February 2009

cpcer

Centre for Palliative Care
Education & Research

Family meetings in palliative care: multidisciplinary clinical practice guidelines

Authors: Peter Hudson[1], Karen Quinn[1], Brendan O'Hanlon[2], Sanchia Aranda[3]

1 Centre for Palliative Care Education & Research, St Vincent's and The University of Melbourne, Victoria, Australia
2 The Bouverie Centre, La Trobe University, Victoria, Australia
3 School of Nursing and Social Work, The University of Melbourne, Victoria, Australia

Background

Support for family carers is a core function of palliative care service provision. Family meetings provide an opportunity to enhance the quality of care provided to palliative care patients and their family carers. The clinical guidelines outlined here offer a framework for preparing, conducting and evaluating family meetings.

For more information regarding the development and evidence base of these guidelines please refer to our international journal articles (see references #1 and #2) or contact the Centre for Palliative Care Education & Research, St Vincent's and The University of Melbourne +61 3 9416 0000, **cpcpa@medstv.unimelb.edu.au** or **www.pallcare.unimelb.edu.au**

There is a multi-media resource titled *Conducting Family Meetings: a resource for health professionals working in cancer and palliative care* available which demonstrates how to use these guidelines. For information on how to access this resource, please visit the Centre for Palliative Care Education and Research website **www.pallcare.unimelb.edu.au**

Guiding principles for convening and conducting family meetings

- Family meetings can be a useful way to assist patients and family members to clarify goals of care, consider site of care options, and to share information. Ideally they provide a safe environment where issues and questions can be raised and appropriate strategies agreed upon.
- Strategies to support family carers are a core component of palliative care; hence service providers have a responsibility to *offer* family meetings based on need.
- Service providers should view family meetings as mutually beneficial. They are not only potentially valuable for patients and family carers; they may also provide a resource effective way to explain what the service can and cannot offer. Such meetings provide an opportunity to triage priority issues and a way to make referrals to other health professionals or other institutions early in the care planning phase.
- Family meetings should *not* be used as an opportunity for health care professionals to debate a patient's medical status; in this situation, a case conference should be convened prior to the family meeting.

Centre for Palliative Care Education & Research
St. Vincent's & The University of Melbourne

Postal address
PO Box 2900 Fitzroy
Victoria 3065 Australia

Street address
6 Gertrude Street Fitzroy
Victoria 3065 Australia

Telephone 61 3 9416 0000
Facsimile 61 3 9416 3919

cpcpa@medstv.unimelb.edu.au
www.pallcare.unimelb.edu.au

- Family meetings should not be saved for 'crisis' situations. Instead, a preventative approach is advocated where issues are anticipated before they become major dilemmas. Hence a proactive rather than reactive approach to care is fostered.
- Ideally, family meetings are *offered* routinely on admission, and conducted at a pertinent time thereafter.
- Facilitators of family meetings require appropriate skills in group work, therapeutic communication and palliative care. We contend that the decision about who (i.e. which discipline) should convene and facilitate a family meeting is best determined on pragmatic grounds (local, site specific reasons) and not based on hierarchical reasons (i.e. based on authority). Hence the multidisciplinary team should determine who conducts the family meeting and presumably this may change dependant upon skills, knowledge of the family and resources.
- Occasionally, family members may want to withhold details of the patient's prognosis from the patient; there may incongruent wishes about the site of care; 'desire to die' statements may have been made by the patient; or there may be conflict within the family or difficulties regarding the transition from curative treatment to palliative care. In these circumstances we recommend the key resources and references to support therapeutic communication outlined in the reference list (#3 to #9). Additionally, if it is known in advance that there is significant conflict (or other major issues) within the family, involving a family therapist or health psychologist may be appropriate.
- Pre-planning for the actual meeting is imperative (see Box 2) as is comprehensive follow up after the meeting (see Box 3 and 4).
- Suitable resources should be available to patients and family members who attend the meeting in order to complement the verbal information (e.g. brochures about services available, carer guidebooks, treatment and drug information, etc).

Box 1: Guidelines for Convening, Conducting and Evaluating Family Meetings

1. Preparing for a family meeting

a) On admission to the palliative care service the relevant health professional should introduce the purpose of a family meeting and offer a family meeting to all lucid patients. This discussion should incorporate the role that palliative care has in supporting families as well as the patient.

b) Ask the patient to confirm one or two key family carers and/or friends who they approve to be involved in medical and care planning discussions. Note this in the medical record.

c) Conduct a family genogram to determine key relationships within the patient's family. It could be introduced thus: "Can I spend a few minutes just working out who is in your family?"

d) Seek the patient's permission to arrange a family meeting and ask if they have any particular issues/concerns or questions they would like discussed at the meeting. If the patient does not want to attend, seek their permission to conduct a meeting with key family and/or friends (as above). If the patient is unable to make an informed decision, offer the meeting to the next of kin or key family/friends who have been identified to receive information and care planning decisions related to the patient. Note: Where a patient has no family or appropriate proxy a legal guardian may need to be appointed.

e) Identify the most appropriately skilled person from the multidisciplinary team to convene the family meeting. This person will take responsibility for scheduling, invitations and coordination. Ideally this person should also act as the primary contact point for the key family carer.

f) Contact the primary family carer(s): provide an overview of purpose of the family meeting; offer to convene a meeting at a mutually acceptable time. Advise the carer that the meeting time will be confirmed in due course (i.e., once other attendees are arranged). Where pertinent, and if resources allow offer to conduct the meeting via teleconference. Establish the main questions and issues that the family carer would like discussed (refer Box 2). If the patient is participating in the meeting ask him/her to identify their key concerns.

Note: If significant family conflict (or other major issue) is identified consider referral to a practitioner who is trained to work with complex issues within families (e.g. family therapist or health psychologist).

g) Determine which health care professionals should attend the family meeting. Invite key health care professionals based on the identified needs of the patient and family carer. The number of staff should be restricted, inviting only the relevant health professionals, so that the patient and family/friends do not feel overwhelmed. Note: Include a professional interpreter if required.

h) Identify the family meeting time and location where the meeting will be held. Inform attendees of the scheduled start and finish time for the meeting. A comfortable room free of interruptions (including pagers and phones), tissues made available and conducive seating arrangements is recommended.

2. Conducting a family meeting

a) Introduction

Chairperson to:

i) Thank everyone for attending and introduce him/herself and invite others to introduce themselves and state their role.

ii) Establish ground rules in a non patronising way e.g. *"We would like to hear from all of you, however if possible could one person please speak at a time, each person will have a chance to ask questions and express views"*. Request no interruptions such as phones etc.

iii) Indicate the duration of meeting (recommended maximum time of 60 minutes).

b) Determine the understanding of the purpose of the family meeting.

Chairperson to:

i) Briefly outline the broad purpose of the family meeting (based on previous steps), and then confirm with the family and patient that their interpretation of the purpose of the meeting concurs.

For example:

"We arranged this meeting to consider discharge planning options. Is this your understanding of the purpose of the meeting?" (If not reframe the meeting's purpose).

or

"From the things you mentioned on the questionnaire what is the most important thing you would like to discuss?"

or

"How could we be most helpful to you today?"

ii) Ask the patient/family if there are any additional key concerns, and if pertinent, prioritise these and confirm which ones will be attempted to be dealt with at this meeting (others can be discussed at a future meeting or can perhaps be dealt with on a one on one basis).

iii) Clarify if specific decisions need to be made (e.g. if the patient is to go home or not).

c) Determine what the patient and family already know. Possible questions may include,

"What have you been told about palliative care" as a way of clarifying, confirming etc.

"Tell me your understanding of the current medical condition or current situation?"

If pertinent provide information (in accordance with desire) on the patient's current status, prognosis and treatment options.

Ask each family member in turn if they have any questions about current status, plan and prognosis. Helpful questions may include, *"Do you have questions or concerns about the treatment or care plan?"*

For family discussion with non-competent patient (i.e. cognitively impaired or imminently dying), ask each family member in turn:

"What do you believe your relative/friend would choose if they could speak for himself/herself?"

"In the light of that knowledge, what do you think should be done?"

d) Address specific objectives of the meeting (as previously determined).

e) 'Check in' periodically throughout with the patient and family carer to see if the discussion seems to be valuable and is in keeping with their needs e.g. *"Are we on track?"; "Is this what you wanted from today's meeting?"; "What haven't we touched on that's important to you?"*

Also consider taking a short break during the meeting (to give participants time to digest information) and then allow some time to refocus.

f) Offer relevant written or audiovisual resources. Examples include guidebooks, brochures, enduring power of attorney documents, advance care directive information and so forth.

g) Identify other resources, including possible referral to other members of the multidisciplinary team. Suggest scheduling a follow-up meeting if pertinent.

h) Concluding the discussion.

Summarize any areas of consensus, disagreements, decisions and the ongoing plan (i.e. clarify next steps) and seek endorsement from attendees (e.g. *"Are we all clear on the next steps?"*)

Emphasize positive outcomes arising from the meeting.

Offer final opportunity for questions, concerns, or comments. E.g. *"What hasn't been covered today that you would have liked to discuss?"* or *"Are there any questions you had that haven't been answered yet?"*

Remind patient and family carers to review the recommended written resources.

Identify one family spokesperson for ongoing communication.

Thank everyone for attending.

3. Documentation and follow-up

a) Document who was present, what decisions were made, what the follow-up plan is and share this with the care team (see Box 3).

b) Offer the patient/family a copy of the main content of the meeting and file a copy of this document in the patient's medical record.

c) Liaise with the primary family carer within a few days after the meeting to determine if the meeting was helpful (see Box 4).

d) Maintain contact with the key family spokesperson, including attending scheduled follow-up meetings or telephone calls as needed.

Box 2: Pre-Family Meeting Primary Family Carer Questionnaire

N.B. Conducted by phone ❒ or face to face ❒ by family meeting convenor [insert name]

Now that I have explained about the family meeting and you have agreed to attend, it would be useful for us if we had some more information in order to prepare for the family meeting.

What are the main issues for you at the moment?

(a) Greatest concern:

(b) Second greatest concern:

How upset / worried are you about these concerns? *(Place a cross on the line)*

(1) Not at all — *As worried as I could possibly be (10)*

How often do these concerns arise? (Place a cross on the line)

(1) Not at all — *All the time (10)*

Are there other difficulties you are coping with now? Please outline below:

How much is the problem (or problems) interfering in your life? *(Place a cross on the line)*

(1) Not at all — *Dominating my life completely (10)*

How confident do you feel in dealing with the problem(s)? *(Place a cross on the line)*

(1) Not at all — *Extremely (10)*

What questions would you like to ask at the family meeting?

If you think of other questions between now and the family meeting, please write them down and bring them with you to the meeting.

Adapted with permission from Single Session Therapy Resource Guide (The Bouverie Centre 2006)

Box 3: Outcome of the Family Meeting

Below are key points to be recorded at the completion of the family meeting by the family meeting's facilitator.

A copy should be provided to the patient and family carer and one copy kept in the medical record.

Date of meeting: _____

Name of family meeting facilitator: _____

Proposed purpose of the meeting: _____

_____

_____

Family members present

Name:	Relationship:
Name:	Relationship:
Name:	Relationship:

Staff members present

Name:	Role/discipline:
Name:	Role/discipline:
Name:	Role/discipline:

Key issues raised at the meeting

_____

_____

_____

Key actions from the meeting

Current situation	Goal	Action	Key person to follow up	Review date

Adapted (with permission) from Single Session Therapy Resource Guide (The Bouverie Centre 2006)

Box 4: Post-Family Meeting Primary Family Carer Questionnaire

N.B. Conducted by phone ❒ or face to face ❒ by family meeting convenor [insert name]

As a follow up to the recent family meeting we are interested in finding out how things are for you at the moment.

Before the family meeting you nominated:

as the main problem to be discussed at the family meeting, and

as your second greatest problem.

How upset/worried are you about this problem (or these problems) at the present time? *(Place a cross on the line)*

(1) Not at all — *As worried as I could possibly be (10)*

How often do these problems happen? *(Place a cross on the line)*

(1) Not at all — *All the time (10)*

How much is the problem (or problems) interfering in your life? *(Place a cross on the line)*

(1) Not at all — *Dominating my life completely (10)*

In what ways?

How confident do you feel in dealing with the problem(s)? *(Place a cross on the line)*

(1) Not at all — *Extremely (10)*

You nominated the following questions as those you would like addressed in the family meeting:

To what extent do you feel these questions were addressed?

Office use only:

	Pre-session	Post-session	Difference
How upset/worried:			
Problem frequency:			
Life interference:			
Confidence:			

References

1. Hudson, P, Quinn, K, O'Hanlon, B, Aranda, S. **Family meetings in palliative care: multidisciplinary clinical practice guidelines.** *BMC Palliative Care* 2008, 7: 12.
2. Hudson, P, Thomas, T, Quinn, K , Aranda, S. **Family meetings in palliative care: are they effective?** *Palliative Medicine*, published online on 21 Nov.
3. National Breast Cancer Centre. **Clinical practice guidelines for the psychosocial care of adults with cancer.** Canberra: National Health and Medical Research Council; 2003.
4. Maguire P, Piceathly C. **Key communication skills and how to acquire them.** *BMJ* 2002, 325:697-700.
5. Young J, Weir S, Rycroft P, Whittle T. **Single session work: Implementation resource parcel.** The Bouverie Centre, Latrobe University; 2006.
6. Clayton JM, Hancock KM, Butow PN, Tattersall MHN, Currow DC. **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.** *Medical Journal of Australia* 2007, 186(12):S77-S108.
7. Hudson PL, Schofield P, Kelly B, Hudson R, Street A, O'Connor M, Kristjanson LJ, Ashby M, Aranda S. **Responding to desire to die statements from patients with advanced disease: recommendations for health professionals.** *Palliative Medicine* 2006, 20(7):703–710.
8. Hudson P. **Supporting a person who requires palliative care: A guide for family and friends.** Melbourne: Palliative Care Victoria; 2004.
9. Schofield P, Carey M, Love A, Nehill C, Wein S. **'Would you like to talk about your future treatment options?' discussing the transition from curative cancer treatment to palliative care.** *Palliative Medicine* 2006, 20:397–406.

Acknowledgements

- Nurses Board of Victoria for the Mona Menzies Postdoctoral Research Grant
- Project officers: Dr Tina Thomas and Dr Colleen Nordstrom
- Expert panel members: Dr Maxine Braithwaite; Ms Helen Kean; Dr Tamsin Bryan; Dr Carrie Lethborg; Dr Michael Summers; A/Professor Rosalie Hudson; Dr Annabel Pollard
- Focus group participants from: Monash Medical Centre; The Alfred Hospital; Caritas Christi Hospice; Royal Melbourne Hospital, Calvary Health Care Bethlehem; Peter MacCallum Cancer Centre

ERC: 090024 Feb 2009