The Advance Project Guide (Dementia)

Initiating advance care planning (ACP) and assessing palliative care needs of people living with dementia

Early dementia	Moderate dementia	Advanced dementia
1. Identify the approach required **(Please note a person's ability to make healthcare decisions and communicate their symptoms and concerns may fluctuate over time depending on their overall health or stress levels)**		
Encourage the person to *make their own* healthcare decisions Generally, the person with early dementia can make their own ACP decisions and report their own symptoms and concerns, and may have capacity to complete legal documents if desired.	**Usually a *supported approach for* healthcare decisions is required** Generally, the person will need support to be involved in the ACP discussion and communicate their symptoms and concerns.	**Usually a *substituted approach for* healthcare decisions is required** Generally, the person will no longer have capacity to make ACP decisions and have difficulty communicating their symptoms and concerns.
2. Initiate ACP discussion		
Own Approach Initiate ACP discussion using **Quick Guide** or **Screening Interview (own or supported approach versions)** with person themselves +/- support person. Provide the **"Planning together"** guide and **"Who will speak for you…"** resource and encourage them to complete the guide with their preferred support person(s). Arrange follow up discussion to further discuss **ACP** and consider the appropriate documentation. Encourage person to legally appoint substitute decision maker +/- complete **Advance Care Directive** if appropriate.	**Supported Approach** Initiate ACP discussion using **Quick Guide** or **Screening Interview (own or supported approach versions)** with person themselves +/- support person. Provide the **"Planning together"** resource and encourage them to complete this guide with their preferred support person(s). Arrange follow up discussion to further discuss **ACP** and consider the appropriate documentation. Complete **Advance Care Plan** with person and their preferred substitute decision maker as appropriate.	**Substituted Approach** Initiate ACP discussion using **Quick Guide** or **Screening Interview (substituted approach versions)** with family member/ proxy. Provide substitute decision maker with the **"Planning for…"** resource. Arrange follow up discussion to further discuss **ACP** and consider the appropriate documentation. Complete **Advance Care Plan** with person's substitute decision maker as appropriate (please note an Advance Care Directive is not appropriate as can only be signed by a person with capacity for health care decisions)
3. Assess palliative care needs		
• If other health conditions indicate this is required. • Consider the **surprise question** *"would you be surprised if this person died in the next 6 to 12 months?"* **+/- SPICT™** • Review care plan and consider **Referral Triage Tool** for residential or home care settings (as applicable).	• If other health conditions indicate this is required. • Consider the **surprise question** *"would you be surprised if this person died in the next 6 to 12 months?"* **+/- SPICT™** • Review care plan and consider **Referral Triage Tool** for residential or home care settings (as applicable).	• **Distress Observation Tool (DOT)** • Family needs assessment • Review care plan and consider **Referral Triage Tool** for residential or home care settings (as applicable).
4. Ongoing evaluation		
Ongoing ACP discussion: • Review every 6 to 12 months or sooner if person's condition or care setting changes or if discharged from hospital. **Reassess palliative care needs:** • At least every 6 to 12 months using the **surprise question** and **SPICT™**	**Ongoing ACP discussion:** • Review every 6 to 12 months or sooner if person's condition or care setting changes or if discharged from hospital. **Reassess palliative care needs:** • At least every 6 to 12 months using the **surprise question** and **SPICT™**	**Ongoing ACP discussion:** • Review every 6 to 12 months or sooner if person's condition or care setting changes or if discharged from hospital. **Reassess palliative care needs:** • At least every 3 months using the **Distress Observation Tool (DOT)**, sooner if new distress or changes in the person's condition.

Consider the person's stage of dementia, and their capacity to be involved in ACP discussions, and communicate their symptoms and concerns.

Assessing a person's capacity to be involved in ACP and to communicate their symptoms & concerns

Knowing whether or not a person has capacity to make decisions is not always clear. Generally, when a person does not have capacity to make a particular healthcare decision they cannot:

- ***Understand and appreciate the facts and choices involved***
- ***Weigh up the consequences***
- ***Communicate the decision***

A person's ability to make decisions may also fluctuate over time depending on their health or stress levels.

People should be supported to make their own ACP decisions as much as possible. When this is not possible, it is then appropriate to discuss ACP with the person's family/proxy.

Likewise, people should always be supported to communicate their own symptoms and concerns wherever possible.

When a person is no longer able to verbalise their symptoms and concerns, the observations of family and staff who know the person well are really important to guide care.

Stages of dementia and role of palliative care

Early dementia

"Often this phase is only apparent in hindsight. At the time it may be missed, or put down to ageing or overwork.

The onset of dementia is usually very gradual and it is often impossible to identify the exact time it began. The person ***may:***

- Appear more apathetic and to have less 'sparkle'
- Lose interest in hobbies and activities
- Be unwilling to try new things
- Show reduced capacity to adapt to change
- Show poor judgement and make poor decisions
- Be slower to grasp complex ideas and take longer with routine jobs
- Blame others for "stealing" lost items
- Become more self-centred and less concerned with others and their feelings
- Become more forgetful of details of recent events
- Be more likely to repeat themselves or lose the thread of their conversation
- Be more irritable or upset if they fail at something
- Have challenges handling money." *

A person with **early dementia may require** a palliative approach or **palliative care if other conditions indicate this is required.**

Moderate dementia

"At this stage the challenges are more pronounced and disabling. The person ***may:***

- Be more forgetful of recent events. Memory for the distant past generally seems better, but some details may be forgotten or confused
- Be confused regarding time and place
- Become lost if away from familiar surroundings
- Forget names of family or friends, or confuse one family member with another
- Forget saucepans and kettles on the stove or may leave gas unlit
- Wander around streets, perhaps at night, sometimes becoming lost
- Behave in a disinhibited way, for example going outdoors in nightwear
- See or hear things that are not there
- Become very repetitive
- Be forgetful of hygiene or eating and drinking
- Become angry, upset or distressed through frustration." *

A person with **moderate dementia may require** a palliative approach or **palliative care if other conditions indicate this is required.**

Advanced dementia

"At this third and final stage, the person is severely disabled and needs total care. The person ***may:***

- Be unable to remember occurrences for even a few minutes, for instance forgetting that they have just had a meal
- Lose their ability to understand or use speech
- Be incontinent
- Show no recognition of friends and family
- Need help with eating, washing, bathing, toileting and dressing
- Fail to recognise everyday objects
- Be disturbed at night
- Be restless, perhaps looking for a long-dead relative
- Be aggressive, especially when feeling threatened or closed in
- Have difficulty walking, perhaps eventually becoming confined to a wheelchair
- Have uncontrolled movements
- Have permanent immobility, and in the final weeks or months." *

A palliative approach or **palliative care is appropriate for a person with advanced dementia.** Referral to specialist palliative care services may be required.

*Parker D, Lewis J, Gourlay K, Dementia Australia Advisory Committee (2018). Palliative Care and Dementia. Dementia Australia Paper Number 43: A report for Dementia Australia, prepared in collaboration with Palliative Care Australia. ISBN 978-1-921570-30-8. Reproduced with permission from Dementia Australia.

Ongoing advance care planning discussions are important for all stages of dementia