Advance Care Planning & Advance Care Directives
Case Studies and Reflective Questions

Case Study 1: Declining the conversation - “My Family Knows What I Want”

Client: Margaret, 79

Support: Transport + social support

Situation: Margaret lives alone, and her two daughters are interstate. Whilst listed as her contacts, they are hard to reach and quite disengaged. She states that she doesn’t think she has an ACD document and declines the offer for more information about ACP in general during her annual review. Key phrases in the conversations included:

- “What’s one of those?”
- “Surely it doesn’t matter, I’ll be gone anyway.”
- “My family will know what to do when the time comes.”

Reflective Questions

- **How do you respect Margaret’s right not to engage in ACP while still providing information?**
- **What might be behind her reluctance?**
- **How can you respond in a way that is informative but not persuasive?**
- **What should you document about her refusal?**
- **When might an opportunity arise to revisit the topic without pressuring her?**

Considerations

Acknowledging beliefs and wishes without pressure

- Always acknowledge her right to decline: ACP is not mandatory, and it is her choice.
- Clients may be unfamiliar with ACP or unclear about when it would be useful. They may believe an ACD is only about resuscitation and may not understand its wider use and applications.

Risks if ACP is declined

- There may already be documents that the client has forgotten about or does not recognise as an ACD. These documents may still be legally valid but work differently under current laws. Across Australia, laws about Advance Care Directives (ACDs) have changed at different times in each state and territory.
- For CHSP providers, the key role is not to give legal advice, but to pause, check, and refer to an authoritative source, such as the Legal Services Commission, Office for Public Advocate or Advance Care Planning Australia.
- In the past the medical team took more decisions on care – this has seen a large culture shift and now consent must be sought from the patient, a registered Substitute Decision Maker or Responsible Person. If Margaret hasn’t made an ACD she may not know this.

Supporting Margaret and her family without imposing your own views

- Explain practical relevance: These documents are increasingly requested by health providers (e.g., before elective surgery) and by some CHSP services to help them better meet her needs.
- Clarify implications if not in place: Without documentation, family may be asked to decide without guidance, which can cause stress or lead to outcomes she may not have chosen.

Referral pathways/ extra information

- Offer information without pressure: Brochures are included in all review packs and will arrive in the post. She can also read about it in the newsletter, attend an event with a guest speaker, or share the information with her daughters.
- Keep the door open: Note in her file that she declined today but explained there will be other opportunities to revisit the topic and offer assistance at any time in the future if she wishes.

Case Study 2: Diversity - “It’s Not Part of Our Culture”

Client: Minh, 80

Support: Personal care + domestic assistance

Situation: Minh is a first-generation member of the Vietnamese community and was part of the 1970 immigration wave from Vietnam. He accesses your general CHSP services but does not participate in broader social outings with your services due to language barriers. His cultural background means his family believes it is unlucky to talk about end-of-life planning. They insist decisions are left to the doctor.

Reflective Questions

- **How do you acknowledge cultural beliefs while explaining the purpose of ACP?**
- **What risks arise if ACP is avoided due to cultural taboos?**
- **How can you support Minh and his family without imposing your own cultural lens?**
- **What referral pathways (e.g., multicultural liaison, advocacy services) could you offer?**

Considerations

Acknowledging cultural beliefs while explaining ACP

- Begin by validating the family’s perspective: “I understand that in the Vietnamese culture, talking about these things may feel unlucky.”
- Clarify that ACP is not mandatory but explaining its purpose in simple terms: it helps ensure Minh’s own values and wishes are known, rather than leaving decisions entirely to others.
- Frame ACP positively, as a way of supporting good care and reducing stress for family members, rather than focusing only on end-of-life.

Risks if ACP is avoided due to cultural taboos

- Decisions may default to doctors or family members who may not know Minh’s preferences.
- Family conflict can arise if relatives disagree about what Minh would want.
- Doctors may make choices based on clinical norms rather than cultural or personal values.
- Minh’s voice may be lost if he is unable to communicate in the future.

Supporting Minh and his family without imposing your own cultural lens

- Provide information neutrally, without suggesting ACP is “the right way.”

- Offer brochures and translated materials so the family can explore ACP in their own time.
- Emphasise ACP is about choice and empowerment.
- Keep the door open: note his current preference but explain there will be other opportunities to revisit the topic.

Referral pathways

- Suggest multicultural liaison officers or community health workers who can explain ACP in culturally appropriate ways.
- Offer interpreter services, even if every day transaction can be managed. Research shows that complex issues with ethical and moral dimensions are trickier in a second language so people will make different decisions if working in a second language.
- Refer to advocacy services that support CALD clients in navigating health systems.
- Highlight community events, newsletters, or guest speakers who can present ACP in a culturally safe environment.

Case Study 3: Cognitive Impairment - "My Husband Already Has One" (Bill & Joan)

Clients: Bill, 86, and Joan, 84

Support: Meals, shopping, home maintenance

Situation: Bill has early cognitive decline and only occasionally relies on Joan to liaise with services. He can manage everyday tasks and clearly expresses his preferences, including about end-of-life care. Joan states she has completed her own ACD, but Bill's has been lost. She has rewritten one for Bill, naming their main care worker as the Substitute Decision-Maker, and is pressuring both Bill and the worker to sign it. The care worker raised concerns with their manager, feeling uncomfortable and unsure if this reflects Bill's true wishes.

Reflective Questions

- **How do you respond to the care worker's concerns and ensure they have a good knowledge about ACD and ACP?**
- **Is Bill able to complete any ACP documents or has he "lost capacity"?**
- **Where should an ACD be stored?**
- **How would it be appropriate to support their discussions, and what referral pathways could assist?**

Suggested Answers

Responding to concerns

- Validate the worker's discomfort, it is appropriate to raise concerns when pressured to sign.
- Reinforce that ACP and ACDs are voluntary and must reflect the client's own wishes, not those of others.
- Provide staff training resources (e.g., Advance Care Planning Australia and Cognitive Decline Partnership Centre dementia guidance) so they understand ACP principles, capacity, and professional boundaries.
- Clarify that staff must never act as substitute decision-makers for clients.

Explain ACP rules and staff roles

- Acknowledge Joan's effort in wanting Bill's wishes documented. Emphasise that ACP is about supporting Bill's voice, not replacing it
- Explain gently that only Bill can complete his ACP/ACD while he retains capacity although he may get assistance to physically document his wishes by writing/typing his wishes.
- Clarify that CHSP staff cannot be named as SDMs, this role is reserved for trusted family, friends, or legally appointed guardians.
- Offer brochures and referral to the Office of the Public Advocate Substitute Decision-Maker Toolkit, which explains SDM roles and responsibilities.

Questions about capacity

- Capacity is assumed unless formally assessed otherwise (CDPC principle).
- Bill can still make ACP decisions if he can understand, retain, and communicate his preferences.
- Early cognitive decline does not automatically mean loss of capacity so encourage timely documentation while he can still express wishes.
- If there are doubts, suggest referral to his GP or specialist for a capacity assessment.

Supporting discussions, and what referral pathways

- Provide neutral information packs and explain ACP in simple, supportive language.
- Encourage Bill and Joan to discuss ACP together with their GP or a legal adviser.
- Referral pathways:
  - GP or hospital liaison (to check if ACP is stored in medical records).
  - Dementia services (to support Bill's cognitive needs).
  - Legal aid / advocacy services (to help draft or locate ACP documents).
  - Multicultural liaison officers if cultural factors influence decision-making.

Storage of ACP documents

Stress that ACP documents should be current, accessible, and shared with key people. For example:

  - Originals should stay with the client
  - Certified copy family/substitute decision makers and services as necessary
  - GP/specialist and hospital records.
  - Uploaded to My Health Record.
  - Link to Medica alert, use of QLD app, card on fridge, register with ambulance need to check individual state options using Advance Care Planning Australia which covers all states.

Encourage periodic review, especially as health or family circumstances change as Bill has a condition that is likely to deteriorate over time.

Explain that misplaced or outdated ACPs can cause confusion and stress for families and providers.

Disclaimer: This resource was developed in collaboration between the Grampians Sector Development, Hills Positive Ageing Project, Southern Services Reform Group and City of Onkaparinga. as a Sector Support and Development initiative, under the Australian Government Department of Health, Disability and Ageing, to support providers across Australia delivering CHSP. It does not necessarily represent the views or policies of the Australian Government.

For additional free resources, the Exploring Diversity & Wellness Toolkit offers guidance and reflective activities to support diversity, inclusion, wellness, and reablement. Developed by the Grampians Sector Development Team, it includes practical tools and case studies to support culturally responsive practice. www.csdgrampians.org.au/exploring-diversity-and-wellness