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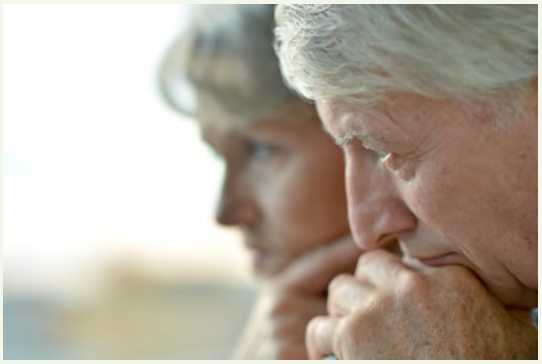
Family meetings for patients with advanced disease: Multidisciplinary clinical practice guidelines (version 2)



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Note: This version is for current research study and not for wider dissemination

Background

Support for family carers is a vital part of caring for a patient with advanced disease and a core function of palliative care service provision. Family meetings provide an opportunity to enhance the quality of care provided to patients with advanced disease and their family carers. Family meetings (also known as family conferences), are meetings between the family carers, the patient (where possible), and health care professionals. The main purposes are to clarify the goals of care, discuss the patient's medical condition and any changes to this condition, also to discuss site of care planning including discharge planning and transition to other services. Ideally family meeting provides a safe environment where issues and questions can be raised and appropriate strategies agreed upon.

The clinical guidelines outlined here offer a framework for preparing, conducting and evaluating family meetings. Sometimes family meetings occur in an unstructured opportunistic way. These guidelines have been designed for use when a meeting is pre-planned and more formal.

For more information regarding the development and evidence base of these guidelines please refer to our international journal articles (see references #1, #2 and #3) or contact the Centre for Palliative Care , Melbourne +61 3 9416 0000, or cpcpa@medstv.unimelb.edu.au

Guiding principles for convening and conducting family meetings

- 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 provide 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.
- 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 facilitation, therapeutic communication and advanced disease. 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 (#4 to #12). Additionally if it is known that there is significant conflict (or other major issues) within the family, involving an appropriately trained specialist may be appropriate.
- Identify whether there is an advance care plan or medical power of attorney before setting up the meeting.
- Be aware of any language and/or cultural preferences that might impact on setting up the family meeting.
- Pre-planning for the actual meeting is imperative (see Box 1 and 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, the relevant health professional should introduce the purpose of a family meeting and offer a family meeting to all patients with capacity. If relevant, 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 whether the patient would like to attend. If they would like to attend, establish the main issues/concerns and questions that the patient would like discussed at the meeting (refer Box 2, Part A) and determine who the patient believes are the important people who should be at the meeting. If they do not want to attend, seek their permission to conduct a meeting with key family and/or friends. 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. In some circumstances, a different person may need to set up the meeting than the person who actually conducts the meeting.

f) Contact the primary family carer(s): provide an overview of the 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 part B).

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.

g) Determine key areas for discussion at the family meeting based on: (a) patient's agenda (Box 2 Part A); family's agenda (Box 2 Part B) and (c) health care team's agenda (Box 3).

Note: Include a professional interpreter if required.

h) Identify the family meeting time and location. Inform the attendees of the details of the meeting, start and finish times and participants of 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

Facilitator 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 45 minutes).

iv) Acknowledge that some of the topics of discussion may be unsettling or sensitive and outline a plan for dealing with distress e.g. *"As part of our discussion today there may be topics that you find unsettling or are challenging to talk about. If you need to take a break, please feel free to step out of the room for a few minutes and a member of the team will accompany you."*

v) Reassure family that the health care team is there to provide best possible care e.g. *"We want to take the best possible care of you and your relative. What are the most important things for us to know about you and your family that will enable us to help you?"*

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

Facilitator 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"

"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, imminently dying, or very young child), ask relevant family member:

"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.

If the patient or family member becomes visibly distressed, reassure them that it is normal to feel upset while having these more difficult conversations and ask if they need anything or would like to take a short break? Providing a few moments of silence can also be useful as it allows the person to feel the emotion and also to collect themselves before the conversation continues.

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

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

h) Concluding the discussion.

Assign tasks for particular individuals.

Summarise 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 spokeperson 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) Liaise with the primary family carer (and patient if they attended) within a few days after the meeting to determine if the meeting was helpful (see Box 4).

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

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ERC: 150612 June 2015

Participant ID Code:_____

Box 2 Part A: Pre-Family Meeting **Patient** Questionnaire

(Only complete if patient would like to attend the meeting)

N.B. Conducted by ☐ phone or ☐ face to face by [*insert name of person*] on [*insert date*]

Now that I have explained about the family meeting we would like to gather a bit more information to ensure we have the right health professionals at the meeting and are dealing with the issues that are of most importance to you and your family.

What are the main issues for you at the moment?

(a) Greatest concern:

_____

_____

(b) Second greatest concern:

_____

_____

How upset/ worried are you about the first concern on a scale from 1 to 10 where 1 is not at all and 10 is as worried as I could possibly be?
(Please enter score)

_____

How upset/worried are you about the second concern on a scale from 1 to 10 where 1 is not at all and 10 is as worried as I could possibly be?
(Please enter score)

_____

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 2 Part B: Pre-Family Meeting Primary **Family Carer** Questionnaire

N.B. Conducted by ☐ phone or ☐ face to face by [*insert name of person*] on [*insert date*]

Now that I have explained about the family meeting we would like to gather a bit more information to ensure we have the right health professionals at the meeting and are dealing with the issues that are of most importance to you and your family.

What are the main issues for you at the moment?

(a) Greatest concern:

_____

_____

(b) Second greatest concern:

_____

_____

How upset/ worried are you about the first concern on a scale from 1 to 10 where 1 is not at all and 10 is as worried as I could possibly be?
(Please enter score)

_____

How upset/worried are you about the second concern on a scale from 1 to 10 where 1 is not at all and 10 is as worried as I could possibly be?
(Please enter score)

_____

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: Key Issues for Health Professionals

Key issues for the health care team to be discussed:

_____

_____

_____

_____

_____

_____

Box 4: Outcomes of the Family Meeting

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

Administrative time in setting up the meeting:_____

Date of meeting: _____ Start time of meeting: _____ End time of meeting: _____

Name of family meeting facilitator: _____

Proposed purpose of the meeting: _____

Patient present: Yes/No (if No, why) _____

_____

Discuss the outcomes of the meeting with the patient: Yes/No

Family members present

Name:	Relationship to patient:
Name:	Relationship to patient:
Name:	Relationship to patient:
Name:	Relationship to patient:

Staff members present

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

Key issues raised at the meeting

_____

_____

_____

_____

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

Key actions from the meeting

Current situation	Goal	Action	Key person to follow up	Review date

Planned further follow up for another meeting? ☐ yes ☐ no

Date: _____

Details: _____

_____

Box 5 Part A: Post-Family Meeting **Patient** Questionnaire

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

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 concern to be discussed at the family meeting, and _____
as your second greatest concern.

How upset/ worried are you about the second concern just now on a scale from 1 to 10 where 1 is not at all and 10 is as worried as I could possibly be? *(Please enter score)* _____

How upset/ worried are you about the first concern just now on a scale from 1 to 10 where 1 is not at all and 10 is as worried as I could possibly be? *(Please enter score)* _____

These were the questions you wanted to be answered at the family meeting:

_____

_____

Were your questions answered at the family meeting?

_____

_____

Other feedback issues for team to follow upon:

_____

_____

Office use only:

	Pre-session	Post-session	Difference
How upset/ worried for 1st concern: How up[set/ worried for 2nd concern:			

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

Box 5 Part B: Post-Family Meeting Primary **Family Carer** Questionnaire

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

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 concern to be discussed at the family meeting, and _____
as your second concern.

How upset/ worried are you about the first concern just now on a scale from 1 to 10 where 1 is not at all and 10 is as worried as I could possibly be? *(Please enter score)* _____

How upset/ worried are you about the second concern just now on a scale from 1 to 10 where 1 is not at all and 10 is as worried as I could possibly be? *(Please enter score)* _____

These were the questions you wanted to be answered at the family meeting:

_____

_____

Were your questions answered at the family meeting?

_____

_____

Other feedback issues for team to follow upon:

_____

_____

Office use only:

	Pre-session	Post-session	Difference
How upset/ worried for 1st concern:			
How upset/ worried for 2nd concern:			

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