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PALLIATIVE
CARE

Clinical Practice Guidelines

for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients

A resource for health professionals to improve the psychosocial and bereavement support of family caregivers of palliative care patients

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Contents

Background

Support for family caregivers is a core function of palliative care. Most family caregivers will adequately respond to their role and even identify positive aspects associated with their experience. However, a considerable proportion of family caregivers will experience poor psychological, social, financial, spiritual and physical well-being and some will also suffer from prolonged grief. It is clear that many family caregivers have unmet needs and would like more information, education, preparation and personal support to assist them in the caregiving role. There is also a shortage of evidence-based strategies to guide health professionals to provide optimal support whilst the caregiver is providing care and after the patient's death.

With the support of *beyondblue*, our research team has developed Clinical Practice Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. The guidelines were developed for multidisciplinary health care professionals and clinical services commonly involved in caring for adult patients receiving palliative care in a variety of care sites throughout Australia. The guidelines may also prove valuable for the international palliative care community and for generalist health care providers who may occasionally care for palliative care patients.

The guidelines were developed in four stages:

1. Systematic review of the relevant literature.
2. Focus groups and structured interviews with key stakeholders within Australia. Stakeholders included representatives from multiple health care disciplines currently involved in palliative or bereavement care, policy-makers and consumers.
3. National and international expert opinion to further develop and refine the guidelines using a modified Delphi survey technique.
4. Endorsement of the guidelines from key palliative care, carer and bereavement organisations (national and international).

Further information on the development of the guidelines and the literature review that supports the guidelines is available online at: www.centreforpallcare.org

These guidelines should be considered alongside palliative care practice standards, the National Palliative Care Program (Department of Health), other key documents and resources. (See page 43 for examples.) The guidelines have been linked to the Standards for Providing Quality Palliative Care for all Australians and National Standards Assessment Program (NSAP) Quality Elements. The guidelines should not replace clinical judgement. We acknowledge that it may not be possible for all health care professionals to practice in accordance with all the guidelines. Nonetheless, we advocate that, where possible, the guidelines are followed and effort is made (e.g. seeking additional resources where relevant) to meet the guidelines in the future.

A glossary of common terms used in the guidelines is on page 41.

A description of the criteria for grading the levels of evidence underpinning the guidelines is on page 47.

To further assist health care professionals, each guideline is complemented by an example of good clinical practice. These examples have been developed via input from stakeholders and expert opinion (as per above) and, where possible, supported by relevant literature.

We sincerely hope these guidelines will improve the quality of support provided to family caregivers of people receiving palliative care.

Professor Peter Hudson
Director, Centre for Palliative Care

Principles for family caregiver support

1. The crucial role of family caregivers[1] in the care of the patient is acknowledged by the interdisciplinary team and accordingly family caregiver and bereavement support should be fully incorporated into service philosophy and standards of care.
2. Family caregivers should be offered needs assessments and access to relevant psychosocial support.
3. The focus of support should be the primary family caregiver(s), as identified by the patient. Where additional resources and skills are readily available, support is extended to other family caregivers.
4. Family caregiver and bereavement support is provided using resources based on the available evidence and best practice guidelines.
5. The focus of advice and support provided to the family caregiver(s) should be based on caregivers' choice and emphasise strategies to optimise their own well-being.
6. Communication with family caregiver(s) should be conducted in a manner that provides direct and clear information in a language they understand via a combination of mediums including verbal, written or multimedia. Relevant confidentiality and legal requirements should be considered.
7. It is recommended that discussions around preparedness for the patient's death are responsive to the individual needs of the family caregiver(s). This may require discussing issues in stages according to the patient's declining physical condition.
8. Health care professionals and volunteers working with family caregivers should receive appropriate and ongoing training, support and supervision relevant to their level of involvement. Training should be based on National Standards and evidence-based guidelines.

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[1] These principles and guidelines focus on the relative or friend who predominantly supports the patient – the Primary Family Caregiver. In these guidelines the term primary family caregiver equates to: 'family caregiver' or 'family caregivers'.

9. Health care professionals, patients and family caregivers should be aware of the limits of palliative and bereavement services. Referral to external specialist services or individuals should be undertaken when appropriate.
10. Family caregiver and bereavement support is provided with respect to individuals and their needs within a safe, confidential and ethical approach that is sensitive to the caregivers' experience, culture and social environment.
11. Although poor bereavement outcomes are associated with identified risk factors, there is minimal evidence to support routine intervention with all bereaved people.
12. Comprehensive care planning by the interdisciplinary team, involving the patient and family caregiver(s), is an ongoing process, rather than a single event.
13. All relevant discussions, assessments and outcomes related to the patient and family caregiver(s) should be clearly documented in the most appropriate location (as per the service protocol).
14. A clear process for consumer complaints and feedback with regard to the quality of health professional support should be easily accessible to patients and family caregivers.

Guidelines summary

Guideline 1	Once a patient has agreed to receive palliative care, inform the patient that the role of palliative care is also to support their family caregiver(s). The family caregiver(s) will be a person(s) who the patient perceives to be their most important support person(s). This may be a family member, partner or friend and may not necessarily be his/her next of kin.
Guideline 2	Ask the patient to identify the primary family caregiver(s). Where only one family caregiver is identified ask the patient if there is another family member/friend who may be willing to be approached and act as an additional family caregiver. Discuss the patient's preferences for the involvement of the family caregiver in medical and care planning discussions and note this in the medical record/care plan.
Guideline 3	Confirm with the family caregiver(s) that they understand the patient has nominated them for this role. Explain the typical role and responsibilities of 'family caregiver' and confirm they are willing to accept this responsibility and note this in the medical record. Discuss any concerns that the family caregiver may have in accepting this role (including possible conflicts with other family members).
Guideline 4	Discuss advance care planning with the patient and family caregiver(s) covering any implications relating to the legal responsibilities of the family caregiver(s).
Guideline 5	Recognise the family caregiver(s) as an important source of information about the patient. Gather information from the family caregiver(s) about their experience as a support person for the patient, including any information (where pertinent) regarding the patient, which they believe may be important for the health professional team to know about.
Guideline 6	Explain to the family caregiver(s) what services and resources can be provided by the palliative care service so that realistic expectations are established.
Guideline 7	Whenever possible, convene a family meeting/case conference, including the patient, if practicable.

Guideline 8	Conduct a needs assessment with the family caregiver(s). This should include psychological and physical health, social, spiritual, cultural, financial and practical elements.
Guideline 9	Once the family caregiver(s)' needs are assessed, develop a plan of action with involvement from the family caregiver(s). Initiate the appropriate interventions as pertinent.
Guideline 10	Based on discussion with the family caregiver(s), determine the current state of and risk for poor psychological health and/or prolonged grief and plan relevant intervention(s).
Guideline 11	When appropriate, assist the family caregiver(s) in how to recognise signs that death may be imminent and the potential implications for the patient's care requirements.
Guideline 12	When death appears imminent, ensure the family caregiver(s) are aware and assess preparedness for death.
Guideline 13	Confirm with the family caregiver(s) the type of support they may desire in the lead-up to death (e.g. last hours, days) and/or immediately after.
Guideline 14	The interdisciplinary team identifies a means of communicating with the family caregiver(s) to determine short-term and long-term post-death responses. Potential external bereavement support services are identified, if required.
Guideline 15	Relevant members of the interdisciplinary team are advised of the patient's death in a timely fashion.
Guideline 16	As soon as practicable after the patient's death, a member of the interdisciplinary team should contact the family caregiver(s) to offer condolences and respond to queries. If death occurred at home, assess the need for a home visit.
Guideline 17	Contact the family caregiver(s) and other family members (as appropriate) to assess needs at three to six weeks post-death and adapt bereavement care plan accordingly.
Guideline 18	Develop a preliminary bereavement care plan based on the needs of the family caregiver(s), the pre-death risk assessment and the circumstances of the death (e.g. unexpected or traumatic).
Guideline 19	Conduct a follow-up assessment of the family caregiver(s) and other family members (if appropriate) six months post-death.
Guideline 20	Following the death of a patient, the interdisciplinary team should have a discussion (at an appropriate time) about the quality of care provided to the patient and family caregiver(s) and the nature of the death.

Guidelines

Setting up support for family caregivers

Guideline 1	Once a patient has agreed to receive palliative care, inform the patient that the role of palliative care is also to support their family caregiver(s)[2]. The family caregiver(s) will be a person(s) who the patient perceives to be their most important support person(s). This may be a family member, partner or friend and may not necessarily be his/her next of kin or substitute decision-maker[3].
Aim of guideline	To ensure the patient understands the role and services of palliative care.
Highest grade of evidence	F
Key supporting references	1, 2
Example of good practice	Example comments/questions *"We have spoken about what palliative care is and how it aims to help you. However, we also want you to know that palliative care can also support a person(s) in your life who you consider to be extremely important to you. The typical types of support we can offer to family members and/or friends includes …"* In circumstances where the patient does not have the cognitive capacity to make a decision regarding their family caregiver, the health professional is required to determine the appropriate person to make this decision. This may be the next of kin, a legal guardian or a person with Enduring Power of Attorney for medical treatment.

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[2] Refer to Standard 5 of the Standards for Providing Quality Palliative Care for All Australians

[3] Refer to Advance Care Directives

Guideline 1 (continued)

Example of good practice (continued)	Case example Susan has been admitted to a palliative care unit for the management of her metastatic breast cancer. She lives alone and doesn't have many visitors. Very soon after her admission, Susan suffers a severe stroke, which leaves her unable to communicate. As Susan cannot state who her primary family caregiver(s) are, staff refer to Susan's medical record to determine who has been identified as her next of kin. Susan's niece, Catherine, is listed, so staff contact her, providing her with an update and assess her willingness to assist in decisions about Susan's ongoing care. Note: Laws regarding Powers of Attorney and next of kin etc. differ in the states and territories of Australia and internationally. For more information contact the Office of Public Advocate or the Office of Trustees in your jurisdiction.

Guideline 2	Ask the patient to identify the primary family caregiver(s). Where only one family caregiver is identified, ask the patient if there is another family member/friend who may be willing to be approached and act as an additional family caregiver. Discuss the patient's preferences for the involvement of the family caregiver in medical and care planning discussions and note this in the medical record/care plan.[4]
Aim of guideline	To ensure the patient decides on the level of involvement of their nominated family caregiver (and any back-up family caregivers), and that this information is clearly documented in the patient's medical records.
Highest grade of evidence	B
Key supporting references	1–6
Example of good practice	Example comments/questions *"Are there one or perhaps two people in your life who you consider to be extremely important and who are currently helping you in some way? … If so, would you be willing for one of the members of the palliative care team to contact this person(s) to determine if they would like to be considered your primary/main support person? … We typically refer to these people as family or non-professional caregivers and, with your permission, they would be included (where pertinent) in your care planning and medical discussions/decisions. We would explain to them about what it means to be identified as your main family caregiver and also outline the support we could provide …"* Family trees, genograms or ecomaps can be effective methods of capturing a patient's close relationships, extended family and networks of support. Talking to the patient about the people involved in their life can also assist in identifying the psychosocial support needs of the patient and significant others (7).

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[4] Refer to Standards 1-5 of the Standards for Providing Quality Palliative Care for All Australians and to NSAP Quality Element 1.5

Guideline 2 (continued)

Example of good practice (continued)	Occasionally, issues arise regarding the disclosure of the patient's diagnosis and/or prognosis. For example, in an effort to protect the patient, family members may request that the patient remains uninformed about the nature of the illness and/or the terminal prognosis. While there are ethical and legal requirements for patients to be told the truth, sensitive negotiation may be necessary to relieve the family's anxieties (8). Clinical practice guidelines for communicating prognosis and end-of-life issues (including disclosure and prognosis), with palliative care patients and their caregivers (6) can be viewed via the following link: www.mja.com.au/public/issues/186_12_180607/cla11246_fm.pdf Recommendations for working through conflicts associated with disclosure of medical information can also be found in Therapeutic Guidelines: Palliative Care, Version 3 (9) or on the website of Therapeutic Guidelines Limited: www.tg.org.au/index.php?sectionid=47

Guideline 3	Confirm with the family caregiver(s) that they understand the patient has nominated them for this role. Explain the typical role and responsibilities of 'family caregiver' and confirm they are willing to accept this responsibility and note this in the medical record. Discuss any concerns that the family caregiver may have in accepting this role (including possible conflicts with other family members).
Aim of guideline	To ensure the family caregiver(s) understand their role and responsibilities.
Highest grade of evidence	B
Key supporting references	1, 4, 5
Example of good practice	Talk with the family caregiver(s) about their main reasons for accepting the responsibility of being a caregiver, their understanding of the role and any uncertainties they may have. Acknowledge that some family caregivers take on the role not because they want to but because they feel obligated to do so. Also recognise that the family caregiver role may vary. For example, in some situations a family caregiver may act as the main 'hands on' support person as well as spokesperson for the family and main point of contact for health professionals. In other situations, these roles may be shared amongst other family members and may change. Case example Jenny, a social worker has come to meet John, a 70-year-old man with COPD and his wife, Irene, at their suburban home. John's hospital report indicates that Irene is John's primary caregiver but a staff member had raised some concern about Irene's capacity to take on this role. Jenny has come to visit Irene and John to see how things are going. After spending 30 minutes talking with John and Irene and observing how they are managing things such as the oxygen tank and John's mobility, it becomes clear that Irene needs more assistance. Jenny: *"I can see that there is a lot to manage with John's illness."* John nods.

Example of good practice (continued)	Irene: *"Yes, especially with the oxygen tank. It seems I have to monitor it constantly."* Jenny: *"Irene, I understand you have your own health problems."* Irene: *"Yes, I'm a diabetic and I have some complications. My blood sugar levels have been up and down over the last few weeks."* Jenny: *"I'm wondering if there is someone in the family or a close friend who would be willing to lend a hand on a daily basis?"* Irene: *"We have a wonderful family, two daughters and a son. They come to visit often and are always asking if we need help, but I don't want to bother them. They have their own lives and I want to do this for John."* Jenny: *"Irene, I can see you that you want to care for John as much as possible but receiving help from your children doesn't mean that you wouldn't still be caring for John. There are many ways to provide care and John now requires increased care due to his constant need for oxygen. I'm also concerned about your own health; your unstable blood sugar levels indicate that your physical health is not the best. Do you think that you could share some of John's care with your children?"* Irene: *"Well, my son is already taking care of our finances so I don't want to ask him to do any more. However, one of my daughters lives nearby and would be happy to pop around every day. I could ask her to help out with some things."* Jenny: *"That sounds like a good idea. Perhaps your daughter could share some of the physical care load and help with some of the household tasks. You would still be John's major support in every way but this might lighten the load for you. What do you think about this arrangement, John?"* John: *"I think it is a good idea. I've been worried about Irene."*

Guideline 4	Discuss advance care planning with the patient and family covering any implications relating to the legal responsibilities of the family caregiver(s).
Aim of guideline	To ensure patients and family caregiver(s) understand the options and implications of advance care planning and, where relevant, family caregiver(s)' consent to taking on this role.
Highest grade of evidence	B
Key supporting references	3, 8, 10-14
Example of good practice	Provide verbal and written information on advance care planning to both the patient and family caregiver(s). A comprehensive evidence-based Australian example of Advance Care Planning Guide for patients and families is available at www.respectingpatientchoices.org.au **Case example** Brian is a 67-year-old man with multiple brain metastases from lung cancer. He has been treated with a variety of chemotherapy agents and total brain irradiation but recent MRIs have shown disease progression. Brian and his wife, Jane (his primary family caregiver), have been advised that a cure is not feasible and death is likely to occur within the next several months. Brian's primary health care professional (HP) introduces the concept of advance care directives to Brian and Jane: Health professional: *"Brian, I know you are aware of the progression of your illness and we've talked about some of the things you might experience in the near future. Today, I would like to talk to you and Jane about your personal wishes regarding advance care plans."* Brian: *"What are advance care plans?"* HP: *"With illnesses such as yours, it is important to think about the sort of medical treatment you might want in the future in case you become too unwell to make these decisions at the time."* Brian: *"What sort of decisions?"*

Guideline 4 (continued)

Example of good practice (continued)	HP: *"Well, decisions about medical treatments such as forms of life support and other procedures that may impact upon your quality of life, but also your personal wishes about who you would like to make legal, financial and medical decisions if you are unable to do so. Have either of you talked about these matters?"* Jane: *"Brian and I have organised a Power of Attorney and he has told me about some of the things he would like me to do for him if he becomes too sick."* HP: *"It's good to hear you both have already discussed some of these things and that you have organised a Power of Attorney. I would also advise organising a Medical Power of Attorney and a formal Advance Care Plan. I have these documents here with me. Would you like to look over them together?"*

Guideline 5	Recognise the family caregiver as an important source of information about the patient. Gather information from the family caregiver about their experience as a support person for the patient, including any information (where pertinent) regarding the patient, which they believe may be important for the health professional team to know about.
Aim of guideline	Recognise and respect the caregiver as a source of expertise and knowledge.
Highest grade of evidence	E
Key supporting references	7, 15, 16
Example of good practice	Before asking the caregiver for information about the patient, ensure (where possible) that the patient's permission has been sought for sharing this type of information as outlined in Guideline 2. Case example Gilbert is a 58-year-old man who has been caring for his partner, David, for just over five years. David is a 61-year-old man with Huntington's Disease. In the last six months, David's condition has rapidly deteriorated and he has been admitted for palliative care. The social worker conducting the intake assessment wants to engage Gilbert in this process as much as possible, to optimise sharing of information and support for both David and Gilbert: Possible question: *"Gilbert, we are mindful that we have a lot of medical information about David, but is there anything else we need to know that would help us provide the best care for him now and into the future?"*

Guideline 6	Explain to the family caregiver(s) what services and resources can be provided by the palliative care service so that realistic expectations are established.
Aim of guideline	To ensure the family caregiver(s) have realistic expectations of their role and clarify services and resources available.
Highest grade of evidence	A
Key supporting references	1, 2, 4, 5, 12, 17-24
Example of good practice	The following comments and questions may be useful in establishing realistic expectations about the services that can be provided. *“Palliative care is not only about managing [your relative’s] pain and symptoms. Palliative care is also about trying to meet your needs. It includes a range of health professionals who can help support you at this time. For example, palliative care services can talk to you about the impact of your relative’s illness on you and about practical matters such as rearranging your finances. They may also be able to organise for a volunteer to spend a few hours with your family member while you do something that you need or want to do.”* *“The palliative care staff may not always be able to meet all of your needs but they can put you in touch with someone who may be able to help you further.”* *“Are there any supports that you think would be useful to you at this stage?”* *“We will work together to develop a list of services and resources who can support you. We will add new items to the list in the future if your needs change.”* *“It’s important that you continue to look after your own health while you are caring for your family member. If you haven’t already, you might want to consider seeing your General Practitioner and telling them what is happening.”*

Assessing need and establishing a plan of care

Guideline 7	Whenever possible, convene a family meeting/case conference, including the patient, if practical.
Aim of guideline	To assess needs and to discuss goals of care, site of care, referral requirements and other key care planning matters, including a process for regular review.
Highest grade of evidence	B
Key supporting references	3, 5, 7, 8, 12, 15, 21, 25
Example of good practice	Multidisciplinary Clinical Practice Guidelines for Conducting Family Meetings in Palliative Care (15) is available at www.biomedcentral.com/1472-684X/7/12 These guidelines comprehensively outline recommended ways for convening and conducting family meetings and include useful examples of comments, phrases and questions. They also suggest that family meetings be routinely offered (rather than just used for crisis intervention), in order to assist care planning and prevent potential problems. While family meetings can be a useful support for family members, they are not the most appropriate way to solve long-standing family problems. In circumstances where there is significant conflict within the family, involving a family therapist or psychologist (or other appropriately qualified health professional) may be appropriate (19). Further information about communicating with families who report conflicts over medical care can be accessed from the End of Life/Palliative Education Resource Centre: 1. Fast Fact and Concept #183 “Conflict Resolution I: Careful Communication” (26) available at www.eperc.mcw.edu/fastFact/ff_183.htm 2. Fast Fact and Concept #184 “Conflict Resolution II: Principled Negotiation” (27) available at www.eperc.mcw.edu/fastFact/ff_184.htm

Guideline 8	Conduct a needs assessment with the family caregiver(s). This should include psychological and physical health, social, spiritual, cultural, financial and practical elements.
Aim of guideline	Determine the needs of the family caregivers(s) (if any).
Highest grade of evidence	B
Key supporting references	1, 4, 5, 12, 17, 19-21, 28-31
Example of good practice	Offer to meet with the family caregiver(s) alone to talk about their experience of caregiving and the impact on their life. A discussion of these matters can provide an opportunity to ask important questions like, *"How are things for you at the moment?" "What are your main concerns?"* and *"What would be helpful to you?"* Explain the needs assessment with the family caregiver(s) and how the assessment assists in the development of a care plan. The aforementioned family meeting may be a useful way to assess needs and plan care. A more formal approach would be the use of tools such as The Needs Assessment Tool – Progressive Disease (NAT:PD; 32) and The Needs Assessment Tool – Progressive Disease Cancer (NAT:PD-C; 33). These tools may assist in identifying complex needs among caregivers of progressive chronic disease and caregivers of cancer patients, respectively, and are available at: www.newcastle.edu.au/research-centre/cherp/professional-resources/ For further recommendations on assessment tools utilised in palliative care, see also: • Palliative Care Outcomes Collaboration (PCOC) http://chsd.uow.edu.au/pcoc • Caresearch www.caresearch.com.au • National Standards Assessment Program (NSAP) www.standards.palliativecare.org.au

Guideline 9	Once the family caregiver(s) needs are assessed, develop a plan of action with involvement from the family caregiver(s). Initiate the appropriate interventions as pertinent.
Aim of guideline	Determine the appropriate level and type of intervention for the family caregiver(s) (if any) and facilitate the implementation of these.
Highest grade of evidence	A
Key supporting references	34-41
Example of good practice	Recent reviews of psychosocial interventions for family caregivers have reported the following examples to be of good and/or high quality: • Enhancing problem-solving or coping through sessions on planning, creativity, optimism and information (35). • Provision of psycho-educational support to prepare family caregivers for their role through home visits and phone calls (36). • Individual and family counselling as well as weekly caregiver support groups (37). • Partner-guided pain management training (42). • Teaching caregivers behaviour strategies to improve their sleep (43). • Group psycho-education programs to prepare family caregivers for their role (44). There are also written resources to help prepare family caregivers for their role, such as: “Supporting a person who needs palliative care: a guide for family and friends” (Palliative Care Victoria, 2004). This resource can be accessed from Palliative Care Victoria or The Centre for Palliative Care www.centreforpallcare.org

Example of good practice (continued)	Case example Raj has been caring for his wife, Amrita, since she was diagnosed with breast cancer two years ago. In the last six months her disease has advanced and Amrita has been admitted to the local community palliative care service. Raj has taken leave from his job to care for Amrita in a full-time capacity. A health professional (HP) from the palliative care service has been in contact with Raj and believes he would benefit from further support. Health professional: *"Raj, it sounds like you have been experiencing significant levels of stress over the last few weeks. You mentioned having frequent headaches, difficulty sleeping and depressive moods. These are all symptoms of stress and indications that your stress levels are impacting on your physical and mental health. I think it's time to take some steps to try and relieve these symptoms. What do you think?"* Raj: *"Well, I've certainly been feeling like I'm not coping as well as I usually do."* HP: *"Sometimes we can get so caught up with everything that needs to be done that we forget to take time out for ourselves and take a break from the stress. This can especially be the case when we are caring for someone who has a life-threatening illness."* Raj: *"I usually play golf once a week and catch up with some mates but I just haven't had time lately."* HP: *"It's also important to address the symptoms of your stress. I can go through some strategies with you to help improve your sleep and recommend some relaxation exercises."* Raj: *"That would be good."* HP: *"The palliative care service also offers a number of programs that may be helpful; these include counselling, support groups and information sessions for family caregivers. Let's go over these options together."*

Guideline 10	Based on discussion with the family caregiver(s) determine the current state of and risk for poor psychological health and/or prolonged grief and plan relevant intervention(s).
Aim of guideline	To identify and respond to early indicators of mental health problems among the family caregiver(s) and other family members.
Highest grade of evidence	A
Key supporting references	3, 4, 12, 19, 28-31, 45-57
Example of good practice	An informal clinical assessment can be conducted by talking to the family caregiver(s) about past deaths, coping strategies, previous and current mental health problems, current physical health, concurrent life stressors, issues relating to children and any other issues that may be important to the family caregiver(s). Predictors of potential for prolonged grief include previous loss, exposure to trauma, a previous psychiatric history, attachment style and the relationship to the deceased (51, 54). There are a number of screening tools that can also be useful in assisting to determine a person's current psychological well-being and risk for prolonged grief disorder (30, 58). Here are some examples: Psychological well-being • The Kessler Psychological Scale (K10) (59) • The Depression, Anxiety and Stress Scale (DASS) (60) • Distress Thermometer (61) Bereavement risk • Bereavement Risk Index (BRI) (62) • Family Relationships Index (FRI) (63) • The Matrix of Range of Responses to Loss (53) • Prolonged Grief Disorder Scale (PG-13, Pre-loss caregiver version) (64) Please note: These screening tools are examples only. We advise health professionals to use only reliable and valid screening tools. Please also note that screening tools do not produce a diagnosis but serve as a guide to inform care planning, decision-making and diagnostic approaches such as a formal psychiatric/psychological assessment, which should be undertaken by suitably qualified health professionals.

Preparing for death

Guideline 11	When appropriate, assist the family caregiver(s) in how to recognise signs that death may be imminent and the potential implications for the patient's care requirements.
Aim of guideline	To ensure the family caregiver(s) have knowledge of the signs of imminent death and the care requirements associated with this stage.
Highest grade of evidence	C
Key supporting references	47, 65
Example of good practice	The End of Life/Palliative Education Resource Centre has published an education resource titled: *Teaching the family what to expect when the patient is dying* (66), available at www.eperc.mcw.edu/fastFact/ff_149.htm Example of comments/questions: *"In our experience, many family caregivers would like to know the typical signs and symptoms of imminent death. They say this helps them feel more prepared. Would you like this information?"* If yes: Proceed to provide the information. If no: *"That's okay. If you change your mind later on, just let me know."*

Guideline 12	When death appears imminent ensure the family caregiver(s) are aware and assess preparedness for death.
Aim of guideline	To ensure the family caregiver(s) and other family members are prepared for the death of the patient.
Highest grade of evidence	C
Key supporting references	11, 47, 51, 65, 67, 68
Example of good practice	Re-assess the family caregiver(s)' support needs, addressing any medical, psychosocial, spiritual, cultural, financial, legal and practical needs. The site of care options and preferences should also be considered. Ensure relevant health care professionals are also made aware that death seems imminent. Case example The following is an example of a discussion with a caregiver from a culturally and linguistically diverse background. Myra has been caring for her mother, Selma, for seven months and there are now signs that Selma is approaching death. As Myra is more comfortable speaking in her first language, the health professional (HP) has arranged for an interpreter to assist with the discussion. The HP faces Myra and maintains eye contact while speaking to her: *"Selma's condition is worsening and there are signs that she is nearing death."* HP pauses and looks at interpreter. While the interpreter is relaying the information, the health professional is observing Myra's response and body language. Myra begins to cry. HP: *"Myra, you have been caring for Selma for some time now; I can see this is painful for you to hear."* Health professional waits for this to be translated. Myra speaks to the interpreter. Interpreter to HP: *"Myra said that although she has seen Selma's health worsen and suspected death was nearing, it was hard to hear it from you just now."*

Example of good practice (continued)	The HP looks at Myra and nods with understanding. The health professional waits for a minute or two and they all sit in silence. HP: *"Myra is there anything we can do to help you and your family at this time?"* HP pauses and waits for the interpreter to relay this to Myra. Myra does not respond. HP: *"For instance, do you need help with Selma's medical or caring needs, or perhaps funeral arrangements, or support for you and the family?"* Interpreter translates to Myra. Myra looks briefly at the HP and then speaks to the interpreter. Interpreter: *"Myra says she needs to speak to a religious leader in the community and organise for Selma to be buried within 24 hours of death."* HP: *"Okay, let's talk about how we can organise for this to happen and assist with some other things that may be important to you at this time."* More information on communicating through the use of interpreters can be accessed from the End of Life/Palliative Education Resource Centre: Fast Fact #154. "Use of interpreters in palliative care" (69) available at www.eperc.mcw.edu/fastFact/ff_154.htm

Guideline 13	Confirm with the family caregiver(s) the type of support they may desire in the lead-up to death (e.g. last hours, days) and/or immediately after.
Aim of guideline	To assess support and bereavement needs pre-death and post-death for the family caregiver(s).
Highest grade of evidence	C
Key supporting references	11, 47, 51, 65, 67, 68, 70
Example of good practice	If death is planned to occur at home, determine the family caregiver(s)' preference for support in the period just prior to and just after the death, e.g. desire for a visit from a health professional (if feasible). Be aware that not all family caregiver(s) and other family members will know what they want at this time. The following comments and questions may be helpful when death is planned to occur at home: *"As we have discussed, it seems that Frank is now dying. We will be making regular contact (either via phone or visit) and just want to remind you to contact the palliative care team in between if you have any concerns. To help us plan for your support needs, would you and your family/friends prefer to manage Frank's care leading up to and at the time of death? Or do you think you would like to have someone from the palliative care team visit? We are aware that you might change your mind, and it's okay if you do."*

Guideline 14	The interdisciplinary team identifies a means of communicating with the family caregiver(s) to determine short-term and long-term post-death responses. Potential external bereavement support services are identified, if required.
Aim of guideline	To ensure grief and bereavement support is available and discussed with the family caregiver(s).
Highest grade of evidence	C
Key supporting references	30, 65, 70-73
Example of good practice	It is recommended that, wherever possible, bereavement follow-up be conducted by a staff member who was involved in the patient's or family's care prior to the patient's death (71). Case example Penny (a nurse in an aged care facility) is organising a bereavement care-plan for the family of a nursing home resident prior to patient death. Mr Tykovski is a 77-year-old man with advanced lung metastases. He receives regular visits from the community palliative care service for the pharmacological management of pain and dyspnea. He has lived at the nursing home for three years and his family is very involved in his life. While the nursing home bereavement supports include a post-death response, condolence card and funeral attendance, Penny also wishes to refer the family to the palliative care bereavement service for longer-term support. She calls Mr Tykovski's daughter, Liz, who is recorded as the next of kin: Penny (the nurse): *"Liz, when you come in next to visit your dad, I wondered if you could stay for a chat? I'd like to ask one of the support workers from palliative care to join us. Would that be okay with you?"*

Bereavement support

Guideline 15	Relevant members of the interdisciplinary team are advised of the patient's death in a timely fashion.
Aim of guideline	To ensure communication to the health care team is prompt following a patient's death.
Highest grade of evidence	C
Key supporting references	48, 71
Example of good practice	The team needs to develop a communication strategy to ensure that those who should know about the patient's death are informed. In community settings, this may involve informing all palliative care staff by email or text messages (in adherence with confidentiality requirements), while also ensuring that other health professionals have been informed, e.g. General Practitioners, specialists and/or other external agencies. Inpatient/hospital teams need to ensure that relevant health professionals in other institutions, departments, wards and administration are notified of the patient's death.

Guideline 16	As soon as practical after the patient's death, a member of the interdisciplinary team should contact the family caregiver(s) to offer condolences and respond to queries. If death occurred at home, assess the need for a home visit.
Aim of guideline	To ensure the health care team provides an appropriate response following death, and grief and bereavement support is offered promptly.
Highest grade of evidence	C
Key supporting references	1, 46-48, 67, 70, 71, 74
Example of good practice	The team needs to discern who the most appropriate person is to make the call. Where possible the health professional needs to have had previous contact with the family and be equipped with knowledge about the experience of the death and other pertinent information. Case example Mrs West had been admitted to the Bone Marrow Transplant (BMT) Unit. However, due to complications after the transplant, Mrs West was transferred to the Intensive Care Unit (ICU). She died shortly afterward. A staff member from ICU phoned the Clinical Care Consultant (CCC) on the BMT Unit to inform her of Mrs West's death. Since Mrs West had received the majority of medical care from staff in the BMT Unit, it was decided that the CCC would call Mrs West's family to inform them of her death and arrange bereavement follow-up.

Guideline 17	Contact the family caregiver(s) and other family members (as appropriate) to assess needs at three (earlier if pertinent) to six weeks post-death and adapt bereavement care plan accordingly.
Aim of guideline	To provide follow-up assessment of the family caregiver(s) and family members three to six weeks post-death.
Highest grade of evidence	A
Key supporting references	29, 30, 47-49, 51-55
Example of good practice	This second contact after the death can be an informal telephone call with the family caregiver(s). The purpose of this contact is: 1. To see how the family caregiver(s) are coping after the death. 2. To remind them of existing services that can support them. 3. To review the bereavement risk assessment made prior to the patient's death (see Guideline 10). Case example A health professional, Sue, makes contact with Alan whose wife died in the palliative care unit four weeks ago. Sue: *"Alan, it's Sue calling from the Palliative Care Unit … I mentioned to you when Jenny died that I would be in touch with you after a few weeks to see how the family was getting along. How have things been for you?"* Alan: *"It's been hard … I haven't been sleeping very well … I miss her a lot. In many ways it was a relief when she died, because she had been struggling for such a long time … but, you know, she leaves a big hole. For so much of our lives we were caring for her – going to appointments, visiting her in hospital, talking to doctors … and now … now that the funeral is over … the cards stop coming … people stop calling … it's empty … meaningless."* Sue: *"This can be a very hard time for families – so much goes on in the first few weeks, then everything goes quiet and it really hits you … Have you been to see your General Practitioner or another health professional about your sleep?"*

Example of good practice (continued)	Alan: “*Yes, I’ve got some tablets to use occasionally and my sister has been a great support. I’ll be alright … but I’m worried about my son, Glen.*” Sue: “*We talked about how Glen was coping, didn’t we? He seemed very angry all the time and was blaming you for not getting the doctors to save Jenny. What’s happening with him now?*” Alan: “*Well … he stays in his room a lot and won’t go to school. It’s an important year for him too … he’s barely eating and just grunts at the rest of us.*” Sue: “*That’s concerning to hear. Has he made contact with the school counsellor again?*” Alan: “*No … he won’t go.*” Sue: “*Did you mention Glen to your GP?*” Alan: “*She said she would come and do a home visit this week.*” Sue: “*Good. If it’s okay with you, I will give the GP and school counsellor a call to fill them in on why we have concerns about Glen.*” Alan: “*Thanks. I don’t think I have much influence on him at the moment – he’s still angry and I don’t have the energy to push him.*” Sue: “*Alan, do you still have the brochures about bereavement support services that I gave you at the hospital?*” Alan: “*They’ll be somewhere among the things I brought back from the hospital. To be honest I haven’t looked at them. I can’t bring myself to go near her things …*” Sue: “*Maybe that’s something you need to do with your sister. You might find some useful information to guide you at this time … If it’s alright with you, I’ll make calls to the GP and school counsellor and ask them to contact you and Glen. If that doesn’t happen, please get back to me so that we can be sure you and Glen are properly supported. Is that plan alright with you?*”

Guideline 18	Develop a preliminary bereavement care plan based on the needs of the family caregiver(s), the pre-death risk assessment, and the circumstances of the death (e.g. unexpected or traumatic).
Aim of guideline	To develop a bereavement care plan with the family caregiver(s) and other family members.
Highest grade of evidence	A
Key supporting references	1, 2, 29-31, 45, 50, 52, 55, 71, 74, 75
Example of good practice	If the bereavement assessment indicates a need for support, explain the nature of this support (e.g. counselling visits or support group attendance) and who will be providing this support. Confirm the family caregiver(s)' willingness to receive supportive bereavement services. Case example George is a 75-year-old man, originally from Greece, who died from pulmonary embolism two days after admission to the palliative care unit (PCU). He had an eight-year history of prostate cancer with bone secondaries and had a previous admission to the PCU for pain management. His family was well-known to the unit. His wife, Ellie, was diagnosed with lymphoma a year ago and was admitted for respite a few months ago when George was unwell. Ellie had been the matriarch of the family but had 'fallen apart' when her own diagnosis was made. She developed a severe, agitated depression and had become very dependent on her husband of 54 years. The couple had been supported by the community palliative care team. Ellie was seeing a psychiatrist and was considered to be at high risk of relapse following her bereavement. A meeting with Ellie, her three adult children and their families was held at the hospital with Angela, a nurse on the unit, and the community family support worker, Jane, to develop a bereavement care plan.

Guideline 18 (continued)

Example of good practice (continued)	Health professional: *"I wanted to meet with you today before you left the hospital to convey our condolences … George and Ellie have been well-known to us over the past few years and we know how close you are as a family … I know that although George has been sick for some time, his death was unexpected, and that might make it harder to accept …"* Turns to Ellie … *"I know, Ellie, that George became your 'rock' when you became sick and that you have been together for 54 happy years … This is a great loss for you …"* Turns to other members of the family … *"I just want to check with you where your mum will be staying over the next few weeks. Jane (bereavement counsellor) would like to visit you at home and I would like to make sure that Ellie will be seeing her psychiatrist soon … I know that all this is overwhelming and that you will have a lot to deal with over the next few weeks ..."* *"I am also wondering what you would like from us at this stage? We've gone over the types of supports that can be provided. Would you like us to contact you or would you prefer to contact us when you are ready? Are you happy for us to contact Ellie's psychiatrist to let her know what has happened?"*

Guideline 19	Conduct a follow-up assessment of the family caregiver(s) and other family members (if appropriate), six months post-death.
Aim of guideline	To review the psychosocial well-being of the family, including symptoms of prolonged grief and other psychosocial health problems.
Highest grade of evidence	A
Key supporting references	29, 30, 47-49, 51-55
Example of good practice	Undertake another review of the family caregiver(s)' psychosocial well-being at six months post-death and adapt bereavement care plan accordingly (76). If prolonged grief and/or other significant psychosocial issues are not apparent then contact should be discontinued with an offer for the family caregiver(s) to re-establish contact with relevant individuals/organisations if additional support is required in the future. If prolonged grief and/or other significant psychosocial issues are apparent, offer interventions based on best available evidence in keeping with scope of professional practice or refer on to a relevant health care professional(s). A further assessment should be undertaken subsequently, if pertinent. Case example Joan was a 58-year-old woman who died from metastatic breast cancer in a palliative care unit six months ago. Her husband, Barry, had been her primary caregiver until brain metastases had made her management at home too difficult, one month prior to her death. Barry had been devoted to her. Anne, a health professional, rings him six months after Joan's death. Anne: "*Hello Barry, it's Anne from the palliative care unit. I'm calling to see how you're going … When I spoke to you a few months ago, your son was staying with you and you were about to go on a fishing trip …*" Barry: "*Yeah, well we did do that … but he's gone back to HIS life now and … well … I've come back to mine … Pause … If you can call it a life (sighs, voice thickens).*"

Guideline 19 (continued)

Example of good practice (continued)	Anne: "*You're finding that difficult, Barry? … to come back to a life without Joan?*" Barry: (choking voice) "*She was my whole life! People don't understand that … They think that because I'm not old I've still got a new chance at life – 'You're young, Barry, you could marry again,' they say. 'I don't know how you managed all those years with Joan in and out of hospital' – my own mother said that to me! It's gotten to the point where I don't want to see anybody … I can't go out into the workshop where I used to make my lures because that's where Joanie used to work alongside me – and she's not there … I walk around the house at night looking at all the little things she made and cry. I reach out for her in the night and she's not there … At the end, when she died, I wasn't sure if she knew I was there … I've always been there for her and it kills me to think that she might not have known.*" Anne: "*Barry, it sounds as if you are having a tough time of it … I'd like you to come in and see one of the team members who specialises in helping people who are struggling with the death of a loved one … I can hear how distressed you are … I want you to speak with someone who understands your grief and may be able to suggest some strategies to assist you. Would you be prepared for me to set up an appointment?*"

Guideline 20	Following the death of a patient, the interdisciplinary team should have a discussion (at an appropriate time) about the quality of care provided to the patient and family caregiver(s) and the nature of the death.
Aim of guideline	To evaluate the quality of care provided to the patient and family.
Highest grade of evidence	C
Supporting references	48, 75, 77, 78
Example of good practice	A 'good' death is typically defined as one that is free from avoidable distress and suffering for patients, families and caregivers (79). Generally, it is appropriate for a death to be reviewed as close as possible to the event. It is recommended that the perspectives of patients (where possible, for example, if their pre-death wishes were documented), family and health professionals are sought. It may also be beneficial to conduct a follow-up review once bereavement support has ceased. Factors to be assessed in a death review may include: Patient 1. Was the patient comfortable? 2. Were symptoms controlled? 3. Were psychosocial and spiritual needs met? 4. To what extent were the patient's wishes followed? a. Site of death b. Completion of desired tasks c. Attendance to spiritual matters d. Saying goodbye to significant others 5. What was the duration of death (e.g. sudden, intermediate or prolonged)?

Example of good practice (continued)	Caregivers and family 1. Were caregivers and family present? 2. Did caregivers and family (or those present) have the opportunity to say goodbye? 3. Were there significant conflicts within the family that remained unresolved? 4. Did caregivers, family members or others appear to be severely distressed by the death? 5. Were any significant bereavement risks apparent? 6. What bereavement support was required and how effective was this?

Glossary of terms

Advance care planning: is a series of steps people can take to help them make plans for their medical care in advance. Advance care planning aims to keep people involved in their medical decisions, both now and in the future, whether they are healthy or have an illness. Advance care planning is especially important when people become so unwell they can no longer speak for themselves because, having created a plan in advance, doctors and family can understand how they would like to be cared for (13).

Caregiver support: Support for caregivers who are assisting a relative/friend requiring palliative care may incorporate practical, educational, psychological, spiritual, financial or social strategies – based on unmet needs and a desire by the caregiver(s) for assistance – with the intention of enhancing the caregiver(s) capacity to undertake their role, respond to its challenges and maintain their own health during and after their relative's/friend's death (1, p.284).

Family: Those closest to the patient in knowledge, care and affection. This may include (a) the biological family, (b) the family of acquisition (related by marriage/contract) and (c) the family of choice and friends. The patient defines who will be involved in his/her care (1).

Family caregiver: A relative, friend or partner who has a significant personal relationship and provides assistance (physical, social and/or psychological) to a person with a life-threatening illness. These individuals may be primary or secondary family caregivers and may or may not reside with the person receiving care (80).

Palliative care: is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening 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 nor 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 families cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of the patients and their families, including bereavement counselling, if indicated
- will enhance quality of life and may positively influence the course of the illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy and radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (81).

Palliative care team: a team of medical, nursing, allied health and volunteer workers who provide a range of palliative care services to patients, caregivers and family members (82).

Primary family caregiver(s): a person (or persons) who usually provides primary support for the patient at all levels of need. This may be the patient's partner, child, another family member or a friend. Although the primary caregiver may be supported by other carers, they generally assume primary responsibility of the coordination and provision of care and support to the patient (2, p.6).

Prolonged grief: the syndrome of prolonged grief, also called pathological, complex or traumatic grief, is chronic and debilitating, results in substantial distress and impairment, worsens quality of life, and has been linked to excess medical morbidity and suicidality. As currently defined, prolonged grief consists of symptoms at least six months after the loss of a loved one that include a sense of disbelief regarding the death, persistent intense longing, yearning and preoccupation with the deceased, recurrent intrusive images of the dying person and avoidance of painful reminders of the death (76).

Psychosocial care: Concern with the psychological and emotional well-being of the patient and their family/caregivers, including issues of self-esteem, insight into an adaption to illness and its consequences, communication, social functioning and relationships and may include existential and cultural elements (83).

Supportive care screening: involves the routine and systematic identification of potential supportive care needs or risk factors before the issue becomes a symptom. Supportive care screening includes the prioritising of needs and providing an immediate response to high level risk as well as arranging follow-up referral(s) and support (84).

Key documents and resources

Standards for providing quality palliative care for all Australians (4th Ed.)

The national standards have been developed to support and enhance quality of care for patients who are at the end of their life, their families and carers. Services and providers adopt the national standards on a voluntary basis. Accreditation services are asked to incorporate the national standards as part of their assessment of palliative care and other services (85).

A National Framework for Advance Care Directives Consultation Draft 2010

This framework acknowledges the practical and ethical challenges and the diversity of legislation across Australia, but also the potential improvements Advance Care Directives may make to care and decision-making during times of impaired capacity, especially towards the end of life (86).

Palliative Care Needs Assessment Guidelines

The Palliative Care Needs Assessment 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 (12).

The Needs Assessment Tool: Progressive Disease (NAT: PD)

The NAT:PD is designed to support the Palliative Care Needs Assessment Guidelines and can assist in matching the types and levels of need experienced by people with progressive chronic disease and their caregivers with the most appropriate people or services to address those needs (32).

The Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C)

The NAT:PD-C is designed to support the Palliative Care Needs Assessment Guidelines and can assist in matching the types and levels of need experienced by people with advanced cancer and their caregivers with the most appropriate people or services to address those needs (33).

Family Meetings in Palliative Care: Multidisciplinary Clinical Practice Guidelines

The clinical guidelines provide a framework for preparing, conducting and evaluating family meetings (15).

Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness and their caregivers

The guidelines are designed to assist with communication of prognosis and end-of-life issues, particularly for health professionals working in palliative care (6).

Guidelines for the assessment of complicated bereavement risk in family members of people receiving palliative care

The guidelines aim to assist health professionals to identify carers and family of dying people who may be at risk of complicated bereavement outcomes (87).

When a patient dies: Advice on developing bereavement services in the NHS

The guidelines aim to provide advice on basic principles and elements necessary in developing bereavement services (88).

Bereavement needs assessment in specialist palliative care: A review of the literature

This paper reviews and identifies appropriate bereavement measurement tools for their suitability for use within bereavement services (30).

MBS Primary Care Items: Chronic Disease Management (CDM) Medicare Items Fact Sheet

This fact sheet provides information on The Chronic Disease Management (CDM) Medicare items, which are for GPs to manage the health care of patients with chronic or terminal medical conditions, including patients with these conditions who require multidisciplinary, team-based care from a GP and at least two other health or care providers (89).

Prolonged Grief Disorder: Psychometric Validation of Criteria Proposed for DSM-V and ICD-11.

This paper outlines and determines the psychometric validity of criteria for Prolonged Grief Disorder (PGD). The criteria set for PGD appear able to identify bereaved persons at heightened risk for enduring distress and dysfunction (76).

Helpful websites and online resources

Palliative Care Outcomes Collaboration (PCOC)

http://chsd.uow.edu.au/pcoc/

PCOC is a quality initiative that assists palliative care service providers to improve practice and provides a number of services to assist in the provision of high-quality palliative care services.

National Standards Assessment Program (NSAP)

www.standards.palliativecare.org.au

The main objective of NSAP is to improve quality in palliative care experiences and outcomes for patients, their families and caregivers.

Palliative Care Australia, Carers and End of Life Position Statement

This can be found on the Palliative Care Australia website www.palliativecare.org.au under the subheading of ‘Policy’ and provides strong support for the provision of assistance for those identifying as a family caregiver.

Caresearch

www.caresearch.com.au

Current research publications, key documents and resources for health professionals and consumers can be found on the Caresearch website.

Palliative Care Australia, consumer brochures

www.palliativecare.org.au/Default.aspx?tabid=2015

A series of consumer brochures is available on the Palliative Care Australia website. Brochures on a number of key topics are available, in many languages.

beyondblue: the depression initiative

www.beyondblue.org.au

The beyondblue website includes information on mental health disorders, useful mental health related resources and on mental health research.

Australian Centre for Grief and Bereavement

www.grief.org.au

The Australian Centre for Grief and Bereavement website has information on grief and bereavement counselling services, education and training, and grief and bereavement resources.

International Palliative Care Family Carer Research Collaboration (IPCFRC)

http://ipcfrc.centreforpallcare.org

The IPCFRC website has information on family carer research in palliative care.

The International Association of Hospice and Palliative Care
www.hospicecare.com

This association focuses on improving palliative care throughout the world and the website has lots of information and resources.

Levels of evidence

The evidence to support the guidelines has been rated in accordance with the National Health and Medical Research Council (NHMRC) guidelines (90). The NHMRC sets out the basis for rating five key components of the 'body of evidence' for each recommendation. These components are:

1. The evidence base, in terms of the number of studies, level of evidence and quality of studies (risk of bias).
2. The consistency of the study results.
3. The potential clinical impact of the proposed recommendation.
4. The generalisability of the body of evidence to the target population for the guideline.
5. The applicability of the body of evidence to the Australian health care context.

NHMRC overall grades of recommendation are intended to indicate the strength of the body of evidence underpinning the recommendation. This should assist users of the clinical practice guidelines to make appropriate and informed clinical judgments.

Grade A or B recommendations are generally based on a body of evidence that can be trusted to guide clinical practice, whereas Grades C or D recommendations must be applied carefully to individual clinical and organisational circumstances and should be interpreted with care (see Table 1).

The NHMRC rating scales are designed for research questions regarding interventions, diagnosis, aetiology, screening and prognostic factors, hence they are not completely relevant to these guidelines. As such, two further levels of evidence have been added (E and F) in order to acknowledge qualitative studies and expert opinion that have been drawn upon to support some of the guidelines.

Table 1. Definition of NHMRC grades of recommendations

Grade of recommendation	Description
A	Body of evidence can be trusted to guide practice.
B	Body of evidence can be trusted to guide practice in most situations.
C	Body of evidence provides some support for recommendation(s) but care should be taken with its applications.
D	Body of evidence is weak and recommendation(s) must be applied with caution.
E	Qualitative research (not an NHMRC grade)
F	Expert opinion (not an NHMRC grade) including books, theoretical papers, non-systematic reviews and guidelines

Grading of evidence

Ref No.	Authors	Grade
1	Hudson & Payne (2009)	F
2	Palliative Care Australia (2005)	F
3	Hudson et al (2004)	B
4	Burridge et al (2007)	B
5	Docherty et al (2008)	D
6	Clayton et al (2007)	F
7	Monroe & Oliviere (2009)	F
8	Ashby & Mendelson (2009)	No Grade
11	Kirchhoff & Faas (2007)	B
12	Girgis et al (2006)	E
13	Austin Health (2007)	No Grade
15	Hudson et al (2008)	E
16	Egan et al (2006)	E
17	Aoun et al (2005)	F
18	Bee et al (2008)	D
19	Andershed (2006)	C
20	Hudson (2003)	F
21	Parker et al (2007)	B
22	Kehl et al (2008)	B
23	Brazil et al (2005)	C
24	Abernethy et al (2008)	A
25	Hudson et al (2009)	C
28	Kristjanson & Aoun (2004)	F
29	Zhang et al (2006)	F
30	Agnew et al (2009)	C
31	Palliative Care Australia (2008)	F
34	McMillan (2005)	F
35	McMillan et al (2006)	A
36	Hudson et al (2005)	A
37	Haley (2008)	B
39	Carter (2006)	C
41	Grande et al (2009)	F
42	Keefe et al (2005)	B
44	Hudson et al (2009)	C
45	Centre for Palliative Care (2000)	F
46	Mather et al (2008)	D

Grading of evidence (continued)

Ref No.	Authors	Grade
47	Grande & Ewing (2009)	C
48	Holtslander (2008)	F
49	Ray & Prigerson (2006)	F
50	Tomarken et al (2008)	C
51	Smith et al (2009)	F
52	Cherlin et al (2007)	C
53	Relf et al (2008)	F
54	Stroebe et al (2007)	F
55	Currow et al (2008)	A
56	Chiu et al (2009)	C
57	Hudson et al (2010)	C
58	Luckett et al (2010)	A
59	Kessler et al (2003)	No Grade
60	Lovibond & Lovibond (1995)	No Grade
61	Roth et al (1998)	No Grade
62	Parkes (1993)	F
63	Moos & Moos (2002)	No Grade
64	Prigerson et al (2006)	No Grade
65	Hebert et al (2006)	F
67	Hudson (2006)	C
68	Hebert et al (2009)	E
70	Collins-Tracey et al (2009)	E
71	Milberg et al (2008)	C
72	Bergman & Haley (2009)	C
73	Agnew et al (2010)	E
74	Roberts & McGilloway (2008)	C
75	O’Connor et al (2009)	C
77	Engelberg (2006)	F
78	Cohen et al (2001)	No Grade
91	McMillan & Small (2007)	B
92	Moss (2001)	F
93	Schwartz et al (2003)	D

Notes:

Ref No. = Reference number

No Grade = Grading system was not applicable to psychometric or clinical scales

References

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