POLICY BRIEF

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Advance Care Planning

"Once you've filled it out you can go and live!" – *Arthur Te Anini (Ngāti Whanaunga), ACP Conference 2016.*

Advance Care Planning (ACP) is an ongoing conversation patients have with their friends, whānau and health care team about what they would want for their end-of-life care.[1] The purpose of ACP is to give patients the opportunity to direct their care and inform health professionals what they would want to happen at the end of their life. These conversations can be difficult and require a high level of empathy. However, as they are significant, it is important GPs have the skills and resources to undertake them effectively.

Who is it for?

ACP is relevant and can be beneficial for everyone. However, having a plan should be a high priority for the following groups:

- Those with a serious or terminal diagnosis (where the clinician's involvement is likely to be more important in pre-empting situation(s) the patient and their family might reasonably expect).
- Those who are likely to lose their ability to communicate in the next five years; for example, patients with early signs of dementia.[2]
- Older patients (65+ years).
- Those who participate in extreme/high risk sports or other behaviours that increase the risk of experiencing a health crisis.

Importantly, ACP cannot be completed by someone who is already incapacitated, which is why it is better to start ACP conversations early, when a patient is well or has been recently diagnosed with a life-threatening illness.

For the most part, an advance care plan is not legally binding; however, some aspects of the plan may be (assuming correct procedure and criteria are met). For instance:

- **Advance directive:** an advance directive is a statement (preferably signed) setting out the treatment patients do or do not want if they become unwell in the future and are considered unable to give consent. More information on advance directives is available on the Health and Disability Commissioner website.
- **Enduring power of attorney:** an authority that a person gives to another person or company to act on their behalf if they are not able to make decisions for themselves (or are not able to communicate those decisions). More information is available on the Community Law website.

Benefits of ACP

ACP has been shown to improve end-of-life care, empower patients and their families and improve patient and family satisfaction.[3–6]

Many doctors say they believe treatment at the end of life is too often provided inappropriately or against patient wishes – with little chance

Key messages

- If they are no longer able to speak for themselves, an advance care plan can tell a patient's health carers and their family/whānau what is important to them for their end-of-life care.
- The process of developing an advance care plan (reflection, discussion and communication) is a core part of the value a physical advance care plan provides.
- The Advance Care Planning website has a suite of resources, downloadable templates and training material available for GPs and their patients.
- One of the key aspects of an advance care plan document is that it is accessible to health carers and family/whānau if and when they need it. The patient's primary carer should have a copy, and the patient's family should know where they can find a copy. In some regions, advance care plans can be made available electronically. Advance care plans should, ideally, be connected to (or be part of) Shared Care Plans.
- The College encourages all GPs to complete the Advance Care Planning eLearning module (Level 1 Training) accessible through the learning management system on the Advance Care Planning website.

of significant benefit – and by specialists lacking knowledge of the legal frameworks for ACP.[7]

Some benefits of starting a conversation about death include:[8]

- reduced death-related anxiety and increased acceptance of mortality[9,10]
- increased knowledge, documentation and stability of end-of-life care wishes[11,12]
- increased engagement with palliative services and reduced hospitalisation[12]
- increased engagement with health promotion interventions.[13]

Challenges of ACP

Not surprisingly, there are some reported challenges around developing an advance care plan. Conversations about death have the potential to change the clinician–patient relationship, especially if they do not go well. As such, we suggest that GPs start by preparing an advance care plan for themselves and encourage other staff members at their practice to prepare one. This will provide useful experience and help you understand the process from a patient's point of view.

Although there is a risk that talking about ACP may offend some patients, the overall research suggests that these conversations tend to have more benefits than risks.[14] We also recommend that GPs spend time debriefing difficult conversations with a colleague.

There can be a fear of stepping on colleagues' toes by suggesting that a patient's advance care plan should be considered. Some clinicians may interpret this as a proposal to shift the patient towards palliative care and that ACP automatically means stopping treatment interventions. However, this is not necessarily the case – ACP is about considering all care options. Discussing ACP with the health care team will help avoid misperceptions. This is particularly important when patients have comorbidities and may be seeing several different care teams. Each team needs to consider what the other teams are doing and (re)act accordingly.

Finally, conversations about end of life can be resource intensive. Ideally, a separate stream of funding would be developed for these consultations.

The GP's role

The longitudinal, trusting relationship that GPs develop with their patients means they are well positioned to initiate, continue and promote ACP. Your role is not to make decisions; it is to provide information, clarify any medical or unknown terms as they arise (eg comfort care) and mediate the sometimes difficult process of ACP. It is noted that practice nurses are often an equally appropriate mediator of this process.

In terms of practical actions, the clinician may need to help the patient fill out the 'When I am dying' and 'My treatment and care choices' sections of their advance care plan.

Although you and your patient will be the key people involved, it's important friends and whānau are also included in the process. However, the overall objective is to ensure that the patient's voice is heard. The conversation about ACP could be initiated by a family member, an aged residential care facilitator, a GP, or at hospital following an acute event. Regardless of how it starts, it is likely the conversation will be continued (and a written plan developed) with the patient's GP or nurse in a primary care setting.

Tools and resources

Having a conversation with a patient about ACP can be a daunting task; however, there are tools and resources available to help make the process easier:

- The College recommends members visit the **Advance Care Planning** website. This site has a range of resources, downloadable templates and training material available for both the public and clinicians.
- The College encourages all GPs to complete the **Advance Care Planning eLearning module (Level 1 Training)**. This is accessible through the learning management system on the Advance Care Planning website.

One of the key aspects of an advance care plan is that it is accessible to health carers and family members. The patient's primary carer should have a copy, and the patient's family/whānau should know where they can find a copy. In some regions, advance care plans can be made available electronically.

What is currently happening at a sector level?

The **New Zealand Health Strategy: Roadmap of actions 2016** includes an action under the 'closer to home' theme that states that the health sector needs to 'Support clinicians and people in developing advance care plans and advance directives by building existing national and international resources and networks.'[15]

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An advance care plan also clearly relates to the 'people-powered' theme of the strategy and falls under the Health Quality and Safety Commission's campaign **Conversations that Count**.[16] In late 2016, the DHBs collectively agreed to contribute to an ACP funding model and develop initiatives to systemise and increase ACP usage.

Practical considerations

Conversation starters

Starting a conversation about ACP can be difficult – often because of fears about the patient's reaction and a common reluctance to talk about death. It is usually best to avoid starting a conversation about ACP at the same time as providing an unwelcome diagnosis. Instead, it is preferable to schedule a future appointment to start that discussion. With a growing awareness of ACP, patients may be the ones to initiate the ACP conversation with their GP. As such, you need to be ready to have these conversations.

Some possible conversation starters may include:

- "Now would be a good time for us to talk about what's important to you, and what you do and don't want to happen if you can't speak for yourself."
- "Have you heard of Advance Care Planning? It's where you start to think about what's important to you about your future health care, and what you'd like to happen in certain circumstances."
- "Have you ever thought about who you would want to make decisions about your future health and treatment if you were unable to?"

During the conversation that follows, try and ask the patient open-ended questions about what they would want.

It is important to remember that this should be an ongoing conversation – not a one-off – which will ideally lead to a written statement of the patient's preferences for health care and end-of-life care.

Training

An **ACP Training Manual (2016)** for health professionals is available on the Advance Care Planning website. The College encourages all GPs to complete the **Advance Care Planning eLearning module (Level 1 Training)** which is accessible through the learning management system on the Advance Care Planning website.

Also available is a two-day course for **Level 2 Practitioner Training** (complex ACP conversations and advanced communication skills). Level 3 Facilitator Training is also available, but this course is only run every two to three years, depending on the need for additional trainers.

Practice processes

One method for increasing the utilisation of ACP in your practice is to make it routine. This normalises the offer and can also provide an easy conversation starter. A clear practice policy that includes a process map for broaching the topic, initiating and continuing the conversation, and signing off an advance care plan reduces the risk of uncertainty being used as an excuse to avoid it. This process map ideally details who is responsible for each aspect of the plan's delivery.

Ensuring accessibility

Once completed, both the practice and the patient should retain a copy of the patient's most current advance care plan. Additionally, the patient's close family should know how to access a copy.

As the bulk of ACP does not require clinical input or knowledge, there is potential for ACP to be done via patient portals. That is, the patient could complete most of the planning at home with family and friends before discussing their thoughts and the more clinical aspect with a health professional. Key risks in developing an advance care plan in this way include:

- ensuring the patient's advance care plan remains accessible to other providers, ie that the sharing of information is not limited by the patient management system and can be seen by, for example, the local hospital.
- ensuring that the conversations that count are still occurring and being promoted between the patient and their family, whānau and/or close friends. While it may

Further information, good reads and resources

Ministry of Health. **Advance Care Planning: A guide for the New Zealand health care workforce**. Wellington: Ministry of Health; 2011.

MacLeod R, Vella-Brincat J, Macleod S. **The Palliative Care Handbook: Guidelines for clinical management and symptom control**. 8th ed. 2016. (ACP on pages 75–76). ISBN: 978-0-473-36095-5

RACGP. Practice guides and tools (webpage): **Advance Care Planning**.

TEDx Talks (YouTube): Saul P. **Dying in 21st century Australia, a new experience for all of us**. TEDxNewy; 2011.

Gawande A. **Being Mortal: Medicine and what matters in the end**. New York: Metropolitan Books; 2014.

be the preference of some individuals to complete an advance care plan alone, for the majority of patients, simply filling out an online form would likely remove much of the benefit of ACP.

Cultural considerations

The need for cultural adaptions and translations of the Advance Care Planning resources was acknowledged at the Advance Care Planning Conference 2016, and it is understood that there is work underway in this area.

In general, as with all care, cultural competence is required in ACP, with particular awareness that some patients may find it offensive or inappropriate to talk about death or dying, while others may have a 'what will be, will be' attitude.

A guide, **He Waka Kakarauri: Rarangi Tohutohu o te Waka Kakarauri**, has been developed to assist Māori patients, whānau and health care workers engage in ACP conversations in a way that is culturally appropriate. The booklet (which contains a tear-out resource for patients) and related material are available on the **Northland DHB** website.

Key factors identified as being important to Māori when engaging in ACP conversations include:

- **Te Ao Hurihuri:** Māori are not a homogenous culture, so caution should be taken not to make assumptions.
- **Tapu:** Discussing health care needs, particularly end-of-life needs, can be a tapu (sacred) subject, so consideration is needed as to whether patients feel comfortable talking about this subject in the presence of kai (food).
- **Karakia:** A prayer and translation that can be offered to the patient to start and finish an ACP conversation is included in the guide.
- **Manaaki:** The importance of whānau, family and health care workers supporting the patient when discussing ACP cannot be underestimated – particularly if the patient needs assistance assessing the options available and understanding medical language.

Summary

ACP is an ongoing conversation about end-of-life care. Although these conversations can be difficult, they are essential and beneficial for patients. While completing an advance care plan can be daunting, there is a range of training and resources available to help GPs through this process.

References:

1. Northland DHB. He Waka Kakarauri: Rarangi Tohutohu o te Waka Kakarauri. Whangarei: Northland District Health Board; 2016 [cited 2017 August 25]. Available from: http://www.northlanddhb.org.nz/Services/AZ/M%C4%81oriinAdvanceCarePlanningACPconversations.aspx.
2. Ampe S, Sevenants A, Smets T, et al. (2015). Advance care planning for nursing home residents with dementia: policy vs. practice. J Adv Nurs. 2016;72(3):569–81.
3. Detering KM, Hancock AD, Reade MC, et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ. 2010;340:c1354.
4. Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. BMJ. 2006:33:886–89.
5. Tierney WM, Dexter PR, Gramelspacher GP, et al. The effect of discussions about advance directives on patients' satisfaction with primary care. J Gen Intern Med. 2001;16(1):32–40.
6. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA. 2008;300(14): 1665–73.
7. RACP. End-of-life care: Let's talk. Sydney: Royal Australasian College of Physicians; 2016 [cited 2017 March 28]. Available from: https://www.racp.edu.au/docs/default-source/advocacy-library/pa-racp-end-of-life-fact-sheet.pdf
8. Llewellyn R, Jaye C, Egan R, et al. Cracking open death: death conversations in primary care. J Prim Health Care. 2016;8(4):303–11.
9. Ma-Kellams C, Blascovich J. Enjoying life in the face of death: East-West differences in responses to mortality salience. J Pers Soc Psychol. 2012;103(5):773–86. Available from: https://www.ncbi.nlm.nih.gov/pubmed/22823291
10. Routledge C, Juhl J. When death thoughts lead to death fears: Mortality salience increases death anxiety for individuals who lack meaning in life. Cognition and Emotion. 2010;24(5):848–54. Available from: http://www.tandfonline.com/doi/abs/10.1080/02699930902847144
11. Chan HY, Pang SM. (2010). Let me talk – an advance care planning programme for frail nursing home residents. J Clin Nurs. 2010;19(21–22):3073-84. Available from: https://www.ncbi.nlm.nih.gov/pubmed/21040013
12. Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. Palliat Med. 2014;28(8):1000–25. Available from: https://www.ncbi.nlm.nih.gov/pubmed/24651708
13. Goldenberg JL, Arndt J. The implications of death for health: a terror management health model for behavioral health promotion. Psychol Rev. 2008;115(4):1032–53. Available from: https://www.ncbi.nlm.nih.gov/pubmed/18954213
14. Cornally N, McGlade C, Weathers E, et al. Evaluating the systematic implementation of the 'Let Me Decide' advance care planning programme in long term care through focus groups: staff perspectives. BMC Palliat Care. 2015;14(55). Available from: https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-015-0051-x.
15. Ministry of Health. New Zealand Health Strategy: Roadmap of actions 2016. Wellington: Ministry of Health; 2016 [cited March 2017]. Available from: http://www.health.govt.nz/system/files/documents/publications/new-zealand-health-strategy-roadmapofactions-2016-apr16.pdf
16. Health Quality and Safety Commission. (2017, March 27). Get them talking . Retrieved from Our Voice - Advance Care Planning: http://www.advancecareplanning.org.nz/ctc/

If you have any questions about this issue, or would like to express a view on this topic, please contact the College's policy team: policy@rnzcgp.org.nz

The Royal New Zealand College of General Practitioners is the professional body that provides training and ongoing professional development for general practitioners and rural hospital generalists, and sets standards for general practice.