The Advance Project Dementia – ARIIA Grant Advisory Group Meeting

4th July 2023

Supporting implementation of aged care staff initiated advance care planning and palliative care needs assessment for people living with dementia

HammondCare
Champion Life

Meeting agenda 4th July 2023

1. Start recording – check all members agree
2. Acknowledgement of country
3. Introductions as needed
4. Brief summary on background/progress
5. Evaluation protocol discussion points
6. Draft terms of reference
7. Consumer representative
8. Other?

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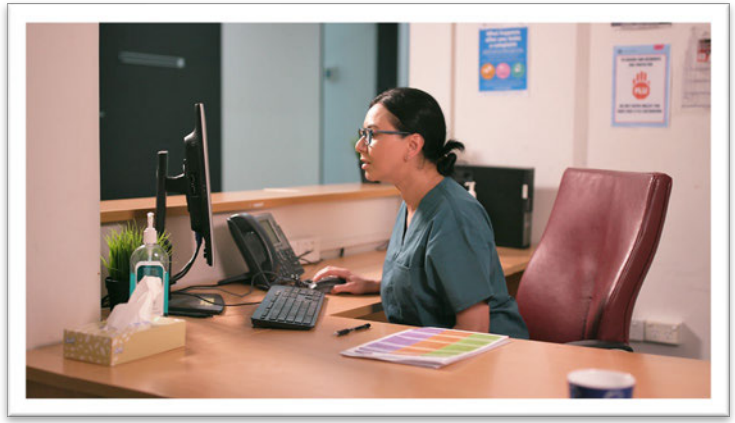
Enable better care: Initiating end-of-life conversations and assessing palliative care needs in people living with dementia

Our dementia specific training and resources have been specifically created to empower aged and primary care teams, to build greater confidence, capacity, and skills in this area.

Dementia-specific resources



Free eLearning

Train-the-Trainer & Mentoring Support

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CARESEARCH palliative care knowledge network
Funded by the Australian Government
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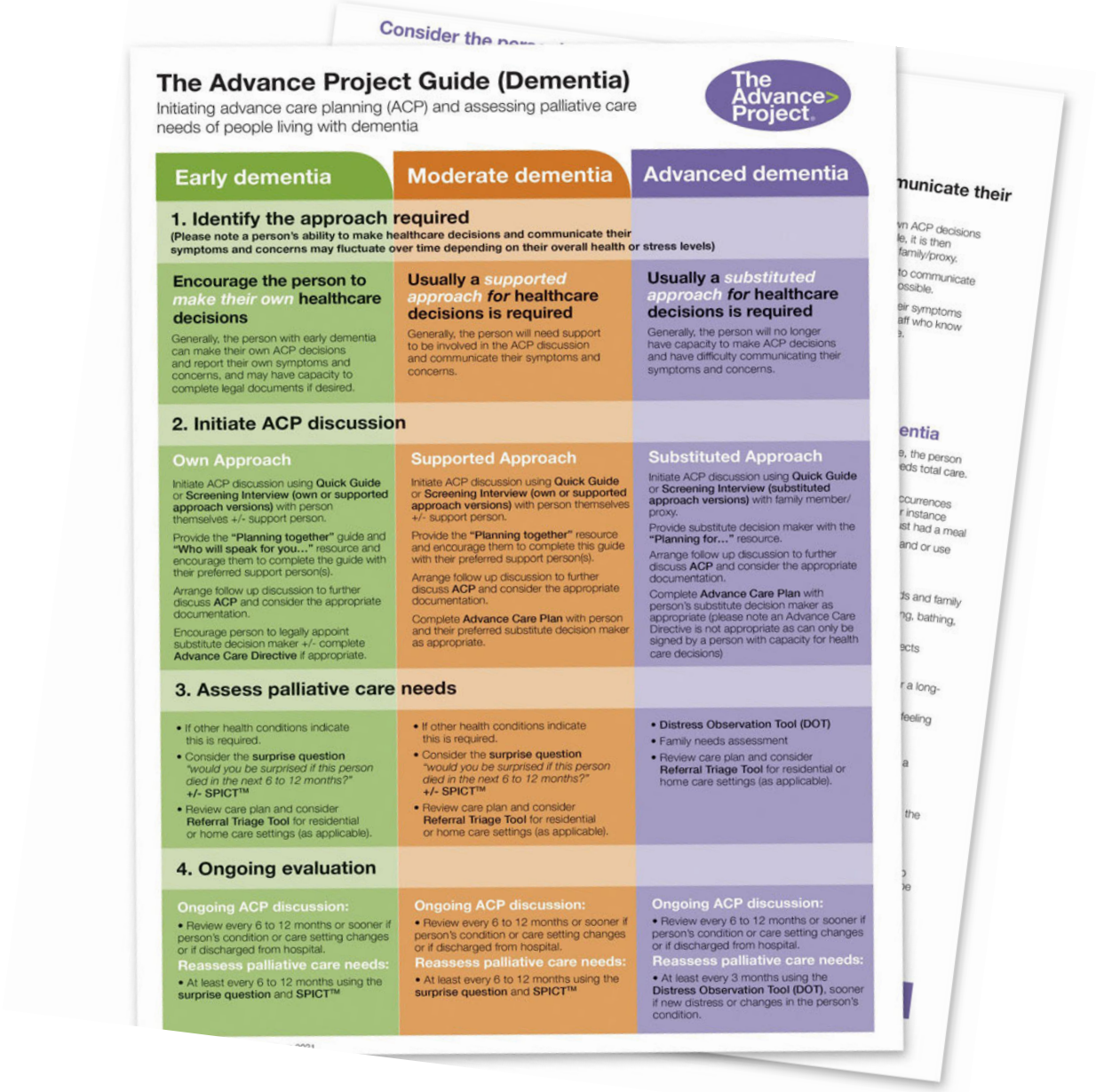
The Advance Project Guide (Dementia)



The Advance Project Guide (Dementia)

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

The Advance> Project

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.

*Outline steps involved and resources that can be used to initiate ACP and palliative care for people living with different stages of dementia

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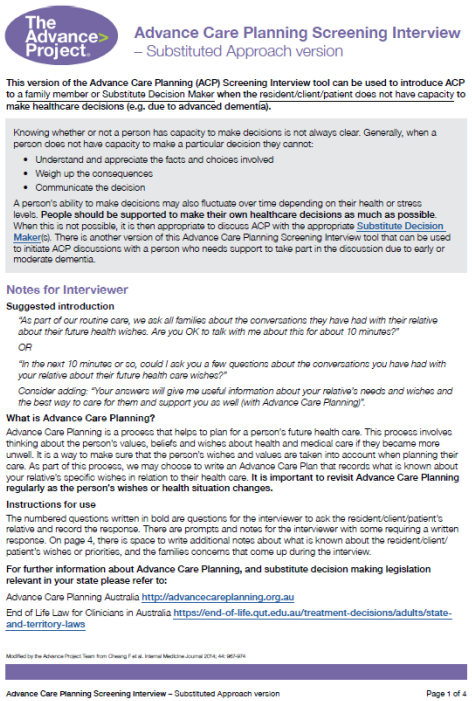
Tools to support staff to start ACP conversations

- Formal structured ACP screening interview and quick guides
- Initially developed for inpatient acute hospital setting, then adapted for general practice and rolled out nationally for use in routine health assessments.
- Not the whole ACP conversation – a way to get started. Aims:
  - Introduce and promote awareness of ACP
  - Determine person's preferred SDM
  - Ensure aged care home/GP is aware of any ACP already completed
  - Assess person's and/or SDM's readiness to further discuss ACP

Tools to support staff to start ACP conversations

- ACP screening interview tools/quick guides now adapted for use with:
  - people living with mild/moderate dementia (own/supported approach version)
  - family members/SDMs of people living with advanced dementia (substituted approach version)

- ACP screening interview tools are fillable PDFs that can be stored in resident's record



The Advance> Project.

Advance Care Planning Screening Interview
– Substituted Approach version

This version of the Advance Care Planning (ACP) Screening Interview tool can be used to introduce ACP to a family member or Substitute Decision Maker when the resident/client/patient does not have capacity to make healthcare decisions (e.g. due to advanced dementia).

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 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 healthcare decisions as much as possible.** When this is not possible, it is then appropriate to discuss ACP with the appropriate Substitute Decision Maker(s). There is another version of this Advance Care Planning Screening Interview tool that can be used to initiate ACP discussions with a person who needs support to take part in the discussion due to early or moderate dementia.

Notes for Interviewer

Suggested introduction

"As part of our routine care, we ask all families about the conversations they have had with their relative about their future health wishes. Are you OK to talk with me about this for about 10 minutes?"

OR

"In the next 10 minutes or so, could I ask you a few questions about the conversations you have had with your relative about their future health care wishes?"

Consider adding: "Your answers will give me useful information about your relative's needs and wishes and the best way to care for them and support you as well (with Advance Care Planning)".

What is Advance Care Planning?

Advance Care Planning is a process that helps to plan for a person's future health care. This process involves thinking about the person's values, beliefs and wishes about health and medical care if they became more unwell. It is a way to make sure that the person's wishes and values are taken into account when planning their care. As part of this process, we may choose to write an Advance Care Plan that records what is known about your relative's specific wishes in relation to their health care. **It is important to revisit Advance Care Planning regularly as the person's wishes or health situation changes.**

Instructions for use

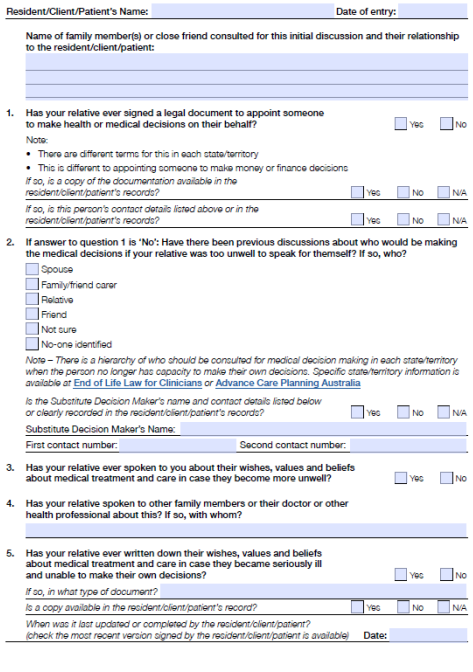
The numbered questions written in bold are questions for the interviewer to ask the resident/client/patient's relative and record the response. There are prompts and notes for the interviewer with some requiring a written response. On page 4, there is space to write additional notes about what is known about the resident/client/patient's wishes or priorities, and the families concerns that come up during the interview.

For further information about Advance Care Planning, and substitute decision making legislation relevant in your state please refer to:

Advance Care Planning Australia http://advancecareplanning.org.au

End of Life Law for Clinicians in Australia https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws

Modified by the Advance Project Team from Cheung F et al. Internal Medicine Journal 2014; 44: 987-974



Resident/Client/Patient's Name: Date of entry:

Name of family member(s) or close friend consulted for this initial discussion and their relationship to the resident/client/patient:

1. **Has your relative ever signed a legal document to appoint someone to make health or medical decisions on their behalf?** ☐ Yes ☐ No

   Note:
   - There are different terms for this in each state/territory
   - This is different to appointing someone to make money or finance decisions

   If so, is a copy of the documentation available in the resident/client/patient's records? ☐ Yes ☐ No ☐ N/A

   If so, is this person's contact details listed above or in the resident/client/patient's records? ☐ Yes ☐ No ☐ N/A

2. **If answer to question 1 is 'No': Have there been previous discussions about who would be making the medical decisions if your relative was too unwell to speak for themself? If so, who?**

   ☐ Spouse
   ☐ Family/friend carer
   ☐ Relative
   ☐ Friend
   ☐ Not sure
   ☐ No-one identified

   Note – There is a hierarchy of who should be consulted for medical decision making in each state/territory when the person no longer has capacity to make their own decisions. Specific state/territory information is available at End of Life Law for Clinicians or Advance Care Planning Australia

   Is the Substitute Decision Maker's name and contact details listed below or clearly recorded in the resident/client/patient's records? ☐ Yes ☐ No ☐ N/A

   Substitute Decision Maker's Name:

   First contact number: Second contact number:

3. **Has your relative ever spoken to you about their wishes, values and beliefs about medical treatment and care in case they become more unwell?** ☐ Yes ☐ No

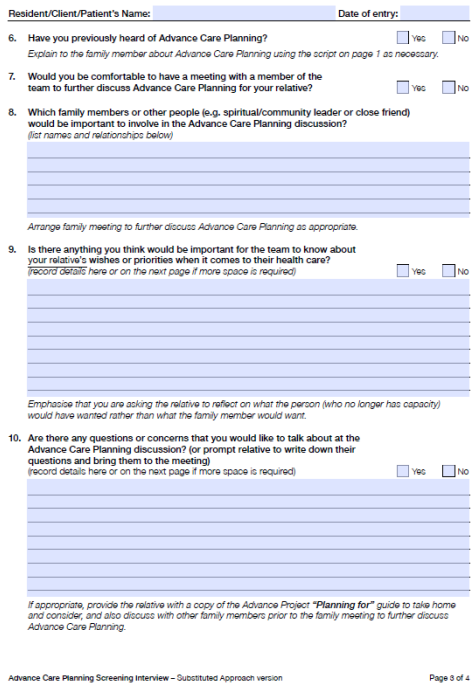
4. **Has your relative spoken to other family members or their doctor or other health professional about this? If so, with whom?**

5. **Has your relative ever written down their wishes, values and beliefs about medical treatment and care in case they became seriously ill and unable to make their own decisions?** ☐ Yes ☐ No

   If so, in what type of document?

   Is a copy available in the resident/client/patient's record? ☐ Yes ☐ No ☐ N/A

   When was it last updated or completed by the resident/client/patient? (check the most recent version signed by the resident/client/patient is available) **Date:**



Resident/Client/Patient's Name: Date of entry:

6. **Have you previously heard of Advance Care Planning?** ☐ Yes ☐ No

   Explain to the family member about Advance Care Planning using the script on page 1 as necessary.

7. **Would you be comfortable to have a meeting with a member of the team to further discuss Advance Care Planning for your relative?** ☐ Yes ☐ No

8. **Which family members or other people (e.g. spiritual/community leader or close friend) would be important to involve in the Advance Care Planning discussion?**
   (list names and relationships below)

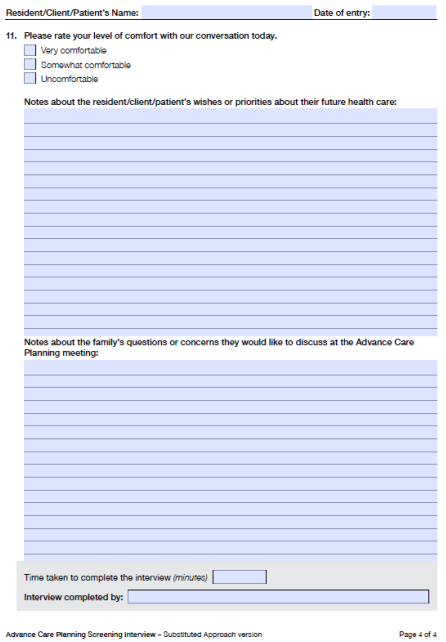
   Arrange family meeting to further discuss Advance Care Planning as appropriate.

9. **Is there anything you think would be important for the team to know about your relative's wishes or priorities when it comes to their health care?**
   (record details here or on the next page if more space is required) ☐ Yes ☐ No

   Emphasise that you are asking the relative to reflect on what the person (who no longer has capacity) would have wanted rather than what the family member would want.

10. **Are there any questions or concerns that you would like to talk about at the Advance Care Planning discussion? (or prompt relative to write down their questions and bring them to the meeting)**
    (record details here or on the next page if more space is required) ☐ Yes ☐ No

    If appropriate, provide the relative with a copy of the Advance Project ***"Planning for"*** *guide to take home and consider, and also discuss with other family members prior to the family meeting to further discuss Advance Care Planning.*



Resident/Client/Patient's Name: Date of entry:

11. **Please rate your level of comfort with our conversation today.**
    ☐ Very comfortable
    ☐ Somewhat comfortable
    ☐ Uncomfortable

Notes about the resident/client/patient's wishes or priorities about their future health care:

Notes about the family's questions or concerns they would like to discuss at the Advance Care Planning meeting:

Time taken to complete the interview *(minutes)*

Interview completed by:

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Introducing ACP

Initiate **ACP** discussion using **quick guide** or **screening interview** tool

If person ready to further discuss ACP, provide them with the appropriate resource

Arrange follow up with case conference to further discuss ACP

↓

Assist person/SDM to document person's wishes in advance care plan

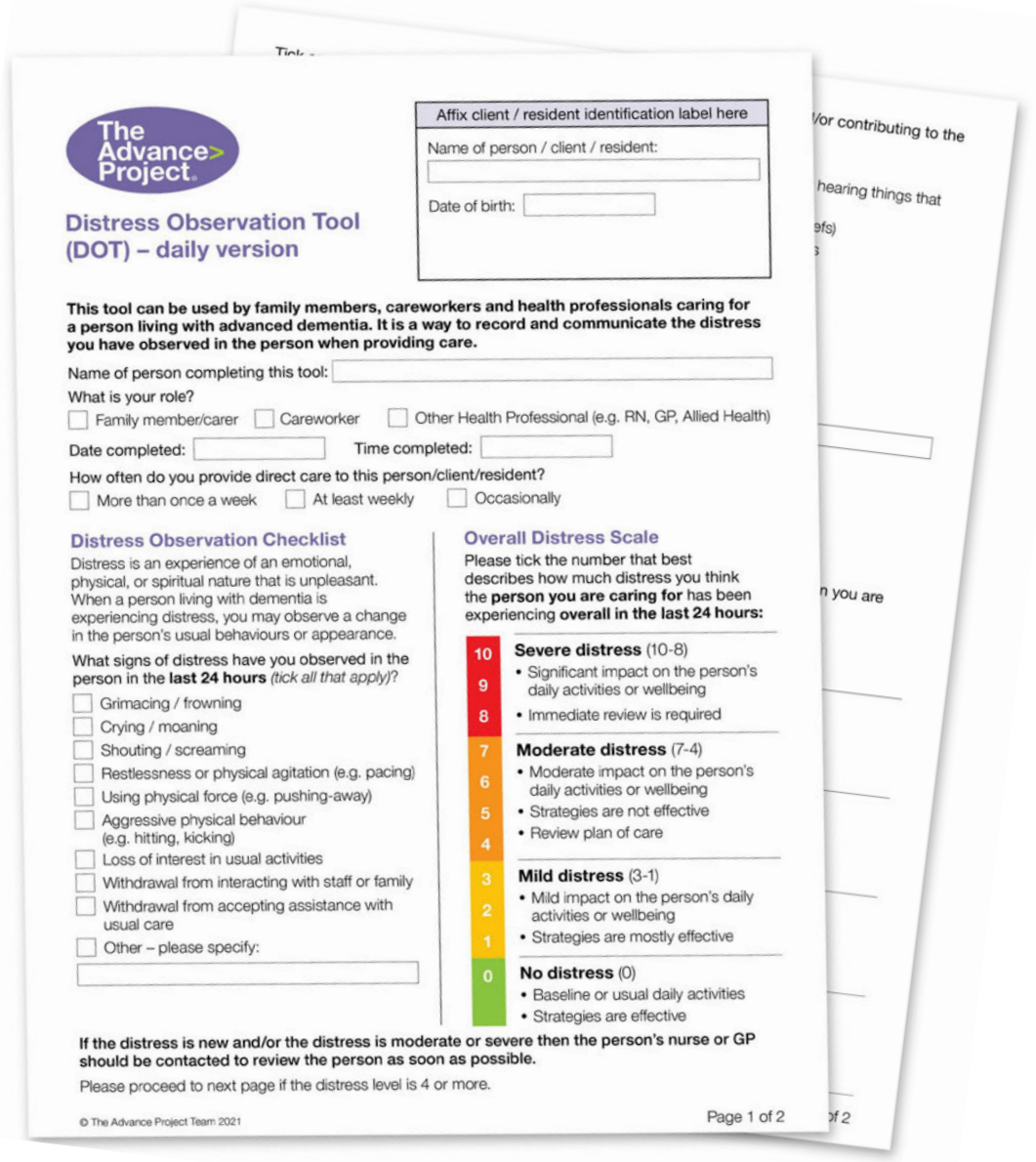
↓

Ongoing regular ACP discussions and review of advance care plan as person's circumstances change

Distress Observation Tool

"It helps to understand the level of distress the person you are caring for is experiencing"
Careworker

"Assists in discussions with GP's regarding peoples' level of distress and management of it."
RAC Manager



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Affix client / resident identification label here

Name of person / client / resident:

Date of birth:

Distress Observation Tool (DOT) – daily version

This tool can be used by family members, careworkers and health professionals caring for a person living with advanced dementia. It is a way to record and communicate the distress you have observed in the person when providing care.

Name of person completing this tool:

What is your role?

☐ Family member/carer ☐ Careworker ☐ Other Health Professional (e.g. RN, GP, Allied Health)

Date completed: Time completed:

How often do you provide direct care to this person/client/resident?

☐ More than once a week ☐ At least weekly ☐ Occasionally

Distress Observation Checklist

Distress is an experience of an emotional, physical, or spiritual nature that is unpleasant. When a person living with dementia is experiencing distress, you may observe a change in the person's usual behaviours or appearance.

What signs of distress have you observed in the person in the **last 24 hours** *(tick all that apply)*?

- ☐ Grimacing / frowning
- ☐ Crying / moaning
- ☐ Shouting / screaming
- ☐ Restlessness or physical agitation (e.g. pacing)
- ☐ Using physical force (e.g. pushing-away)
- ☐ Aggressive physical behaviour (e.g. hitting, kicking)
- ☐ Loss of interest in usual activities
- ☐ Withdrawal from interacting with staff or family
- ☐ Withdrawal from accepting assistance with usual care
- ☐ Other – please specify:

Overall Distress Scale

Please tick the number that best describes how much distress you think the **person you are caring for** has been experiencing **overall in the last 24 hours:**

10 9 8 **Severe distress** (10-8)
- Significant impact on the person's daily activities or wellbeing
- Immediate review is required

7 6 5 4 **Moderate distress** (7-4)
- Moderate impact on the person's daily activities or wellbeing
- Strategies are not effective
- Review plan of care

3 2 1 **Mild distress** (3-1)
- Mild impact on the person's daily activities or wellbeing
- Strategies are mostly effective

0 **No distress** (0)
- Baseline or usual daily activities
- Strategies are effective

If the distress is new and/or the distress is moderate or severe then the person's nurse or GP should be contacted to review the person as soon as possible.

Please proceed to next page if the distress level is 4 or more.

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Our new free training and resources make initiating end-of-life conversations and assessing palliative care needs of people living with dementia easier, to enable better care.

Making it easier to care better>

Access **FREE** Dementia Training and Resources today at **theadvanceproject.com.au/dementia**

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ariia Aged Care Research & Industry Innovation Australia

ARIIA Grant Round 2:

Implementation and evaluation of Advance Project Dementia in two HammondCare Residential Aged Care sites*

Team members:

- Professor Josephine Clayton
- Jon San Martin
- Dr Craig Sinclair
- Dr Srivalli Nagarajan
- Natalie Duggan
- Angela Raguz
- Dr Andrew Montague
- Professor Deborah Parker
- Professor Susan Kurrle

Huge thanks to Woy Woy/Horsley ☺

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ARIIA Project Goals

Implementation and Evaluation

Co-design suitable implementation approach to embed relevant resources into routine care

A train-the-trainer approach

Support staff to undertake the training and use the resources in routine care

Undertake a mixed method evaluation of the resources

Refine resources and optimise strategies for wider implementation and dissemination

Local Working Groups ⟷ Advance Project CNC ⟷ Local Clinical Support Leads

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Implementation Timeline

May Goal:

Establish Working Group for each sites and commence **co-design process**

June:

Reach consensus on which **resources to implement** for individual sites

July Goal:

Finalise **implementation plan** and strategies

All staff to commence **eLearning**

August Goal:

Integrate use of Advance Project resources and tools into **routine care**

September Goal:

Clinical Support Lead to help progress local implementation

January Goal:

>50% of staff have completed eLearning and engaged with Advance Project resources and tools

S	W	O	T
Strengths	**Weaknesses**	**Opportunities**	**Threats**
Teamwork, Relationship-based Care, Case Management Approach, Cottage Model	Staff confidence to talk about ACP and Palliative Care, Understanding of Palliative Care for people living with Dementia	Improve staff involvement with ACP discussions, Better collaboration and partnerships with health team, residents and family, Quality improvements	Staffing issues, Conflict with other priorities impacting commitment, Issues with technology, Cultural influences from both staff and residents

Evaluation Objectives

(1) Assess the **acceptability, useability, feasibility and perceived utility** of implementing the Advance Project (Dementia) online training and selected resources;

(2) Assess the impact of the Advance Project (Dementia) training and selected resources on **staff confidence and comfort levels to initiate conversations about advance care planning** with people living with dementia and their families/care partners;

(3) Assess the impact of the Advance Project (Dementia) training and the Distress Observational tool on **staff and care partner confidence to identify and communicate signs and symptoms of distress** in people living with advanced dementia;

(4) assess the impact of the implementation project on **documented advance care planning discussions and palliative care needs assessment** for residents living with dementia.

(5) **document the process of the implementation project**, to better understand how collaboration with site-level working groups can support change management in the residential aged care setting.

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Evaluation Components

- **Focus groups** with site-level working groups: *documenting the implementation process, barriers to implementation and trialing short improvement cycles to address these*
- **Surveys with staff**: *post-training self-reported confidence; feedback on resources to understand acceptability, useability, feasibility and perceived utility*
- **Surveys with residents and care partners**: *feedback on resources to understand acceptability, comfort with advance care planning discussions, and to inform further refinements*
- **Semi-structured interviews**: *interviews with front-line staff about their experiences using the resources*
- **Structured notes audit**: *audit pre- and post-implementation to assess use of Advance Project Dementia resources and impacts on care processes*

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Evaluation Protocol – Discussion Points

Estimated staff time:

Surveys – all eligible staff (single point in time)

- Care workers – approximately 10 – 15 minutes for survey
- Clinical/manager/pastoral care – between 10 – 20 minutes for survey (depending on resources used)

Interviews/Group Discussions – smaller sub-sample

- Care workers – ~ 30 mins for interview or 45 mins for group discussion (if in sub-sample)
- Clinical/manager/pastoral care - ~ 30 mins for interview or 45 mins for group discussion (if in sub-sample)
- *Can be undertaken outside of work hours and reimbursed

Structured Clinical Audit

- Undertaken by QSR team, no impact on staff time (other than normal processes to provide QSR access)

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Evaluation Protocol – Discussion Points

Structured Clinical Audit (two participating sites + two matched control sites – audited pre and post)

Point Prevalence of Advance Care Planning (ACP) Documentation (all residents at site)
- Number residents with evidence of ACP documentation
- Characteristics (e.g. type, signed/dated etc) of ACP documentation

Advance Care Planning Processes at key care milestones
- Number residents with evidence of an ACP discussion prior to admission
- Number residents with evidence of an ACP discussion within 8 weeks of admission
- Persons involved in ACP discussion/s

Identifying and responding to distress (Distress Observation Tool (DOT))
- Number residents with documented evidence of DOT use on at least one occasion
- Number of times DOT used and evidence of clinical review/action plan < 24 hrs if DOT > 4

Routine use of the DOT
- Evidence of DOT tool use – routinely at admission, 3 monthly and daily (if responding to specific need)
- Documentation of clinical review/action plan within 24 hours if DOT > 4

Palliative Care (PC) Needs Assessment
- Number residents with documented PC needs assessment within 8 weeks of admission

All current residents at time of PRE and POST audits

New admissions within audit timeframes (PRE 6 months prior to commencing) and (POST 1/8/2023 – 1/2/2024 TBC)

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Expected outcomes from ariia funded project

Evaluation findings will inform:

- Refinements to **HammondCare** wide processes for providing advance care planning and palliative care for people living with dementia in residential aged care

- Quality improvement of the Advance Project Dementia resources and training which are available **nationally to the aged care sector**

Our mission in action

We serve people with complex health or aged care needs, regardless of their circumstances.

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Champion Life

The Advance> Project®

Making it easier to care better>

The ultimate goal is to enable people living with dementia to have the opportunity to express their needs and preferences for care at the end of life, and have access to palliative care and support for their families and carers.

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