



General principles

- Advance care planning is an essential tool for general practitioners (GPs) to understand patients' values and treatment preferences, and to provide person-centred care, including the person's preferred type and location of care across the illness trajectory.
- Advance care planning has been shown to:
 - improve adherence to patients' preferences for care that is consistent with their beliefs and values
 - improve personal and family satisfaction with care, and reduce family members' anxiety, depression and stress
 - improve ongoing and end-of-life care
 - reduce unwanted interventions and non-beneficial transfers to acute care.
- Advance care planning is a process where a person:
 - discusses their values and healthcare preferences with their family, friends and healthcare team
 - can choose a 'medical decision maker' to make decisions for them if they lose capacity to make or communicate their own values and care preferences or decisions
 - can document a formal, written values statement and/or instructional advance care directive to help ensure the person's preferences are respected.
- Initiate advance care planning early when patients have capacity to express their values and directives for care if they become too ill or cognitively impaired to make or communicate decisions.

Introduction

Advance care planning enables a person who has decision-making capacity to plan for their future medical treatment and other care for a time when they are not able to make or communicate decisions. It is a process where a person thinks about possible future needs and discusses their personal values and healthcare preferences with their family, friends, general practitioner (GP) and the wider healthcare team.

Advance care planning may result in the appointment of a substitute medical decision maker, a written values statement and an instructional advance care directive. The rules around the advance care directive differ between states and territories, where some are covered by specific legislation and others by common law. In either case, advance care directives have legal status and must be implemented when making clinical decisions for a patient who lacks decision-making capacity.¹

In an era where many people live into advanced old age with multiple comorbidities, and some patients receive non-beneficial and unwanted medical interventions, making care goals and decisions may be complex and need to balance quality of life with length of life. The discussions involved in advance care planning can help people articulate their thoughts and aid in planning for future care that is consistent with their personal values and preferences.

Many patients will have limited or no capacity to communicate their preferences and make decisions at some time when their health deteriorates. If the family, GP and other healthcare professionals involved are aware of the patient's treatment preferences then much distress can be avoided.

Advance care plans have been shown to:

- improve adherence to patients' preferences for care that is consistent with their beliefs and values²
- improve personal and family satisfaction with care, and reduce family members' anxiety, depression and stress^{2,3}
- improve ongoing and end-of-life care^{2,3,4}
- reduce unwanted interventions and non-beneficial transfers to acute care.³

Role of GPs in advance care planning

All GPs who care for older people are engaging with issues their patients face towards the end of life. As patients approach the end of life, the GP's role is to apply the approach to care presented throughout this Silver Book, particularly the palliative care chapter (refer to [Part A. Palliative and end-of-life care](#)) with a sharp focus on:

- person-centred care to support wellbeing and quality of remaining life, and respect the person's values, goals and treatment choices
- proactive clinical care planning to anticipate and provide care as the person's clinical condition deteriorates, and as goals of care shift from treating illness towards comfort and managing death.

The key to GP care of patients through to the end of life is a proactive, systematic approach based on anticipating clinical needs and care preferences. Three important concepts have been developed that can help clinicians anticipate, discuss and plan clinical care to meet patient needs, and also help patients and carers understand and cope with their situation:

- Typical illness trajectories for chronic conditions
- Advance care planning
- Early identification of palliative care needs

The need for advance care planning is increasing because of multiple interacting factors, including:

- an ageing population with associated progressive, chronic, life-limiting diseases, disability and cognitive impairment
- patients seeking to avoid medical and hospital treatments that are of limited benefit and not wanted at the end of life
- an increasing number of patients selecting palliative care at home or in a residential aged care facility (RACF)
- increasing patient awareness of advance care planning for voicing their values and preferences for end-of-life care and place of death.

GPs have an essential role in advance care planning, and are well placed to initiate and implement an advance care plan or advance care directive. They have ongoing and trusting relationships with patients, and can discuss future care at a time when patients have stable health and decision-making capacity. An advance care planning

conversation fits well with health assessments and giving advice on healthcare options for any current diagnosis and realistic assessment of prognosis.^{4,5}

Advance care planning supports GPs to provide a proactive, person-centred approach to advanced chronic disease management and palliative care.

The GP's role in advance care planning entails:

- establishing an advance care plan with patients
- assessing decision-making capacity
- using the advance care plan or advance care directive in clinical decision-making for care provision
- organising practice systems to support advance care planning.

Euthanasia and voluntary assisted dying

Some people may wish to discuss euthanasia. It is important to differentiate this from advance care planning and palliative and end-of-life care. There is a significant ethical and legal difference between the concept of an advance care plan and euthanasia. Advance care planning is a fundamental right of patients to accept or reject treatment options; this is in contrast with euthanasia, where the primary purpose is to actively cause or hasten death.

At the time of writing, euthanasia is illegal in all Australian states and territories. Since 19 June 2019, voluntary assisted dying (VAD) is legal in Victoria, and is being considered in other states. VAD involves administering a medication for the purpose of causing death in accordance with the steps and processes set out through legislation. Health practitioners can conscientiously object to being involved with VAD, and, in Victoria, cannot raise the issue of VAD with patients (even indirectly).

The process for an individual who is eligible and has decision-making capacity to request and access VAD is separate from, and cannot be included in, advance care planning or palliative care. However, VAD can be accessed separately by an eligible person who has an advance care/directive and/or is receiving palliative care. Once a person requests information about VAD, knowledge of best practice for end-of-life discussions is an important part of communicating about VAD.

Establish an advance care plan

Steps to establish an advance care plan with patients at the general practice:

1. Initiate advance care planning.
2. Discuss and document advance care plan.
3. Store and share advance care plan documents with the patient, medical decision-maker and relevant care providers.

Steps to establish an advance care plan with patients living in an RACF:

1. Initiate advance care planning on admission, and review annually or with major changes in health.
2. Discuss advance care planning with the RACF staff (usually the registered nurse or nurse unit manager), resident and family (and other medical specialists, if appropriate).
3. Assess and document patient decision-making capacity to appoint a medical decision-maker, and to make an advance care plan.
4. Document and witness appointment of the medical decision-maker, patient values (often done with RACF staff), instructional directive (usually done with the GP).
5. Store the advance care plan documents at the RACF and general practice, and share with the patient, medical decision-maker and relevant care providers (eg ambulance, locum doctor, emergency department).

Initiate advance care planning

While advance care planning could be considered for every patient, initiating discussion is particularly salient for an older person at health assessment, diagnosis of a life-limiting condition, care planning, after admission to an RACF or hospital, or key event with deterioration of health.

Advance care planning discussions are often ongoing at various consultations across the patient's illness trajectory with the GP and/or practice nurse. It may be helpful to identify the person's preparedness to consider advance care planning (eg using the Prochaska and DiClemente stages of change).⁶ Patients may initially be in 'precontemplation' stage, where giving limited information is the appropriate GP response, and they may later move into 'contemplation' or 'action' phase.

Identifying suitable patients

Identify suitable patients when well in the community or when triggered by a change in health. Consider an advance care plan if a person:⁷

- raises advance care planning with a member of the general practice team
- attends a health assessment – aged ≥ 75 years, or ≥ 55 years if they are of Aboriginal and/or Torres Strait Islander descent
- is a resident of or is about to enter an RACF
- requires a carer
- does not have anyone (eg family, caregiver or friend) who could act as substitute decision maker
- may anticipate decision-making conflict about their future healthcare – for example, people with uncommon treatment preferences (eg prohibit blood transfusion) or where there is disagreement among family members
- is at risk of losing decision-making capacity (eg early dementia at whatever age)
- is at care planning for progressive chronic disease/s
- has a life-threatening or advanced chronic disease (eg chronic obstructive pulmonary disease [COPD], heart failure)
- has a terminal or life-limiting illness (eg dementia, metastatic cancer)
- has a new significant diagnosis (eg frailty, transient ischemic attack)
- is at a key point in their illness trajectory (eg recent or repeated hospitalisation, commenced on home oxygen, moving into a palliative care phase)

Whatever the cause, consider an advance care plan if you would not be surprised if the person were to die in the next 12 months.

To initiate discussion, the practice nurse may:

- introduce advance care planning at a health assessment or care planning consultation
- provide information pamphlets and blank advance care plan documents (subject to state and territory requirements) to discuss with the substitute decision maker and/or family
- arrange follow-up appointment/s for patients with the nurse and/or GP to discuss and complete the documents.

RACF staff may initiate advance care planning with a resident and their family on admission to the RACF, after a hospital attendance or a change in health status, and arrange a consultation with the GP to discuss and witness documents.

Often, the practice nurse or RACF staff will discuss and help patients document the 'values' aspect of the advance care plan. The GP can then discuss medical conditions and treatment options for the instructional advance directive, answer questions and witness the completed documents.

The GP may raise the issue in a patient consultation at the time of review, a new diagnosis or change in health conditions. Advance care planning discussion and follow-up consultations can then be provided by the nurse or GP.

Discuss and document advance care plan

Discuss advance care planning with the patient, family, carer and other healthcare practitioners as appropriate (refer to Part B. Families and carers). It is important for GPs and practice nurses to think about how to approach this topic with patients so as to sound relaxed and helpful. The [Advance Project](#) website has some videos with appropriate wording, which can assist GPs and practice nurses to develop their communication skills for advance care planning.

There is a line to be drawn in wording between a suggestion that the person's death is imminent (if it is not) and the need to consider plans for possible future care scenarios. For example, 'I ask all my patients over 70 to consider making an advance care plan in case of severe illness so we know who to contact and what your wishes may be if you unexpectedly become seriously ill'.

Discuss the person's broad values, beliefs and life goals. Some people may be able to articulate quite clearly that they value quality of life over length of life; however, others find it hard to think in this way. Discussion of scenarios may elucidate the person's values and relationships and be very helpful for clinical decision making that delivers the outcome the patient wants. For instance, ask what the person considers is compatible with a reasonable quality of life versus what they see as a fate worse than death.

A discussion of some possible future clinical scenarios may help to elucidate care goals and treatment preferences for an instructional advance directive. For example, the person may not want to be resuscitated following a medical event if they already have a terminal illness (eg early dementia), which will inevitably lead to a decline and then death. If death is imminent, they may wish to die at home, or they may wish not to be a burden on their family and die in a place where care can be provided for the end-of-life and/or terminal phase.

Assess and document patient decision-making capacity if it is in doubt. A person is assumed to have decision-making capacity unless there is evidence to indicate otherwise. Competence or lack thereof can fluctuate over time and for different levels of decision making, and is specific to the issues, actions or decisions at hand (eg appointment of a medical decision maker).

Assessment of capacity should take place as close as possible to the time the decision is required. People should always be involved in decisions that concern them to the maximum extent possible. Appointment of substitute medical decision makers can assist with interpreting the person's wishes if they are not able to express these.

Document and witness the advance care plan or advance care directive according to requirements and forms in the relevant state or territory for:

- appointment of a medical decision maker (medical power of attorney)
- advance care plan values statement and/or instructional advance care directive.

Resources and information are available for competent adults and those with impaired decision-making capacity to undertake advance care planning. Forms and requirements for each state and territory can be found at [Advance Care Planning Australia](#).⁸ Although not strictly a health issue, it may be worthwhile to encourage patients to also write a will and appoint a financial power of attorney.

Store and share advance care plan documents

Copies of completed advance care planning documents should be held by the patient, substitute decision maker, family and GP for communication and implementation as needed to all others providing patient care. A person who has decision-making capacity can review and change their advance care plan at any time. If a change is made, then a copy must be given to all relevant people.

The documented advance care plan, advance care directive and substitute decision maker should be stored and prominently flagged in the GP's patient record and at the RACF so these are easily accessible. The GP or nurse could also encourage the patient to upload the documents into My Health Record and perhaps give a copy to their lawyer.

Share advance care plan documents to ensure these are available at the location of care when it is required for clinical decision making and care planning, that is, when health conditions change and the patient may lack decision-making capacity:

- Share a copy of the advance care plan with the patient, medical decision makers and family.
- Encourage the patient to upload their advance care plan to My Health Record and keep a copy accessible at home to inform ambulance staff, locum doctor and visiting medical practitioners.
- Provide a copy of the advance care plan to the resident's RACF and after-hours GP locum service (if appropriate).
- Attach the patient's advance care plan to referral letters (with medication list) to other medical practitioners, emergency departments, hospitals, and other healthcare services (especially where shared care arrangements; eg hospital outreach services, community, palliative and hospice care).
- For patients at risk of life-threatening events, an emergency information pack could be prepared, with a care plan, current medication list and advance care plan, which could be sent to the ambulance service and local hospital.

Decision-making capacity

Capacity is the ability to make and communicate a decision. Capacity and the lack of capacity are legal concepts; under common law, and consistent with Article 12 of the UN Convention on the Rights of Persons with Disabilities, a person is presumed to have the capacity to make decisions unless there is evidence to indicate this is in doubt.⁹

A capable person knows the decision facing them and the choices available, appreciates the reasonably foreseeable outcomes of the options available, and weighs the information to make a choice not based on delusional constructs.

There are three broad areas or domains of capacity: personal, financial and health.

Capacity is not a unitary or global concept; it is domain specific (ie particular to the type of decision being made) and it is decision specific or task specific, even within one domain (eg health). Capacity can fluctuate over time and for different levels of decision making. For example, illness can temporarily impair capacity, and a diagnosis of chronic conditions (eg Alzheimer's disease) do not automatically mean incapacity.

Decision making in various domains involves a mixture of cognitive and functional abilities. Capacity is determined by whether a person can understand information about the context and decision at hand. Patients should always be involved in decisions that concern them to the maximum extent possible.⁸

Assessment of capacity

GPs may be asked or need to assess a patient's capacity to make decisions about specific health, financial or personal matters, including:

- appointing a power of attorney or substitute medical decision maker
- documenting an advance care plan
- choosing a medical investigation or treatment
- making a will or financial decision
- managing personal care.

Particular circumstances, events, behaviours or medical conditions might lead the GP to question a person's capacity at any point in time. This is particularly true for decisions that put the patient at significant risk of harm or mistreatment, or are very different from their usual decisions.¹⁰ The [Cognitive Decline Partnership Centre](#) published a series of questions to help determine if a patient has the capacity to make a healthcare decision.¹¹

It is easy to judge the capacity of someone who is clearly capable or incapable. When a person has partial understanding and their capacity is borderline, the GP may undertake a more systematic assessment or refer to a geriatrician, psycho-geriatrician or psychologist for a second opinion.

Assessment of capacity should take place as close as possible to the time the decision is required. A patient has decision-making capacity (or competence) if they can:

- understand the information relevant to the decision (eg their illness, treatment options, risk and benefits of treatments)
- retain that information to the extent necessary to make the decision
- use/weigh the information as part of the process of making the decision
- communicate their decision in some way.

A six-step assessment process has been developed to help judge capacity:¹²

1. Ensure that assessment of decision-making capacity is done only when a valid trigger is present (eg situations that place the allegedly incapable person or others at risk, and on the face of it appear to be due to lack of capacity).
2. Engage the person being assessed in the process.
3. Gather information to describe the context, choices and their consequences.
4. Educate the person about the context, choices and their consequences.
5. Assess capacity (and document assessment).
6. Take action based on results of the assessment.

Impaired decision-making capacity

Several important ethical principles may need to be considered in planning healthcare for people with impaired decision-making capacity:¹³

- Autonomy is the individual's right to be self-governing (ie exercise self-direction, freedom and moral independence).
- Beneficence (ie doing good or conferring benefits that enhance personal or social wellbeing) and non-maleficence (ie doing no harm).
- Justice is about fairness and impartiality, and the need to find a balance between competing interests; for example, balancing the desire of the person with dementia to live alone in their own home with the concerns of caregivers about hygiene and safety, and balancing the potential benefits and adverse effects of treatments or no treatment.

Valid assessments of capacity are necessary to honour these ethical principles, as a declaration of incapacity implies a need to assume responsibility for that person's wellbeing.¹²

When a patient is found to be incompetent to make a decision, it is essential that the needs of the person, rather than the needs of caregivers, health professionals or others, be the basis of the decision and provide a just outcome for the person.

When a person lacks capacity to make medical treatment decisions themselves, there are three ways in which decisions can be made by, or for, them with reference to local state or territory requirements:

- An advance care directive made by the person before they lose capacity can provide directions about medical treatment.
- A substitute decision maker can make the decision, based on what they believe the person would want and their best interests. This can be informed and guided by prior advance care planning discussions and/or documentation of the person's values.
- A tribunal or the courts can provide consent or make a treatment decision.

Patients with impaired capacity may be supported to make decisions, including the use of:

- an interpreter
- plain language and simple sentences
- pictures or photos
- a quiet comfortable space.

Speech pathologists may be able to assist people who have difficulty articulating their decisions.⁹ Under Victorian legislation, a person can appoint a support person to help them make medical treatment decisions.¹⁴ The Cognitive Decline Partnership Centre has published a guideline about supported decision making, which may be of assistance.¹⁵

Review and implement the advance care plan

The purpose of the advance care plan or advance care directive is to ensure patients receive clinical care that is consistent with their own values, goals and treatment choices, if they become unable to make or communicate their decisions.

In some jurisdictions (eg Victoria), advance care directives have legal status, and doctors must make a reasonable effort to locate and implement them when making clinical decisions for a patient who lacks decision-making capacity.

Review the advance care plan or advance care directive with the patient and/or medical decision maker when health status changes significantly and major clinical decisions need to be made.

The advance care plan or advance care directive is an essential tool for GPs to understand patients' values and treatment preferences. It is also essential for review and use in planning and providing person-centred care, including the patient's preferred type and location of care at key points across the illness trajectory. This will enhance shared decision making and reduce the need for clinical decision making in emotionally charged circumstances.

Review and/or implementation of the advance care plan or advance care directive is increasingly important as the patient's clinical condition progresses and deteriorates, and goals of care shift from treating illness towards quality of life, comfort and end-of-life care.

Steps to providing a proactive person-centred approach to clinical care towards the end of life:

- Anticipate, identify and assess changes in clinical care needs.
- Discuss and share decision making with the patient and/or medical decision maker, with reference to the advance care plan.
- Develop a person-centred clinical care plan and team care arrangements.
- Provide the clinical care.

When making shared clinical goals of care and treatment decisions:

- Include the patient to the extent they can contribute to ensure their needs and dignity remain the primary focus.
- Discuss the illness trajectory with patient and/or carer so they understand what is happening, especially at transition to a palliative approach, end-of-life care or terminal care.
- Review the advance care plan and patient values, goals and choices, including preferred location of care.
- Address patient and family concerns (eg give honest answers when asked 'What will happen?'); family views and issues are important and need to be understood.
- Use family and team case conferences when needed; for example, some relatives and RACF staff may need GP support to accept a resident's decision for a palliative approach.
- Establish clinical goals of care and treatment decisions with the patient and/or medical decision maker.

Implement instructional advance care directives when a patient lacks capacity for clinical decision making, treatment plans and clinical care to ensure that patient care adheres to the person's wishes and choices.

Practice systems to support advance care planning

The Royal Australian College of General Practitioners (RACGP) believes advance care planning should be incorporated in routine general practice.⁵ Practice organisation strategies to incorporate advance care planning into routine care involve:¹

- planning a practice-team approach
- building capacity for advance care planning in the practice
- establishing systems to optimise the process of advance care planning
- establishing systems to disseminate and implement advance care planning documents.

Planning a practice-team approach

Planning a practice-team approach requires everyone involved in the patient's care to work collaboratively with practice nurses, GP colleagues, general practice registrars, after-hours doctors, other specialist medical practitioners and administrative staff in the practice. It is important to decide roles and working arrangements in any advance care plan.

Build partnerships for advance care planning with the local primary health network (PHN), ambulance, hospital and community services. Build shared care partnership with local palliative care services for early referral.

Building capacity in the practice

Use the [Advance Project](#) for GP and practice nurse education and training around advance care planning. Be aware of the relevant state or territory advance care planning requirements and documentation. Use Medicare Benefits Schedule (MBS) item numbers as appropriate for GP, practice nurse and telehealth consultations, health assessments, care plans and case conferences.

Establishing systems to optimise advance care planning process

Identify priority target patient groups, and audit rates of advance care planning documentation, including patients:

- living in RACFs
- with selected chronic diseases (eg dementia, cancers, COPD, congestive cardiac failure)
- receiving palliative care.

Decide when and how to initiate and conduct advance care planning during practice nurse and GP consultations.

Select patient information brochures, advance care planning documents and resources to store for easy access. Use advance care planning clinical apps, tools and guidelines, including for patients with dementia, Aboriginal and Torres Strait Islander peoples (refer to Part B. Older Aboriginal and Torres Strait Islander people) and those from different religious and cultural backgrounds (refer to Part B. Multiculturalism in aged care).

Establishing systems to disseminate and implement

Use medical software templates, recall and reminder systems and letters in establishing systems to disseminate and implement advance care planning documents. Establish a system to store and access relevant documentation.

Routinely include brief review of advance care planning and advance care directive in discussions for shared decision making at care planning, and when there are changes or acute events in the patient illness trajectory.

Share advance care planning documents with other service providers as needed (eg referral letters, care plans, hospital emergency pack). It is essential that all service providers are aware of the advance care plan and instructional advance directive when the patient lacks decision-making capacity.

Resources

Excellent resources are available, including GP and practice nurse training, advance care planning information and end-of-life advisory services, advance care planning information, and forms for each state and territory. Additionally, specific patient resources for people with dementia and people from diverse cultural and religious backgrounds are also available.

Professional development

- [Advance Project](#) – a training package and toolkit to help GPs and practice nurses initiate advance care planning, assess likely end-of-life care needs and provide team-based palliative care.
- [ThinkGP module](#) on advance care planning.
- RACGP's [gplearning](#) – online modules available (log-in required).
- [Caresearch](#) – there is a section for GPs on the first page, and additional resources, including:
 - [Advance Care Planning Australia](#)
 - [Research and evidence on advance care planning](#).

Guidelines and tools

- [Advance Care Planning Australia](#) – extensive resources on advance care planning, including [specialised training](#).
- [Advance Care Planning Australia](#) – forms and requirements for advance care plans for each state and territory.
- [ELDAC](#) – end-of-life directions for aged care, a national specialist palliative care and advance care directive advisory service, which includes some useful tools for GPs and practice nurses to use:
 - [Advance care planning](#)
 - [End-of-life law in aged care](#) – including information about capacity and consent to medical treatment, advance directives, substitute decision maker, withholding and withdrawing life-sustaining treatment, palliative medication, futile or non-beneficial treatment, emergency medical treatment, managing disputes.

People with dementia

- [Capacity Australia](#) provides:
 - [information on decision-making capacity](#)
 - [Capacity mini-legal kits](#) – for use by GPs and other healthcare professionals to assess capacity in each decision-making domain for people with dementia, other impairments or disabilities.
- [Cognitive Decline Partnership Centre](#) – provides evidence-based resources for GPs, other health professionals, and carers specific to the needs of people with dementia, including:
 - [advance care planning](#)
 - [supported decision making](#).

Sensitive cultural advance care planning

- [Localised advance care planning pathways](#) – Health Pathways is localised and available from local PHNs. *Health pathways in palliative care and advance care planning* is designed and written for use during the consultation and provides clear, concise guidance for patient assessment, management and referral to local health services. It includes pathways that contain information specific to Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse communities.

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