



Flinders University



Palliative Care Needs Assessment Guidelines



THE UNIVERSITY
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Acronyms used in this report

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| 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 |

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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.

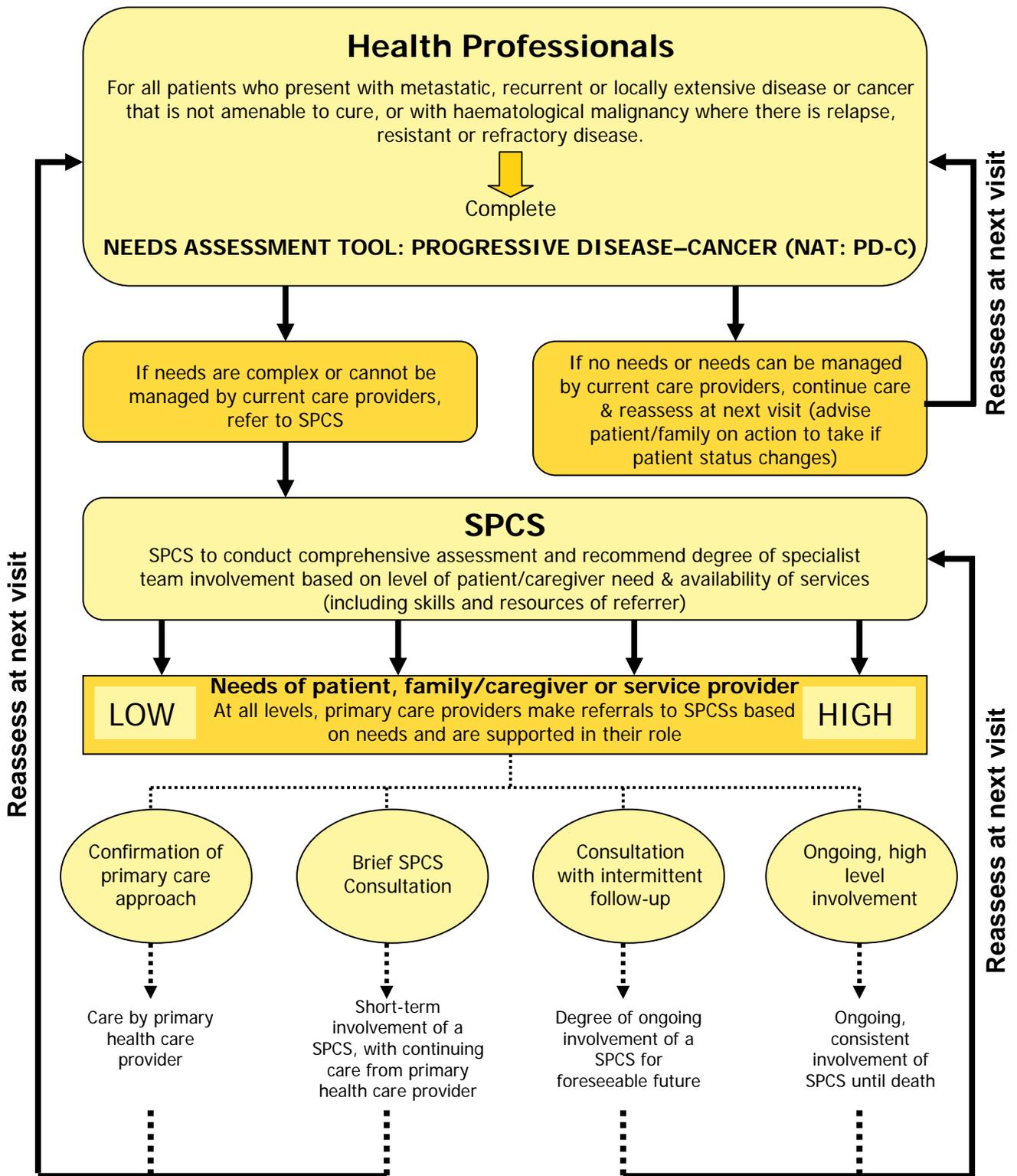


Figure 1: Model for needs-based assessment and triage to appropriate level of palliative care service involvement

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

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| 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 |
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| 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.

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| 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 |

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| 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 |

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| 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 |

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| 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 |

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| 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 |

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| 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 |

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| 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 |

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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 |

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| 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 |