

Palliative Care Needs Assessment Guidelines Summary

Developed by:

Afaf Girgis, Claire Johnson, David Currow
Amy Waller, Linda Kristjanson, Geoff Mitchell
Patsy Yates, Amanda Neil, Brian Kelly
Martin Tattersall, Deborah Bowman

August 2006



Flinders University



THE UNIVERSITY
OF QUEENSLAND



University of Sydney
Medical Psychology Research Unit



THE UNIVERSITY OF
NEWCASTLE
AUSTRALIA



ACKNOWLEDGEMENTS

The development of these Guidelines was funded by the Australian Government Department of Health and Ageing and managed through the Centre for Health Research & Psycho-oncology (CHeRP), based at The University of Newcastle, NSW, Australia.

The Guidelines project team includes:

Professor Afaf Girgis
Director
Centre for Health Research & Psycho-oncology (CHeRP)
The Cancer Council NSW & The University of Newcastle, NSW

Mrs Claire Johnson
Senior Research Officer, CHeRP

Ms Amy Waller
PhD Student, CHeRP

Ms Deborah Bowman
Senior Research Officer, CHeRP

Professor David Currow
Professor of Palliative & Supportive Services
Flinders University, Adelaide, SA

Professor Linda Kristjanson
Director
WA Centre for Cancer & Palliative Care
Curtin University of Technology, WA

A/Professor Geoff Mitchell
Principal Research Fellow
Discipline of General Practice
University of Queensland, QLD

Professor Patsy Yates
A/Director
Centre for Palliative Care Research and Education, QLD Health
Queensland University of Technology, QLD

Dr Amanda Neil
Senior Lecturer in Health Economics
University of Newcastle, NSW

Professor Brian Kelly
Director
NSW Centre for Rural & Remote Mental Health, Orange, NSW

Professor Martin Tattersall
Professor of Cancer Medicine
University of Sydney, NSW

We extend our sincere thanks to the many individuals and groups across Australia who provided constructive feedback on the draft of these Guidelines.

Acronyms used in this report

CALD	Culturally and linguistically diverse
GP	General practitioner
PC	Palliative care
PCA	Palliative Care Australia
NAT: PD-C	Needs Assessment Tool: Progressive Disease-Cancer
QoL	Quality of life
SPC	Specialist palliative care
SPCS	Specialist palliative care service

The suggested citation for this document is:

Girgis A, Johnson C, Currow D, Waller A, Kristjanson L, Mitchell G, Yates P, Neil A, Kelly B, Tattersall M & Bowman D (2006). *Palliative Care Needs Assessment Guidelines*. The Centre for Health Research & Psycho-oncology, Newcastle, NSW.

FOREWORD

Community expectations about quality care for someone experiencing a life-limiting illness have continued to evolve rapidly in the last 20 years. There is now a clear demand by the whole community for people at the end of life to have access to care that matches the complex and ever-changing needs that they encounter. Given the range of places in which such care occurs (home, hospital, other community settings) and the wide range of life-limiting illnesses, this requires careful coordination of limited resources and a shared understanding of the goals of care – optimising comfort and function in areas such as physical, emotional, existential, sexual, social and financial care.

Diagnosis and prognosis are poor indicators of need for *this person* in the context of *his/her life*. In palliative care, equitable and timely access to services for people with more complex needs is an imperative. Such an approach is not limited to people for whom active treatment has ceased; these issues need to be raised from the time a life-limiting illness is first recognised.

One audience for the *Palliative Care Needs Assessment Guidelines* are clinicians whose work encounters people with life-limiting illnesses from time to time – general practitioners, community allied health and nursing staff, and doctors from other specialties. For these clinicians, the *Guidelines* can establish whether needs are currently being met, or a specialist assessment may add to the care plan.

For palliative care teams working along side general practitioners and community nurses, the *Guidelines* can help to determine the complexity of ongoing needs. Are the needs assessed today (not at the time of referral) best met with ongoing specialist input or will these needs continue to be met by generalist clinicians who are already involved in care? This is a dynamic process as the needs of the person and their family changes over time. Such assessments then occur with every encounter to best match needs with the complexity of input.

There is a fundamental challenge in delivering good care for people (and their families) facing an expected death – whose needs are being met currently and whose needs require more input to optimise care? By creating a more transparent and objective mechanism for the decision about who accesses (or does not need to access) specialist services, it is hoped that the care that can be offered for everyone with a life-limiting illness will more equitably address the needs of the tens of thousands of Australians who face this path every year.

Professor David Currow
President, Palliative Care Australia
July 2006

IMPORTANT NOTICE

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

The Guidelines are designed to provide information to assist decision-making and are based on the best evidence available at the time of publication. The accompanying *Needs Assessment Tool: Progressive Disease-Cancer* is available at <http://www.newcastle.edu.au/research-centre/cherp/professional-resources/>.

Readers may also find the following module helpful in guiding their discussions with patients about palliative care issues: National Breast Cancer Centre. *Discussing the transition from curative care to palliative care - Evidence from the literature*. 2005 National Breast Cancer Centre, Camperdown, NSW.

EXECUTIVE SUMMARY

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness. Referral to specialist palliative care services is appropriate at any time in the disease trajectory when a patient with a life-limiting illness, or significant others associated with the patient, have identified needs that are not being adequately addressed, whether these needs are physical, psychological, social or spiritual. However, since not all patients for whom death is expected will need specialist palliative care, the challenge facing managers of health services and policy makers is to develop objective, cost-efficient and needs-based strategies for palliative care resource allocation. This is particularly important given the potential expected increase in the demand for specialist palliative care services, poor articulation about how and when to best refer patients and the likelihood that resources will remain relatively static at least in the foreseeable future.

Palliative Care Australia has argued that central to the development of an integrated plan to deliver quality end-of-life care is the “development of well defined and transparent referral and admission protocols and procedures”. The ***Palliative Care Needs Assessment Guidelines*** (hereafter referred to as the Guidelines), together with the ***Needs Assessment Tool: Progressive Disease-Cancer***, are pivotal to facilitate equity of access, ie equal access for equal need, to finite palliative care resources.

The Guidelines are intended to provide guidance to those caring for people with a life-limiting illness and their families, to ensure that they are offered the most appropriate care to meet their specific needs. They cover all aspects of patient, caregiver and primary health care provider characteristics that may influence the decision to provide more specialist palliative care to a particular patient or family. The introduction of the Guidelines and Needs Assessment Tool: Progressive Disease-Cancer is expected to reduce the incidence of late and crisis referral and improve referral where psychological, social, physical and spiritual problems are evident. Improved outcomes for patients and families are expected to include improved symptom control, quality of life and satisfaction with care.

Since the cancer patient population currently represents approximately 90% of the palliative care services' caseload, this group has been identified as the most appropriate target population for the first edition of these Guidelines. It is planned that the Guidelines will be generalised to the non-cancer palliative population after comprehensive evaluation.

BACKGROUND & SUMMARY OF KEY EVIDENCE

1. PALLIATIVE CARE

World Health Organisation definition of palliative care

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing complications.

World Health Organisation 2002¹

National Cancer Control Programmes: Policies and managerial guidelines 2nd Ed, Page 83

Timing of referral to specialist palliative care services

Referral to specialist palliative care services (SPCSs)^a is appropriate at any time in the disease trajectory when a patient with cancer, or significant others associated with the patient, have identified needs that are not being adequately addressed, whether these needs are physical, psychological, social or spiritual. Local SPCSs may, however, have specific access criteria, which primary health care providers would need to be aware of.

Quality of life issues

Promotion of an individual’s quality of life (QoL) is a central tenet of PC. The impetus for studies on QoL is linked to treatment advances that have resulted in prolonged survival times with side effects of treatment that may impact on QoL. In non-curative situations, quality rather than quantity of life becomes important and is considered the primary care outcome to

^a Multi-disciplinary health care services whose substantive work is with patients who have a life-limiting illness.²

assess. Quality of life is a broad concept that encompasses physical, social, psychological and spiritual domains. A focus on QoL helps to prevent health professionals from separating the patient's body from his/her biography during care.

Although there are different approaches to conceptualising QoL, there is agreement that four aspects of QoL are central: subjectivity, dynamism, multi-dimensionality, and positive and negative dimensions (Level IVb).³ Subjectivity refers to the notion that the person who is best able to evaluate and reflect upon QoL is the individual him/herself. An external judgement about another's QoL is always second best.

Dynamism refers to the view that perceptions of QoL change over time and are influenced by many factors. The WHO Quality of Life Group (1993)⁴ defines QoL as an individual's perception of his/her position in life in the context of the culture and value system in which he/she lives, and in relation to personal goals, expectations, standards and concerns. Therefore, as circumstances change, health status shifts and personal goals are re-aligned, a person's view of QoL changes. Hence, finding a sensitive and trustworthy way to continue to assess an individual's perception of QoL is important in providing responsive PC.

The multidimensional aspect of QoL is a relevant construct when attempting to understand the various domains that comprise QoL: physical, functional, emotional, social and spiritual. Knowing how these various domains inter-relate and shape a person's sense of QoL is helpful in being able to tailor interventions to specific QoL needs that may be a priority. There is also merit in considering a global approach to QoL, inviting a patient to consider his/her overall sense of QoL as a simple cumulative view. In the end stages of a person's life when energy is limited, this type of simple global assessment is often most practical and appropriate.

Finally, it is worthwhile noting that QoL considerations may have both negative and positive dimensions. Some patients may report that although there have been negative aspects of their illness, positive outcomes have also emerged. This attribute of a QoL assessment invites health professionals to consider the strengths and positive capacities of patients in the context of their care, rather than only focusing on issues of loss and distress.

In the context of this review, the concept of QoL is considered to be the over-arching construct that encompasses the domains of care considered here. The key principles that underpin this notion of QoL are apparent throughout the review and help define questions about when to refer to a SPCS.

1.2 DEVELOPMENT OF THE GUIDELINES

The need for Palliative Care Needs Assessment Guidelines

Late referral, crisis referral, and in some instances non-referral of patients with a life-limiting illness^b to SPCSs can significantly impact the QoL of patients and their caregivers.

Uncertainty regarding when to refer and the reasons to refer are also common amongst the general health professional community. More recently however, there has been a growing recognition that palliative care (PC) services may be appropriate for a wider range of patients than has traditionally been the case.⁵

Given the potential expected increase in the demand for SPCSs, poor articulation about how and when to best refer patients, and the likelihood that resources will remain relatively static at least in the foreseeable future, the challenge facing managers of health services and policy makers is to develop objective, cost-efficient and needs-based strategies for resource allocation. The development of resource allocation strategies will require identifying a) the sub-groups who would most benefit from receiving specialist palliative care (SPC) and ensuring they are offered such care in a timely way; and b) the sub-groups who would gain minimal or no benefit from receiving SPC and offering them alternative care (eg a palliative approach rather than SPC) which is best suited to their needs and strengths.

Palliative Care Australia (PCA) and the Australian Government Department of Health and Ageing have developed the following landmark national policy documents and guides which, together, provide a framework for needs and strengths-based access to quality end-of-life care:

1. PCA (2005) *A Guide to Palliative Care Service Development: A population based approach*²
2. PCA (2005) *Standards for Palliative Care Provision*⁶
3. PCA (2003) *Palliative Care Service Provision in Australia: A Planning Guide*⁷
4. Commonwealth Department of Health and Aged Care (2000) *National Palliative Care Strategy: A National Framework for Palliative Care Service Development*.⁸

It is important to note that not all patients for whom death is expected will need SPC. PCA has argued that central to the development of an integrated plan to deliver quality end-of-life care is the “development of well defined and transparent referral and admission protocols and procedures”.² The **Palliative Care Needs Assessment Guidelines** (hereafter referred to as the Guidelines), together with the **Needs Assessment Tool: Progressive Disease-Cancer** (hereafter referred to as the NAT: PD-C), are pivotal to facilitate equity of access, ie equal access for equal need, to finite PC resources. The NAT: PD-C will provide a rapid strategy for

^b An illness that can reasonably be expected to cause the death of the patient within a foreseeable future.²

efficiently and systematically identifying patients who need SPC initially, as well as any change in status over the course of their advancing disease, as outlined in Figure 1.

The introduction of the Guidelines and NAT: PD-C is expected to reduce the incidence of late and crisis referral and improve referral where psychological, social, physical and spiritual problems are evident. Improved outcomes for patients and families are expected to include improved symptom control, QoL and satisfaction with care.

The target groups for the Guidelines and Needs Assessment Tool

Since the cancer patient population currently represents approximately 90% of the palliative care services' caseload, this group has been identified as the most appropriate target population for the first edition of these Guidelines. It is planned that the Guidelines will be generalised to the non-cancer palliative population after comprehensive evaluation.

The Guidelines and NAT: PD-C are intended to be utilised by *any health professionals* involved in the care of a person with advanced cancer. They will:

- Assist health professionals (GPs, community nurses, specialists, allied health professionals, etc, whose primary work is not in PC) to objectively determine whether or not they are currently meeting the needs of individual patients and their families.
- Provide a framework for initial and ongoing assessment of the need for and degree of specialist palliative care team involvement in the care of individual patients and their families.
- Enable an assessment of the areas of strength, as well as the areas of need, across each of the domains of referral. In instances where an assessment of strength or need is difficult to make, the default position would be referral to a SPCS for a more detailed assessment or review of the patient's and family's circumstances.

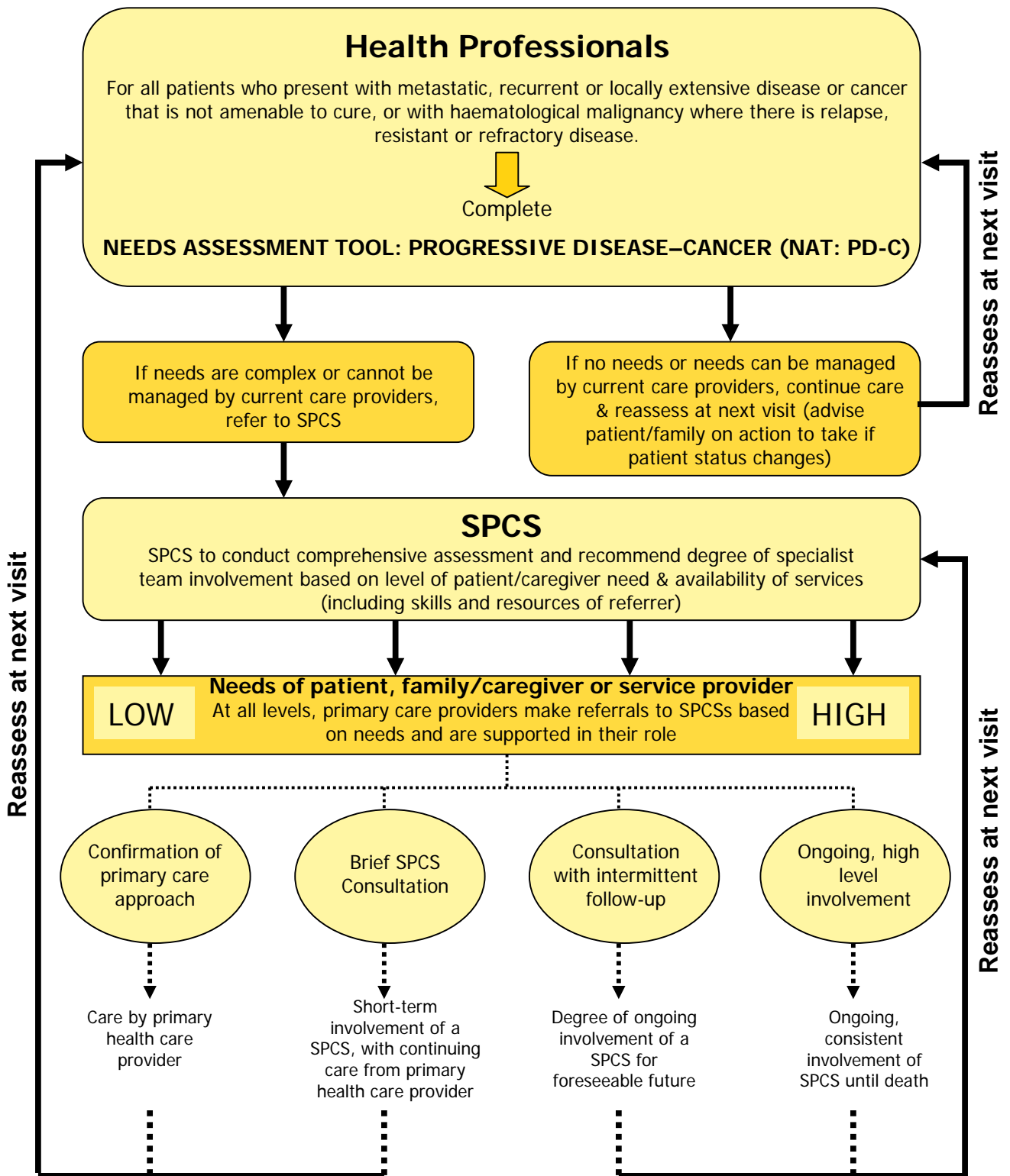


Figure 1: Model for needs-based assessment and triage to appropriate level of palliative care service involvement

How the Guidelines were developed

The Guidelines have been developed after a major search and review of the relevant literature. Each study referred to in this document is given a number (referring to the Reference list) and a “level” indicating the type of study undertaken. All retrieved articles were reviewed using the following NHMRC Levels of Evidence.^c

Level I	evidence is obtained from a systematic review of all relevant randomised controlled trials, usually found in meta-analysis.
Level II	evidence is obtained from at least one properly designed randomised controlled trial.
Level III	evidence is obtained from well-designed controlled trials without randomisation; or from well designed cohort or case control analytic studies, preferably from more than one centre of research; or from multiple time series, with or without the intervention.
Level IVa	evidence is obtained from descriptive studies of provider practices, patient behaviours, knowledge, or attitudes or a systematic review of the descriptive studies.
Level IVb	represents the opinions of respected authorities based on clinical experience or reports of expert committees.
Level QS	Evidence from qualitative studies. [NB: this level has been added to the standard NHMRC levels of evidence given the significant amount of qualitative research on some aspects of palliative care referral.]

Readers should be mindful of the following points when considering the evidence presented in the Guidelines:

1. Much of the evidence reported in the Guidelines is of the incidence or prevalence of physical and psychosocial morbidity and of various practices, for example. In these types of studies, Level IV evidence is the highest level of evidence that can be collected and should therefore be considered the gold standard.
2. There are very limited numbers of published population based studies in the PC area. A majority of the evidence is drawn from research undertaken with specific sub-populations (eg in a type of SPCS or with a particular group of patients) and, therefore, may be less readily generalised to whole populations.
3. The evidence reported in the Guidelines draws from research undertaken in Australia where possible, as well as research conducted in other countries. It is acknowledged that the health care systems in other countries, particularly the United States of America (USA), are very different to the Australian system and that conclusions drawn from that research may not be directly applicable to the Australian setting.

^c NHMRC National Breast Cancer Centre Psychosocial Working Group. Psychosocial clinical practice guidelines: Information, support and counselling for women with breast cancer. 2000.

1.3 OVERVIEW OF THE GUIDELINES

The Guidelines are intended to provide guidance to those caring for people with a life-limiting illness and their families, to ensure that they are offered the most appropriate care to meet their specific needs. They cover all aspects of patient, caregiver and primary health care provider characteristics that may influence the decision to provide more specialist PC to a particular patient or family.

Each of the sections of the following table, *Summary of key evidence underpinning the Guidelines*, presents the key evidence relating to each major potential referral domain. The first five sections review the evidence relating to the patient domains, including the physical as well as the psychosocial, spiritual, cultural and other relevant issues; the final two sections review the evidence relating to the caregiver and family and to health professional domains.

In consideration of the different capacities of SPCSs, the Guidelines are able to be flexibly applied to the varying settings of care, including rural areas, where access to SPCS is limited. The Guidelines review the evidence for alternative modes of delivering support to primary care providers, and detail the common barriers to care. The Guidelines also provide an evidence base that may assist in increasing the capacity of all level of health services to identify needs and deliver appropriate care to patients in the palliative phase of illness.

Readers should be mindful that although the Guidelines provide a review of the evidence in each domain separately, there are considerable inter-relationships that exist *between* the domains covered in each of the sections. For example, there are strong relationships between the patients' physical outcomes and caregivers' psychological outcomes, with uncontrolled physical symptoms in the patient being a major ongoing stressor for caregivers in the home. The quality of family functioning and availability of community services to assist and support "dysfunctional" families may have a significant impact on the fulfilment of a patient's wish to be cared for and/or to die at home. Health professional variables, including their own level of demoralisation, for example, are strongly related to patient variables, including a wish to hasten death.

The cultural diversity of the Australian population must also be taken into consideration when reviewing the evidence presented in the Guidelines. Australia is an ethnically diverse nation and as such, the attitudes and behaviours of patients and families with regard to treatment and end-of-life care may differ depending on their cultural background. The onus is on health care services, in conjunction with individual health professionals, to promote awareness of these issues so that they are able to identify the culturally specific needs that patients may have and to respond to them with sensitivity. Some of these cultural issues are addressed in the following table of key evidence.

Summary of key evidence underpinning the Guidelines

Key evidence: Physical symptoms and functional status	Highest Level of evidence	Relevant References
Fatigue and weakness are reported as the most prevalent problems encountered by patients with advanced cancer.	III ^d	9-18
Younger age (<65 years) is associated with a higher prevalence of pain and may also be associated with severity of pain.	IVa	19, 20
Problems with dyspnoea, nausea, vomiting and pain are reported more frequently and are of higher intensity as performance status decreases.	III	21
There is a decline in physical function and ability to perform daily activities that occurs in parallel with increasing symptom burden. There may be an increased need for assistance in personal care and activities of daily living at this time.	IVa	22
Towards the end of life, expressed need may be far less than actual need, with some patients not seeking advice for symptoms despite their severity. Periodic reviews of the whole patient situation to assess the impact of the disease may highlight unmet needs.	IVa	23
Patients with unmet needs in physical symptom control, occupational functioning, nutrition, sleep and personal care demonstrate higher symptom distress and psychological distress.	IVa	24
Patients with more intense symptoms are more likely to be depressed, suggesting that psychological distress may result in magnification of physical symptoms, or that physical symptoms may have a role in the development of mood disorders in patients with advanced cancer.	IVa	25
The use of non-pharmacological interventions can serve as an adjunct to existing pharmacological pain management practice, reducing pain and improving quality of life.	I	26-28
The inclusion of allied health professionals may enhance the provision of care at the primary care level and help maintain physical function.	II	29-34
Key evidence: Psychological issues	Highest Level of evidence	Relevant References
Psychosocial morbidity often goes undetected in cancer patients. Assessment using standardised measures and feedback about patients' self-reported wellbeing is useful to clinicians, increases clinicians' perceived awareness of their patients' concerns, and	I	35-43

^d Levels III and IVa are considered the highest levels of evidence for prevalence data.

improves doctor-patient communication.		
A diagnosis of depression may be missed in situations in which depression is presumed to be a normal response to the situation; and when staff are unskilled in the diagnosis of psychological disorders.	IVa	44, 45
A <i>desire</i> to hasten death is not necessarily synonymous with a <i>request</i> to hasten death. People may tire of the symptoms and burden of decreasing ability and, in the face of depression, poor symptom control and lack of support mechanisms, these feelings become dominant. However, few terminally ill sustain over time a desire to hasten death.	III	46-48
Cancer patients perceive sexuality as an important aspect of their quality of life. Patients prefer the health professional or nurse to initiate discussions regarding sexual issues.	III	49-51
Patients reporting loss of dignity are far more likely to report psychological distress, symptom distress, higher dependency needs, loss of will to live, depression, hopelessness, anxiety, issues with their appearance and desire for death. Dignity-preserving care incorporates physical, psychological, social and existential elements of the person.	IVa	52, 53, 54
Acute cognitive impairment is a significant burden in the PC population, affecting almost half of all patients prior to death. It may be the result of prescribed medications, sepsis, brain metastases, organ failure, hypercalcaemia or hyponatraemia. If recognised and treated, significant improvements in cognition may be achieved.	III	20, 55-58
Patients reporting better communication with their doctors, especially regarding decision-making and psychosocial and spiritual needs, are less likely to have high levels of death distress, a measure of anxiety and depression specifically linked to death and dying.	IVa	59
Pre-existing post-traumatic stress disorder (PTSD) in patients with cancer may be complicated by depression, grief, substance abuse, anxiety and adjustment disorders. Be alert to more severe symptoms of PTSD in patients with more advanced disease, more recent treatment, more intrusive treatment and cancer recurrence.	II	60-62
Key evidence: Cultural and social issues	Highest Level of evidence	Relevant References
As with families and patients, health professionals regard language as one of the main barriers to providing adequate care. Use of interpreter services may overcome some of these difficulties.	IVa	63
The family's level of involvement in the patient's illness varies across	IVa	64-69

cultures, as does the family's attitudes toward the provision of information. An understanding of cultural practices and beliefs may assist in providing optimal care to people of culturally and linguistically diverse backgrounds.		
Whilst PC teams need to consider the rituals and practices of different cultural groups, it is important to maintain an individualised approach to the treatment of patients, as membership of a particular cultural group does not necessarily imply that the individual shares all that group's culture, beliefs and values.	IVb	65, 70
Social support helps reduce emotional distress. Lack of social support has been significantly associated with wish to hasten death. As well as encouraging patients to utilise available support systems, health professionals and volunteers are an important source of support.	IVa	46, 71, 72, 73-75
Different types and levels of support may be appropriate to offer to different groups of patients: <ul style="list-style-type: none"> • Female cancer patients report greater unmet support needs than male patients. • Younger patients and their families have greater unmet social needs than older patients. • Practical information regarding services, treatment options, accommodation and travel are especially important for patients in rural areas as they often spend time away from intimate support networks. 	IVa	14, 76, 23, 77-80
Formal support groups can provide social support for patients where they can feel empathy, gain information about methods of coping, stress reduction techniques and problem solving skills. Social support groups improve the mood of patients and may reduce anxiety and depression.	II	81-83
Key evidence: Spiritual issues	Highest Level of evidence	Relevant References
Hope is an important coping mechanism for patients. Families have been shown to have lower levels of hope than palliative care patients; and older family members may experience higher levels of hopelessness and fatigue than younger family members. Health professionals play an important role in nurturing hope, balanced with truth, in patients and their families.	IVa	84-86
For patients with advanced cancer, existential concerns are as prevalent as physical and psychological symptoms and include feelings of isolation, hopelessness and uncertainty.	IVa	87, 88

Spiritual wellbeing is associated with higher quality of life and life satisfaction, lower rates of depression, anxiety, hopelessness and death distress. Patients with greater spiritual wellbeing may also experience less symptom distress.	II	46, 59, 87, 89-91
The attitudes of health professionals towards facilitating the provision of spiritual needs of patients and their families have a significant impact on the delivery of these services.	IVa	92, 93
Almost all family physicians believe spiritual wellbeing is an important component of holistic care for patients with cancer, yet few are likely to address the spiritual needs of patients. Barriers to health professionals providing spiritual care include a lack of time, a lack of training, difficulty identifying who needs to discuss spiritual issues and fear of projecting their own beliefs onto patients.	IVa	93-95
Key evidence: Other issues	Highest Level of evidence	Relevant References
Australian research has identified the costs of caring for patients at home to be substantial and may include the costs of medications, costs for respite care, other health care costs (podiatry, dental), hiring or buying specialist equipment and aids, housing alterations and maintenance, special food or clothing and continence products.	IVa	96, 97
The need to travel for specialist services, gap payments for treatment, loss of income (for the patient and caregiver) and upfront costs such as running two households if the patient has relocated, all complicate financial issues further for patients from a regional, rural or remote area.	IVa	78-80, 98
Despite the significant financial impact of care giving, few people are aware of government caregiver benefits, many have difficulty accessing payments, do not meet criteria, are given incorrect advice or experience delays.	IVa	96
Health professionals need to be aware of the financial situation of their patients with advanced cancer, and patients and families need to be informed of services and programs that may assist with meeting the costs of their palliative care.	IVb	Consensus
If an advanced care directive is in place, the likelihood of doctors following patients' wishes may be significantly increased. This best follows comprehensive discussions regarding treatment options and likely outcomes.	IVa	99-104
Developing and implementing advance care planning and creating Advance Directives can result in increased patient satisfaction, patients knowing that their doctors have a better understanding of	II	105-108

their wishes, greater comfort making end-of-life decisions, continued discussion of patients' concerns with their families and increased likelihood of discussing future health plans with their doctors.		
Barriers to discussing advance care planning include time constraints, discomfort on the part of the patient, family or health professional, fear about being unable to change one's mind, a lack of knowledge, and for Indigenous and Torres Strait Islander patients and patients from culturally and linguistically diverse groups, language.	IVa	65, 68, 109
Key evidence: Caregiver and family issues	Highest Level of evidence	Relevant References
Cancer is one of the 10 most common health conditions in receipt of informal care giving in Australia. Care may be equivalent to a full-time job, with 20% of caregivers providing full-time or constant care. Almost 80% of caregivers live with the person receiving the care; 43% of all caregivers are partners; 25% are children; 21% are parents of the person receiving the care.	III	110-112
There are numerous health implications for caregivers, with increased morbidity and mortality associated with care giving. Caregivers of patients receiving palliative care have lower quality of life (impairment in physical functioning, general health, and vitality) and worse overall physical health than caregivers of patients receiving curative or active treatment. As patients deteriorate physically, caregiver quality of life worsens, suggesting a greater need for support at this time.	III	113, 114
Many caregivers feel positively about caring and derive deep satisfaction in this role. However, the impact of care giving on psychological wellbeing includes: <ul style="list-style-type: none"> • possible increased risk of depression and anxiety, increasing in incidence with proximity to death • traumatic stress and post-traumatic stress disorder • increased risk of complicated grief • feelings of sadness, anger, resentment and inadequacy. 	III	96, 115-129
There may be significant social, financial and employment implications for caregivers, including increased social isolation and loneliness; impact on holidays and personal time; changes in family and other relationships; limited time for personal relationships; a financial burden for family members; both in out-right expenses and in lost income and benefits; reduced chance of being employed, being unable to work or having to work in lower paid jobs or for fewer hours;	IVa	96, 97, 110, 112, 130-132

and loss of superannuation and savings for retirement.		
<p>Health professionals should be aware of the caregiver groups who are at risk of poorer psychological outcomes and higher levels of caregiver burden and facilitate appropriate assistance for them.</p> <p>These groups include:</p> <ul style="list-style-type: none"> • caregiver wives have higher levels of depression and poorer health than caregiver husbands • those with smaller social networks • those with lower perceived caregiver satisfaction and higher perceived levels of stressful behavioural problems and self care problems of the patient • those with higher levels of anxiety • those with higher levels of anger • those who care for patients with higher levels of need • those caring for longer periods • caregivers who are younger (<65 years) • caregivers with limited social networks and more restrictions in their daily activities due to care giving. 	III	133-137
Lack of adequate information is a major concern for caregivers and families. Understanding details relating to the illness helps caregivers cope and reduce fear, stress and anxiety. Both written and verbal information, as well as opportunities for discussion and clarification are important for family understanding and satisfaction with care.	IVa	96, 116, 138-140
Caregivers' psychological wellbeing is predicted by the quality of the relationship with the patient and by a lower Karnofsky score of the patient at the time of referral to SPCS, suggesting a need for earlier referral to reduce caregiver burden.	III	141
Unresolved psychological problems in the caregivers may place the caregiver at risk of medical as well as psychological illness.	III	142
Recognition and treatment of psychological morbidity in patients may not only improve the patients' quality of life, but also has implications for the long term psychological morbidity of surviving partners. Unrelieved psychological symptoms of the patient appear to increase the risk of caregivers' psychological morbidity.	III	135
The level of palliative care received by the patient and his/her family improves psychological wellbeing of the caregiver and family during bereavement.	III	143
Involvement of specialist palliative care services in the care of people with advanced cancer may be associated with increased survival of	III	144

bereaved spouses.		
Caregivers have lower levels of depressive symptoms if they perceive that the doctors listen to them about the patient's needs and consider their opinions regarding the patient's illness and medical treatment.	IVa	136
Families (including children) of people with advanced cancer experience similar psychological problems to caregivers. Physical problems of the family members as well as of the patient can have a negative effect on the psychological health of the family, including poorer mental health and cognitive functioning during and after the patient's illness.	III	116-118, 143, 145-148
Functioning of the family is important, since poor communication between family members may lead to higher family anxiety. Families with open communication, less conflict and high expressiveness have fewer mood disturbances and are more able to share their fears, anxiety and frustrations and solve problems together, leading to lower distress for members.	III	82, 149, 150
Key evidence: Health professional issues	Highest Level of evidence	Relevant References
Health professionals are ideally placed to provide information and proactively assess the need for referral to specialist palliative care services.	IVa	151-153
GPs are ideally situated to coordinate care for patients with advanced cancer; and a formalised team approach to care can potentially improve patient outcomes.	IVa	154, 155
High levels of psychological morbidity are found in oncology doctors and nurses, oncologists, specialist palliative care providers and allied health professionals.	III	34, 156-159
Health professionals report that both formal and informal sources of emotional support are an important aspect in aiding them to provide adequate palliative care; with oncology staff, GPs, nurses and allied health professionals all reporting a paucity of formal support..	III	154, 156, 158, 160-165
Higher levels of professional burnout may be found in health professionals who spend a greater amount of time with patients, and in younger nurses and hospice staff. Reasons for burnout, other than emotional distress, include insufficient personal and/or vacation time, continuous exposure to fatal illness, frustration with limited therapeutic success, uncertainty of reimbursement for physician service, and lack of opportunities for other professional activities such	IVa	164-168

as teaching, research or administration.		
Doctors who report deficiencies or absence of communication skills training, even when they have postgraduate training in a medical specialty, manifest the most anxiety and least confidence when dealing with patients' problems. These doctors are also those with a higher prevalence of depersonalisation, lower personal accomplishment and are most at risk of burnout.	IVa	157

REFERENCES

1. World Health Organization. *National Cancer Control Programmes: Policies and managerial guidelines*. 2nd ed. Geneva: World Health Organization; 2002.
2. Palliative Care Australia. *A guide to palliative care service development: A population based approach*. Deakin West: Palliative Care Australia; February 2005.
3. Nikoletti S, Cohen R. Quality of life and the cancer journey. In: Porock D, Palmer D, eds. *Cancer of the Gastrointestinal Tract*. London: Whurr Publishers; 2004:1-38.
4. World Health Organisation Quality of Life Group. Study protocol for the World Health Organisation project to develop a Quality of Life assessment instrument (WHOQOL). *Qual Life Res*. 1993;2:153-159.
5. World Health Organization. *Palliative care: the solid facts*. Copenhagen: World Health Organization; 2004.
6. Palliative Care Australia. *Standards for palliative care provision*. Deakin West: Palliative Care Australia; 2005.
7. Palliative Care Australia. *Palliative care service provision in Australia: A planning guide*. Deakin West: Palliative Care Australia; September 2003.
8. Australian Government Department of Health and Ageing. *National Palliative Care Strategy: A national framework for palliative care service development*. Canberra: Australian Government Department of Health and Ageing; 2000.
9. Potter J, Hami F, Bryan T, Quigley C. Symptoms of 400 patients referred to palliative care services: Prevalence and patterns. *Palliat Med*. 2003;17:310-314.
10. Donnelly S, Walsh D. The symptoms of advanced cancer. *Semin Oncol*. 1995;22(2, Suppl 3):67-72.
11. Radbruch L, Nauk F, Ostgathe C, et al. What are the problems in palliative care? Results from a representative survey. *Support Care Cancer*. 2003;11(17):442-451.
12. Vainio A, Auvinen A. Prevalence of symptoms among patients with advanced cancer: An international collaborative study. *J Pain Symptom Manage*. 1996;12(1):3-10.
13. Wilson KG, Graham ID, Viola RA, et al. Structured interview assessment of symptoms and concerns in palliative care. *Canadian Journal of Psychiatry*. 2004;49(6):350-358.
14. Lidstone V, Butters E, Seed P, Sinnott C, Beynon T, Richards M. Symptoms and concerns amongst cancer outpatients: Identifying the need for specialist palliative care. *Palliat Med*. 2003;17(7):588.
15. Stone P, Hardy J, Broadley K, Tookman AJ, Kurowska A, A'Hern R. Fatigue in advanced cancer: A prospective controlled cross-sectional study. *Br J Cancer*. 1999;79(9-10):1479-1486.
16. Stromgren AS, Groenvold M, Pedersen L, Olsen AK, Sjogren P. Symptomatology of cancer patients in palliative care: Content validation of self-assessment questionnaires against medical records. *Eur J Cancer*. 2002;38(6):788-794.
17. Jenkins CA, Schulz M, Hanson J. Demographic, symptom and medication profiles of cancer patients seen by a palliative care consult team in a tertiary referral hospital. *J Pain Symptom Manage*. 2000;19(3):174-184.
18. Pautex S, Berger A, Chatelain C, Herrmann F, Zulian GB. Symptom assessment in elderly cancer patients receiving palliative care. *Crit Rev Oncol Hematol*. 2003;47(3):281-286.
19. Donnelly S, Walsh D, Rybicki L. The symptoms of advanced cancer: Identification of clinical and research priorities by assessment of prevalence and severity. *J Palliat Care*. 1995;11(1):27-32.
20. Bruera E, Neumann C, Brenneis C, Quan H. Frequency of symptom distress and poor prognostic indicators in palliative cancer patients admitted to a tertiary palliative care unit, hospices, and acute care hospitals. *J Palliat Care*. 2000;16(3):16-21.
21. Mercadante S, Casuccio A, Fulfarò F. The course of symptom frequency and intensity in advanced cancer patients followed at home. *J Pain Symptom Manage*. 2000;20(2):104-112.
22. Schuit KW, Sleijfer DT, Meijler WJ, et al. Symptoms and functional status of patients with disseminated cancer visiting outpatient departments. *J Pain Symptom Manage*. 1998;16(5):290-297.
23. Davis B, Cowley S, Ryland R. The effects of terminal illness on patients and their carers. *J Adv Nurs*. 1996;23(3):512-520.

24. Morasso G, Capelli M, Viterbori P, et al. Psychological and symptom distress in terminal cancer patients with met and unmet needs. *J Pain Symptom Manage*. 1999;17(6):402-409.
25. Lloyd-Williams M, Dennis M, Taylor F. A prospective study to determine the association between physical symptoms and depression in patients with advanced cancer. *Palliat Med*. 2004;18(6):558-563.
26. Zaza C, Sellick SM, Willan A, Reyno L, Browman GP. Health care professionals' familiarity with non-pharmacological strategies for managing cancer pain. *Psychooncology*. 1999;8(2):99-111.
27. Meyer TJ, Mark MM. Effects of psychosocial interventions with adult cancer patients: a meta-analysis of randomized experiments. *Health Psychol*. 1995;14(2):101-108.
28. Fawzy I, Fawzy N, Arndt LA, Pasnau RO. Critical review of psychosocial interventions in cancer care. *Arch Gen Psychiatry*. 1995;52(2):100-113.
29. Laakso E, McAuliffe AJ, Cantlay A. The impact of physiotherapy intervention on functional dependence and quality of life in palliative patients. *Cancer Forum*. 2003;27(1):15-20.
30. Bye R. When clients are dying: Occupational therapists' perspectives. *The Occupational Therapy Journal of Research*. 1998;18(1):3-24.
31. Armitage K, Crowther L. The role of the occupational therapist in palliative care. *European Journal of Palliative Care*. 1999;6(5):154-157.
32. Kealey P, McIntyre I. An evaluation of the domiciliary occupational therapy service in palliative cancer care in a community trust: a patient and carers perspective. *European Journal of Cancer Care*. 2005;14:232-243.
33. Taylor K, Currow D. A prospective study of patient identified unmet activity of daily living needs among cancer patients at a comprehensive cancer care centre. *Australian Occupational Therapy Journal*. 2003;50:79-85.
34. Rahman H. Journey of providing care in hospice: Perspectives of occupational therapists. *Qual Health Res*. 2000;10(6):806-818.
35. Espallargues M, Valderas J, Alonso J. Provision of feedback on perceived health status to health care professionals: A systematic review of its impact. *Med Care*. 2000;38(2):175-186.
36. Greenhalgh J, Meadows K. The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: a literature review. *J Eval Clin Pract*. 1999;5(4):401-416.
37. Velikova G, Booth L, Smith AB, et al. Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. *J Clin Oncol*. 2004;22(4):714-724.
38. Boyes A, Newell S, Girgis A, McElduff P, Sanson-Fisher R. Does routine assessment and real-time feedback improve cancer patients' psychosocial well-being? *Eur J Cancer Care*. 2006;15:163-171.
39. Fallowfield L, Ratcliffe D, Jenkins V, Saul J. Psychiatric morbidity and its recognition by doctors in patients with cancer. *Br J Cancer*. 2001;84(8):1011-1015.
40. Newell S, Sanson Fisher RW, Girgis A, Bonaventura A. How well do medical oncologists' perceptions reflect their patients' reported physical and psychosocial problems? *Cancer*. 1998;83(8):1640-1651.
41. National Breast Cancer Centre, National Cancer Control Initiative, NHMRC. *Clinical practice guidelines for the psychosocial care of adults with cancer*. Camperdown, NSW: National Breast Cancer Centre; 2003.
42. National Comprehensive Cancer Network. *Distress management guidelines*. Jenkintown, Pennsylvania: National Comprehensive Cancer Network; 2004.
43. Girgis A, Boyes A. Proactive routine monitoring and intervention to reduce the psychosocial impact of cancer therapy. *Clinical Psychologist*. 2005;9(2):70-73.
44. Brugha T. Depression in the terminally ill. *Br J Hosp Med*. 1993;50:175-181.
45. Maguire P, Walsh S, Jeacock J, Kingston R. Physical and psychological needs of patients dying from colorectal cancer. *Palliat Med*. 1999;13(1):45.
46. Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*. 2000;284(22):2907-2911.
47. Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA*. 2000;284(19):2460-2468.

48. Chochinov HM, Wilson KG, Enns M, Mowchun N. Desire for death in the terminally ill. *Am J Psychiatry*. 1995;152(8):1185.
49. Ananth H, Jones L, King M, Tookman A. The impact of cancer on sexual function: a controlled study. *Palliat Med*. 2003;17(2):202-205.
50. Lemieux L, Kaiser S, Pereira J, Meadows LM. Sexuality in palliative care: patient perspectives. *Palliat Med*. 2004;18(7):630-637.
51. Waterhouse J, Metcalfe M. Attitudes towards nurses discussing sexual concerns with patients. *J Adv Nurs*. 1991;16:1048-1054.
52. Chochinov HM. Dignity-conserving care - a model for palliative care. *Journal of the American Medical Association*. 2002;287(17):2253-2260.
53. Chochinov HM, Hack T, Hassard T, Kristjanson LJ. Dignity and psychotherapeutic considerations in end-of-life care. *J Palliat Care*. 2004;20(3):134.
54. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity in the terminally ill: a cross-sectional cohort study. *Lancet*. 2002;360(9350):2026-2030.
55. Stromgren AS, Groenvold M, Pedersen L, Olsen AK, Spile M, Sjogren P. Does the medical record cover the symptoms experienced by cancer patients receiving palliative care? A comparison of the record and patient self-rating. *J Pain Symptom Manage*. 2001;21(3):189-196.
56. Hjermstad MJ, Loge JH, Kaasa S. Methods for assessment of cognitive failure and delirium in palliative care patients: implications for practice and research. *Palliat Med*. 2004;18(6):494-506.
57. Gagnon P, Charbonneau C, Allard P, Soulard C, Dumont S, Fillion L. Delirium in advanced cancer: a psychoeducational intervention for family caregivers. *J Palliat Care*. 2002;18(4):253-261.
58. Bruera E, Miller L, McCallion J, Macmillan K, Krefting L, Hanson J. Cognitive failure in patients with terminal cancer: A prospective study. *J Pain Symptom Manage*. 1992;7(4):192-195.
59. Chibnall JT, Videen SD, Duckro PN, Miller DK. Psychosocial-spiritual correlates of death distress in patients with life-threatening medical conditions. *Palliat Med*. 2002;16(4):331-338.
60. Gurevich M, Devins GM, Rodin GM. Stress response syndromes and cancer: conceptual and assessment issues. *Psychosomatics*. 2002;34(4):259-281.
61. Kangas M, Henry JL, Bryant RA. Posttraumatic stress disorder following cancer: a conceptual and empirical review. *Clin Psychol Rev*. 2002;22(4):499-524.
62. Jacobsen PB, Widows M, Hann D, Andrykowski M, Kronish L, Fields KK. Posttraumatic stress disorder symptoms after bone marrow transplantation for breast cancer. *Psychosom Med*. 1998;60(3):366-371.
63. McNamara B, Martin K, Waddell C, Yuen K. Palliative care in a multicultural society: perceptions of health care professionals. *Palliat Med*. 1997;11:359-367.
64. McGrath P, Vun M, McLeod L. Needs and experiences of non-English-speaking hospice patients and families in an English speaking country. *Am J Hosp Palliat Care*. 2001;18(5):305-312.
65. Trill MD, Holland J. Cross-cultural differences in the care of patients with cancer : a review. *Gen Hosp Psychiatry*. 1993;15(1):21-30.
66. Tong KL, Spicer BJ. The Chinese palliative care patient and family in North America: A cultural perspective. *J Palliat Care*. 1994;10(1):26-28.
67. McGrath P, Ogilvie KF, Rayner R, Holewa H, Patton MA. The "right story" to the "right person": Communication issues in the end-of-life care for Indigenous people. *Aust Health Rev*. 2005;29(3):306-316.
68. Sullivan K. *National Indigenous Palliative Care Needs Study*. Sydney: Australian Government Department of Health and Ageing; 2003.
69. Morgan DL, Slade MD, Morgan CM. Aboriginal philosophy and its impact on health care outcomes. *Aust N Z J Public Health*. 1997;21(6):597-601.
70. Hall P, Stone G, Fiset VJ. Palliative Care: how can we meet the needs of our multicultural communities? *J Palliat Care*. 1998;14(2):46-4946.
71. Roberts CS, Cox CE, Shannon VJ, Wells NL. A closer look at social support as a moderator of stress in breast cancer. *Health Soc Work*. 1994;19(3):157-164.

72. Grassi L, Malacarne P, Masestri A, Ramelli E. Depression, psychosocial variables and occurrence of life events among patients with cancer. *J Affect Disord.* 1997;44:21-30.
73. McIlmurray M, Thomas C, Francis B, Morris S, Soothill K, Al-Hamad A. The psychosocial needs of cancer patients: findings from an observational study. *European Journal of Cancer Care.* 2001;10(261-69).
74. Claxton-Oldfield S, Jefferies J, Fawcett C, Wasykiw L, Claxton-Oldfield J. Palliative care volunteers: Why do they do it? *J Palliat Care.* 2004;20(2):78-84.
75. McKinnon MM. The participation of volunteers in contemporary palliative care. *Aust J Adv Nurs.* 2002;19(4):38-44.
76. Sanson-Fisher RW, Girgis A, Boyes A, Bonevski B, Burton L, Cook P. The unmet supportive care needs of patients with cancer. *Cancer.* 2000;88(1):226-237.
77. Wilkes L, White K, O'Riordan L. Empowerment through information: supporting rural families of oncology patients in palliative care. *Aust J Rural Health.* 2000;8:41-46.
78. McGrath P, Rogers T. Relocation for specialist treatment for paediatric acute lymphoblastic leukaemia. *Austral-Asian Journal of Cancer.* 2003;2(2):107-115.
79. Hegney D, Pearce S, Rogers-Clark C, Martin-McDonald K, Buikstra E. Close, but still too far. The experience of Australian people with cancer commuting from a regional to a capital city for radiotherapy treatment. *European Journal of Cancer Care.* 2005;14(1):75-82.
80. Clavarino A, Lowe JB, Carmont S, Balanda K. The needs of cancer patients and their families from rural and remote areas of Queensland. *Aust J Rural Health.* 2002;10:188-195.
81. Weis J. Support groups for cancer patients. *Support Care Cancer.* 2003;11(12):763-768.
82. Spiegel D, Bloom JR, Gottheil E. Family environment as a predictor of adjustment to metastatic breast carcinoma. *Journal of Psychosocial Oncology.* 1983;1(1):33-44.
83. Owen JE, Klapow JC, Hicken B, Tucker DC. Psychosocial interventions for cancer: a review and analysis using a three tiered outcomes model. *Psychooncology.* 2001;10:218-230.
84. Nikolaichuk CL, Bruera E. On the nature of hope in palliative care. *J Palliat Care.* 1998;14(1):36.
85. Clayton J, Butow PN, Arnold RM, Tattersall MHN. Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer.* 2005;103(9):1965-1975.
86. Benzein E, Berg A. The level of and relation between hope, hopelessness and fatigue in patients and family members in palliative care. *Palliat Med.* 2005;19:234-240.
87. Breitbart W. Spirituality and meaning in supportive care: spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. *Support Care Cancer.* 2002;10(4):272-280.
88. Morita T, Kawa M, Honke Y, et al. Existential concerns of terminally ill cancer patients receiving specialised palliative care in Japan. *Support Care Cancer.* 2004;12:137-140.
89. Levine EG, Targ E. Can psychosocial status affect functional well-being in women with breast cancer? Paper presented at: International Congress of Behavioural Medicine, 2002; Helsinki.
90. Tate DG, Forchheimer M. Quality of life, life satisfaction, and spirituality. *American Journal of Medical Rehabilitation.* 2002;81:400-410.
91. Mytko JJ, Knight SJ. Body, mind and spirit: towards the integration of religiosity and spirituality in cancer quality of life research. *Psychooncology.* 1999;8:439-450.
92. Kristeller JL, Zumbrun CS, Schilling RF. 'I would if I could': How oncologists and oncology nurses address spiritual distress in cancer patients. *Psychooncology.* 1999;8:451-458.
93. Sheldon JE. Spirituality as a part of nursing. *Journal of Hospice and Palliative Nursing.* 2000;2(3):101-108.
94. Ellis MR, Vinson DC, Ewigman B. Addressing spiritual concerns of patients: family physicians attitudes and practices. *J Fam Pract.* 1999;48(2):105-109.
95. Daaleman TP, VandeCreek L. Placing religion and spirituality in end-of-life care. *JAMA.* 2000;284(19):2514-2517.

96. Grbich CF, Maddocks I, Parker D. Family caregivers, their needs, and home-based palliative care services. *Journal of Family Health*. 2001;7(2):171-188.
97. Fisher D. *Caring Costs. A survey of tax issues and health and disability related costs for carer families*. Canberra: Carers Association of Australia; 1998.
98. McGrath P. "It's horrendous - but really, what can you do?" Preliminary findings on financial impact of relocation for specialist treatment. *Aust Health Rev*. 2000;23(3):94-103.
99. Waddell C, Clarnette RM, Smith M, Oldham L, Kellehear A. Treatment decision-making at the end of life: a survey of Australian doctors' attitudes towards patients' wishes and euthanasia. *Med J Aust*. 1996;165:540-544.
100. Hawkins H, Cartwright C. Advance health care planning and the GP. Is it time to move forward? *Aust Fam Physician*. 2000;29:704-707.
101. Kerridge IH, Pearson S-A, Rolfe IE, Lowe M. Decision making in CPR: attitudes of hospital patients and health care professionals. *Med J Aust*. 1998;169:128-131.
102. Ryan C. Matters of life and death: the challenge of CPR decision making. How can we improve patient involvement in this complex process? *Med J Aust*. 1998;169:124-125.
103. Taylor D, Ugoni A, Cameron P, McNeil J. Advance directives and emergency department patients: ownership rates and perceptions of use. *Internal Medicine Journal*. 2003;33:586-592.
104. Nair B, Kerridge I, Dobson A, McPhee J, Saul P. Advance care planning in residential care. *Aust N Z J Med*. 2000;30(3):339-343.
105. Smucker WD, Ditto PH, Moore KA. Elderly outpatients respond favourably to a physician-initiated advance directive discussion. *J Am Board Fam Pract*. 1993;6(5):473-482.
106. Tierney WM, Dexter PR, Gramelspacher GP, et al. The effect of discussions about advance directives on patients' satisfaction with primary care. *J Gen Intern Med*. 2001;16:32-40.
107. Ditto PH, Danks JH, Smucker WD, et al. Advance directives as acts of communication. A randomized controlled trial. *Arch Intern Med*. 2001;161:421-430.
108. Virmani J, Schneiderman LJ, Kaplan RM. Relationship of advance directives to physician-patient communication. *Arch Intern Med*. 1994;154:909-913.
109. NSW Health Department. *Using advance care directives*: NSW Health Department; 2004.
110. Aoun S. *The hardest thing we have ever done: The social impact of caring for terminally ill people In Australia 2004*. Deakin West: Palliative Care Australia; 2004.
111. Hayman JA, Langa KM, Kabeto MU, et al. Estimating the cost of informal caregiving for elderly patients with cancer. *J Clin Oncol*. 2001;19(13):3219-3225.
112. Australian Bureau of Statistics. *Disability, ageing and carers, Australia: summary of findings, 1998*: Australian Bureau of Statistics; April 1999. Cat no. 44330.0.
113. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the caregiver health effects study. *JAMA*. 1999;282(23):2215-2219.
114. Weitzner MA, McMillan SC, Jacobsen PB. Family caregiver quality of life: differences between curative and palliative cancer treatment settings. *J Pain Symptom Manage*. 1999;17(6):418-428.
115. Grunfeld E, Coyle D, Whelan T, et al. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *Can Med Assoc J*. 2004;170(12):1795-1801.
116. Lewis FM. Strengthening family supports. *Cancer*. 1990;65:752-759.
117. Kissane DW, Bloch S, Burns W, McKenzies D, Posterino M. Psychological morbidity in the families of patients with cancer. *Psychooncology*. 1994;3(1):47-56.
118. Harrison J, Haddad P, Maguire P. The impact of cancer on key relatives: a comparison of relative and patient concerns. *Eur J Cancer*. 1995;31(11):1736-1740.
119. Carter PA, Chang BL, Lobchuk MM, Degner LF. Sleep and depression in cancer caregivers. *Cancer Nurs*. 2000;23(6):410-415.
120. Aranda SK, Hayman-White K. Home caregivers of the person with advanced cancer. *Cancer Nurs*. 2001;24(11):300-306.
121. Grov EK, Dahl AA, Moum T, Fossa SD. Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Ann Oncol*. 2005;16(7):1185-1191.

122. Vanderwerker LC, Laff RE, Kadan-Lottick NS, McColl S, Prigerson H. Psychiatric disorders and mental health service use among caregivers of advanced cancer patients. *J Clin Oncol.* 2005;23(28):6899-6907.
123. Butler LD, Field N, Busch A, Seplaki J, Hastings T, Spiegel D. Anticipating loss and other temporal stressors predict traumatic stress symptoms among partners of metastatic/recurrent breast cancer patients. *Psychooncology.* 2005;14:492-502.
124. Barg FK, Pasacreta JV, Nuamah I, Robinaon K, Angelitti K, Yasko JM. A description of psychoeducational intervention for family caregivers of cancer patients. *Journal of Family Nursing.* 1998;44:394-413.
125. Yates PRNM. Family coping: issues and challenges for cancer nursing. *Cancer Nurs.* 1999;22(1):63-71.
126. Nijboer C, Tempelaar R, Sanderman R, Triemstra M, Spruijt RJ, van den Bos GA. Cancer and caregiving: the impact on the caregiver's health. *Psychooncology.* 1998;7(1):3-13.
127. Haley WE, LaMonde LA, Han B, Narramore S, Schonwetter R. Family caregiving in hospice: effects on psychological and health functioning among spousal caregivers of hospice patients with lung cancer and dementia. *Hosp J.* 2001;15(4):1-18.
128. Prigerson HG, Frank E, Kasl SV, et al. Complicated grief and bereavement-related depression as distinct disorder: preliminary empirical validation in elderly bereaved spouses. *Am J Psychiatry.* 1995;152:22-30.
129. Horowitz M, Siegel B, Holen A, Bonanno GA, Millbrath C, Stinson CH. Diagnostic criteria for complicated grief disorder. *The American Journal of Psychiatry.* 1997;154(7):904-910.
130. Schofield HL, Herrman HE, Bloch S. A profile of Australian family caregivers: diversity of roles and circumstances. *Aust N Z J Public Health.* 1997;21(1):59-66.
131. Briggs H, Fisher D. *Warning- caring is a health hazard.* Canberra: Carers Association of Australia; 2000.
132. Payne S, Smith P, Dean S. Identifying the concerns of informal carers in palliative care. *Palliat Med.* 1999;13(1):37-44.
133. Haley WE, LaMonde LA, Han B, Burton AM, Schonwetter R. Predictors of depression and life satisfaction among spousal caregivers in hospice: Application of a Stress Process Model. *Journal of Palliative Medicine.* 2003;6(2):215-224.
134. Flaskerud JH, Carter PA, Lee P. Distressing emotions in female caregivers of people with AIDS, age-related dementias, and advanced-stage cancers. *Perspect Psychiatr Care.* 2000;36(4):121-130,.
135. Valdimarsdottir U, Helgason AR, Furst CJ, Adolfsson J, Steineck G. The unrecognised cost of cancer patients' unrelieved symptoms: a nationwide follow-up of their surviving partners. *Br J Cancer.* 2002;86(10):1540-1545.
136. Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. *Ann Intern Med.* 2000;132(6):451-459.
137. Goldstein NE, Concato J, Fried TR, Kasl SV, Johnson-Hurzeler R, Bradley EH. Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *J Palliat Care.* 2004;20(1):38-43.
138. Kirk P, Kirk I, Kristjanson LJ. What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *Br Med J.* 2004;328(7452):5.
139. Rose K. A qualitative analysis of the information needs of informal carers of terminally ill cancer patients. *J Clin Nurs.* 1999;8(1):81-88.
140. Leonard KM, Enzle S, McTavish J, Cumming C, Cumming D. Prolonged cancer death: a family affair. *Cancer Nurs.* 1995;18(3):222-227.
141. Kelly B, Edwards P, Synott R, Neil C, Baillie R, Battistutta D. Predictors of bereavement outcome for family carers of cancer patients. *Psychooncology.* 1999;8(3):237-249.
142. Kurtz ME, Kurtz JC, Given CW, Given B. Predictors of post bereavement depressive symptomatology among family caregivers of cancer patients. *Support Care Cancer.* 1997;5(1):53-60.
143. Kristjanson LJ, Sloan JA, Dudgeon D, Adaskin E. Family members' perceptions of palliative cancer care: predictors of family functioning and family members' health. *J Palliat Care.* 1996;12(4):10-20.

144. Christakis NA, Iwashyna TJ. The health impact of health care on families: A matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Soc Sci Med*. 2003;57:465-475.
145. Vachon ML, Kristjanson L, Higginson I. Psychosocial issues in palliative care: the patient, the family, and the process and outcome of care. *J Pain Symptom Manage*. 1995;10(2):142-150.
146. Welch AS, Wadsworth ME, Compas BE. Adjustment of children and adolescents to parental cancer. *Cancer*. 1996;77(7):1409-1418.
147. Nelson E, Sloper P, Charlton A, While D. Children who have a parent with cancer. *J Cancer Educ*. 1994;9:30-36.
148. Christ GH, Siegel K, Freund B, et al. Impact of parental terminal cancer on latency-age children. *Am J Orthopsychiatry*. 1993;63(3):417-425.
149. Davies B, Reimer J, Martens N. Family functioning and its implications for palliative care. *J Palliat Care*. 1994;10(1):29-36.
150. Hodgson C, Higginson IJ, McDonnell M, Butters E. Family anxiety in advanced cancer: A multicentre prospective study in Ireland. *Br J Cancer*. 1997;76(9):121-1214.
151. Sanders BS, Burkett TL, Dickinson GE, Tournier RE. Hospice referral decisions: The role of physicians. *Am J Hosp Palliat Care*. 2004;21(3):196-202.
152. McNeilly DP, Hillary K. The hospice decision: Psychosocial facilitators and barriers. *Omega*. 1997;35(2):193-217.
153. Quantum Market Research. *Community Attitudes To Palliative Care Issues - Quantitative Report*. Canberra: Australian Government Department of Health and Ageing; January 2003.
154. Mount Olivet Community Service. *Research study into the educational, training and support needs of general practitioners in palliative care*. Canberra: Rural Health and Palliative Care Branch, Australian Government Department of Health and Ageing; June 2003.
155. Mitchell G, De Jong IC, De Mar CB, Clavarino AM, Kennedy R. General practitioner attitudes to case conferences: how can we increase participation and effectiveness? *Med J Aust*. 2002;177(2):93-94.
156. Catalan J, Burgess A, Pergami A, Hulme N, Gazzard B, Phillips R. The psychological impact on staff of caring for people with serious diseases: the case of HIV infection and oncology. *J Psychosom Res*. 1996;40(4):425-435.
157. Ramirez AJ, Graham J, Richards MA, et al. Burnout and psychiatric disorder among cancer clinicians. *Br J Cancer*. 1995;71:1263-1269.
158. Cipriani J, Crea J, Cvrkel K, Dagle S, Monaghan K, Seldomridge L. Coping with the death of clients: A pilot study of occupational therapy practitioners. *Physical and Occupational Therapy in Geriatrics*. 2000;17(4):65-77.
159. Prochnau C, Liu L, Boman J. Personal-professional connections in palliative care occupational therapy. *The American Journal of Occupational Therapy*. 2003;57(2):196-204.
160. Llamas K, Llamas M, Pickhaver A, Piller N. Provider perspectives on palliative care needs at a major teaching hospital. *Palliat Med*. 2001;15(6):461-470.
161. Barclay S, Wyatt P, Shore S, Finlay I, Grande G, Todd C. Caring for the dying: how well prepared are general practitioners? A questionnaire study in Wales. *Palliat Med*. 2003;17:23-39.
162. Jezewski MA, Meeker MA, Schrader M. Voices of oncology nurses. *Cancer Nurs*. 2003;26(2):105-112.
163. Jones A. Some experiences of professional practice and beneficial changes derived from clinical supervision by community Macmillan nurses. *Eur J Cancer*. 2000;10:21-20.
164. Meier DE, Back A, Morrison RS. The inner life of physicians and carers of the seriously ill. *Journal of American Medical Association*. 2001;286(23):3007-3014.
165. Yasko JM. Variables which predict burnout experienced by oncology clinical nurse specialists. *Cancer Nurs*. 1983;6:109-116.
166. Whippen DA, Canellos GP. Burnout syndrome in the practice of oncology: results of a random survey of 1000 oncologists. *J Clin Oncol*. 1991;9(10):1916-1920.
167. Boyle FM. Chairman's Report. *MOG Newsletter*. 2002:1-2.
168. Vachon MLS. Staff stress in hospice/palliative care: a review. *Palliat Med*. 1995;9:91-122.

APPENDICES

APPENDIX A: ORGANISATIONS AND GROUPS INVOLVED IN REVIEW OF DRAFT GUIDELINES

Australasian Chapter of Palliative Medicine, RACP
Australasian College for Emergency Medicine
Australia Government Department of Health and Ageing
Australasian Society for HIV Medicine Inc.
Australia & New Zealand Haematology Society
Oncology social Workers Australia
Australian Council of community Nursing Services
Australian Council on Healthcare Standards
Australian Divisions of General Practice
Australian Health Ethics Committee
Australian Music Therapy Association
Australian Physiotherapy Association
Australian Psychological Society
Australian Practice Nurses Association
Australian Psychological Society
Australian Thoracic Society - Lung cancer SIG
Breast Cancer Network of Australia
Cancer Nurses Society Australia
Cancer Voices NSW
Carers Australia
Caritas Christi Hospice
Centre for Health Service Development
Centre for Mental Health
Centre for Palliative Care Research & Education
Centre for Rural and Remote Mental Health
Centre for Health Economic Research and Evaluation (CHERE)
Centre for Health Research & Psycho-oncology (CHeRP)
Clinical Oncological Society of Australia (COSA)
College of Emergency Nursing Australasia
Consumers' Health Forum of Australia
Council on the Ageing (Australia)
Curtin University of Technology
Dietitians Association of Australia
Diversional Therapy Association National Council
Division of Palliative Care

Haematology Society of Australia & New Zealand
Health Economists
Health Informatics Society of Australia Ltd
Health Planner
Indigenous Coordination Centre
Medical Oncology Group of Australia
National Palliative Care Nurses
National Rural Health Alliance
Occupational Therapists Australia
Palliative Care Australia
Palliative Care Inter-Governmental Forum
Pastoral Care Workers
Royal Australian College of Surgeons
Royal College of Nursing, Australia
Speech Pathology Association of Australia
Territory Palliative Care
The Australian Pain Society
The Cancer Council – NSW
The Pharmacy Guild of Australia
The University of Queensland
University of Sydney
University of Western Australia
Rural Palliative Care Program

APPENDIX B: NATIONAL CONSENSUS MEETING ATTENDEES

Organisations Represented	Attending representative
Australasian Chapter of Palliative Medicine, RACP	Associate Professor Richard Chye
Australasian Society for HIV Medicine Inc	Ms Kelly Tank
Australian and New Zealand Society of Palliative Medicine	Professor Paul Glare
Australian Association of Social Workers, Palliative Care social Workers – the Children’s Hospital Westmead	Ms Cay Camden
Australian Council of Community Nursing Services	Ms Anne Oakley
Australian Council on Healthcare Standards	Ms Anne Rauch
Australia Government Department of Health and Ageing	Ms Jennie Della
Australia Government Department of Health and Ageing	Ms Rita Evans
Australian Music Therapy Association	Dr Clare O’Callaghan
Australian Pain Society	Mr Paul Gray
Australian Physiotherapy Association	Ms Kay Matthews
Australian Psychological Society	Ms Eva Fera
Breast Cancer Network of Australia	Ms Lyn Swinburne
Cancer Nurses Society of Australia	Dr Catherine Jones
Cancer Voices NSW	Ms Sally Crossing
Carers Australia	Ms Fran McArdle
Centre for Health Economics Research & Evaluation	Mr Kees Van Gool
Centre for Health Research & Psycho-oncology	Professor Afaf Girgis
Centre for Health Research & Psycho-oncology	Ms Amy Waller
Centre for Health Research & Psycho-oncology	Ms Claire Johnson
Centre for Health Research & Psycho-oncology	Ms Deborah Bowman
Centre for Health Service Development	Ms Maree Banfield
Centre for Palliative Care Research & Education	Professor Patsy Yates
Clinical Oncological Society of Australia	Professor Stephen Ackland
College of Emergency Nursing Australasia	Mr Cyril Dixon
Consumer Representative	Mr George Dreimanis
Consumer Representative	Ms Mireille Dreimanis
Consumer Representative	Mr Paul Burns
Consumer Representative	Ms Midori Burns
Consumer Representative	Mr John Newsom
Consumer Representative	Ms Glenys Fist
Consumer Representative	Ms Susan Chung
Consumer Representative	Ms Janelle Huxley
Consumer Representative	Ms Linda Guthrie
Consumer Representative	Ms Pat Booth

Dieticians Association of Australia	Ms Jane Kellett
Division of Palliative Care	Ms Lynne O'Brien
Facilitator	Dr Norman Swan
Haematology Society of Australia and New Zealand	Mr Hamish Holewa
Health Planner	Ms Meran Lethbridge
National Cancer Control Initiative	Professor Brian McAvoy
National Cancer Strategies Group	Dr David Woods
National Palliative Care Nurses	Professor Margaret O'Connor
National Rural Health Alliance	Ms Mary Miles
Occupational Therapists Australia	Ms Deirdre Burgess
Oncology Social Work Australia	Ms Angela Cotroneo
Palliative Care Australia	Ms Angela Magarry
Palliative Care Inter-governmental Forum	Ms Susan Hanson
Pastoral Care Worker	Dr Bruce Rumbold
Royal Australian and New Zealand College of Psychiatrists	Dr Cathy Mason
Royal Australian and New Zealand College of Radiology	Dr Tanya Holt
Royal Australian Children's Hospital, Melbourne	Dr Jenny Hynson
Royal College of Nursing, Australia	Ms Peta McVey
Rural Palliative Care Program	Mr Ian Hatton
South Eastern Sydney & Illawarra Area Health Service	Professor Sue Hanson
South Western Sydney Area Health Service	Associate Professor Trish Davidson
Palliative Care Australia	Professor David Currow
Speech Pathology Association of Australia	Ms Nadine Manison
Territory Palliative Care	Mr Simon Murphy
The Cancer Council NSW	Ms Gillian Batt
The Pharmacy Guild of Australia	Mr Harvey Cuthill
The University of Queensland	Associate Professor Geoff Mitchell
University of Newcastle	Dr Amanda Neil
University of Sydney	Professor Martin Tattersall
University of Western Australia	Dr Lorna Rosenwax
WA Centre for Cancer & Palliative Care	Professor Linda Kristjanson