCER NETWORK (NCCN) DISTRESS THERMOMETER SCREENING TOOL²

The NCCN *Distress thermometer screening tool* is designed to be filled out by the patient to support the information recorded on the *Psychosocial care referral checklist*. By completing the screening tool patients will be able to identify their present level of distress and any concerns they have which may be impacting on their distress. Patients should be screened for distress at initial presentation, at follow-up and at other times of significant change to their disease and/or treatment status.

REFERRAL INFORMATION AND OPTIONS

This *Psychosocial care referral checklist* may perform the function of highlighting the extent of psychosocial and supportive care needed by patients being treated for cancer in your centre or unit. In some circumstances, there may be a need to think flexibly about who can provide such care.

Before using this checklist it is important to consider:

- What specialist expertise in psychological and/or supportive interventions are available at your local cancer centre or unit? If specialist services are not available at your local centre, who else could you refer to? It may be useful to discuss the patient's needs with their GP.
- Are there local cancer support groups that could help?

Before making a referral it is important to consider:

- Does this patient want to be referred to specialist services at this time?
- Does this patient prefer individual or group-based psychosocial intervention?

² The NCCN 1. 2005 Distress Management Guidelines. The Complete Library of NCCN Clinical Practice Guidelines in Oncology (CD-Rom) Jenkintown, Pennsylvania. © National Comprehensive Cancer Network, May 2006.



The following table outlines possible service providers with demonstrated effectiveness for specific problems experienced by people with cancer. It will be useful for services to establish a referral network and develop a contact list for possible psychosocial care referrals.

Table 1: A guide to appropriate referral for specific problems

Problem	Discipline to refer to
Depression/psychiatric illness/mental health problems	Clinical psychologist/Psychiatrist
Interpersonal problems	Clinical psychologist/Psychiatrist/Social worker
Financial concerns	Social worker/Welfare worker
High alcohol intake/ drug use	Clinical psychologist/Psychiatrist/Drug & alcohol counsellor
Distress caused by physical symptoms	Clinical psychologist/Psychiatrist/Social worker
Distress caused by disease burden	Clinical psychologist/Psychiatrist
Impaired ability to perform daily tasks	Occupational therapist/Support services/ Physiotherapist
Lymphoedema	Physiotherapist/Occupational therapist
Chronic pain	Specialist pain services/Clinical psychologist/Psychiatrist
Fatigue	Occupational therapist/Dietitian

Adapted from National Breast Cancer Centre and National Cancer Control Initiative, 2003. Clinical practice guidelines for the psychosocial care of adults with cancer. National Breast Cancer Centre, Camperdown, NSW: Pg, 103.



Appendix 5a: NBCC & NCCI Guidelines table of Recommended General Interactional Skills in Any Consultation With a Person With Cancer (Table 3.1 pg 42 NBCC & NCCI)

GENERAL INTERACTION 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 categorization (provide information clearly groups 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

- Access the person's level of family or social support
- Provide the names and contact details of relevant persons or organizations 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."



**Appendix 5b: NBCC & NCCI Guidelines table of Recommended Steps
Involved in Ensuring That All People With Cancer Have
Adequate Emotional and Social Support (Table 3.3A pg 70
NBCC & NCCI)**

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 allied health professional, e.g. 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 patients about:
 - Their support network and the level of support provided
 - How their family and partner are dealing with their cancer
 - Other with whom they can openly discuss their thoughts and feelings about their situation
 - Who they have to assist with practical issues, e.g. 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



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**WA Cancer & Palliative
Care Network
Level 1, 1 Centro Ave
Subiaco
Western Australia 6008**