



Planning dementia care through case conferencing

ANSWERS TO FREQUENTLY ASKED QUESTIONS (FAQS) BY FAMILY AND OTHER 'PERSONS RESPONSIBLE'

What is a case conference?

A case conference is a formal meeting between persons responsible, family and relevant health professionals and care staff aimed at making shared decisions about a person with dementia's care where that person is unable to decide for themselves. Case conferencing is intended to inform both current care and 'advance care planning'.

What is a person responsible?

A person responsible is someone with legal authority to make healthcare decisions on behalf of someone who cannot make decisions for themselves. The term 'person responsible' is used in New South Wales, but varies between other states and territories.

What is advance care planning?

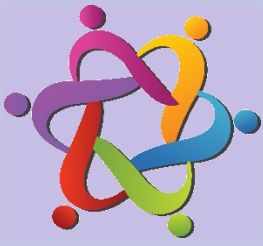
Advance care planning is a process of discussion and reflection through which a person's values and beliefs are clarified in order to make decisions about future care that are consistent with what they would have wanted were they able to decide for themselves.

The process of advance care planning is more important than whether specific paperwork is completed, for example a 'Do Not Resuscitate' order. The aim is to equip health professionals and families with the knowledge and confidence to make on-the-spot decisions even in complex situations that could not have been foreseen. Advance preparation with 'a cool head' will mean that decisions are likely to be better than if they are made during the emotional turmoil of a medical crisis.

Who should be involved in a case conference?

Case conferences should ideally involve:

- One or more person(s) responsible
- Other family members and/or friends via invitation by the person(s) responsible
- A health professional who has skills and experience to facilitate the case conference – i.e. ensure everyone has a chance to contribute to the discussion and all the necessary topics are covered
- Where relevant
 - Aged care staff who know the person well and are familiar with their current strengths and needs
 - A general practitioner (GP) who can assist with decision-making and actions related to medications and referrals.
 - Other allied health professionals such as physiotherapists or speech pathologists who can help with particular needs such as pain or swallowing problems.



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What does case conferencing involve for a family member or other person responsible?

Family and other personal representatives have an important role to play in deciding how to care for their loved one as they approach the end of life. In particular, these people:

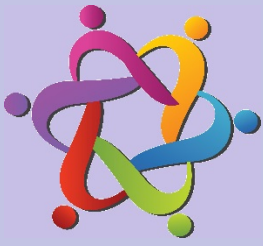
- Are best placed to know what the person would have wanted from care if they were able to decide for themselves. This is because they knew the resident before they developed dementia and can remember their personal beliefs and values and tell other case conference attendees about these.
- Can offer advice on the person's likes and dislikes, including ways to settle the person if they becomes agitated or cheer them up if they are unhappy.
- Can provide information on medical history, including the diagnosis of dementia and how the family is coping with the changes that have occurred.
- Can tell other case conference attendees about the views of other family members, to ensure a full range of perspectives are taken into account.
- Can communicate decisions made about the person's care to other family members afterwards.

Which family members or other person responsible should attend?

A family member should be willing and able to discuss health and care needs and assist in making decisions that the individual would have wanted if they were able to express their needs. Importance is given to the person responsible who is legally entitled to make healthcare decisions on behalf of the person. This responsibility is called the 'person responsible', 'enduring power of attorney (medical treatment)' or other legal term depending on the state/territory. More than one family member or person responsible can attend a case conference to support one another or present different views respectfully.

What preparation should family members or other person responsible do before attending a case conference?

Before attending a case conference, please think about what priorities the person would have for their care were they able to speak for themselves. Talk to other family members and friends of the person to get an understanding of their views. The person who will facilitate the case conference should make contact with you before the case conference to ask what topics you would like to be discussed so they can be added to the agenda.



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What topics will be discussed at the case conference?

Everyone attending a case conference is welcome to put forward their ideas on what issues need to be discussed. Common topics may include:

- Management of symptoms such as pain or constipation
- Issues related to personal care such as bathing, toileting and eating
- Ways to improve the person's quality of life through recreational and other daily activities
- Behavioural and psychological symptoms of dementia (e.g. agitation, wandering)
- Aspects of care that you think the person would want more of or not be happy with (e.g. music or massage)
- Family issues that are relevant to care, such as those influencing frequency of visits or impacting on family involvement in decision-making (e.g. disagreement between family members).

This is not an exhaustive list, so feel free to raise any topic you would like discussed.

What decisions might be made at a case conference?

Decisions will depend on the individual person's health and needs, and taking into account what the individual would have wanted if they had been able to choose for themselves. Depending on these factors, decisions may be made either to continue with care unchanged or else to change the care plan to:

- add or remove particular medications
- use other, non-medical, approaches to making the person comfortable, such as massage or a change in room lighting
- change the person's diet or positioning whilst eating to reduce the risk of chest infection or encourage them to eat and drink.
- support a new role for the family in caring for the person (e.g. in feeding or pain relief), including the provision of any necessary training.
- acknowledge that care should prioritise the person's comfort rather than solely seeking to prolong her/his life.

If, after reading this, you have any further questions about case conferencing, please make a time to discuss these with health professional who is able to advise.