



Position Statement 27

Advance Care Planning

Recommendations

1. Advance care planning is a process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known so that they can guide decision-making at a future time when that person cannot make or communicate his or her decisions.
2. An Advance Care Plan may incorporate a combination of a written document, such as an Advance Care Directive or documentation in medical records, the appointment of substitute decision maker, such as an Enduring Power of Attorney*, or a verbal instruction or communication.
3. A key goal of advance care planning is to be respectful of person's autonomy and as such, should remain voluntary and should be done when the person is ready to engage with the process.
4. In considering the ethical aspects of advance care planning, geriatricians should be aware of the interplay between well-meaning paternalism and patient autonomy
5. Geriatricians should continue to advocate for a uniform legal framework in Australia and New Zealand. In the meantime, health professionals should be familiar with their country, state or territory legislation, processes and documentation on advance care planning
6. Geriatricians should ensure that older persons with progressive, chronic disease or multiple comorbidities are aware of their illness, its disease trajectory, treatment options and prognosis as this is a necessary step in facilitating informed discussion.
7. Geriatricians should initiate the advance care planning conversation and should review the Advance Care Plan with older persons at regular intervals, particularly after changes in health status.
8. Discussion of resuscitation orders in a hospital or residential aged care setting should follow an ethical model of decision-making that involves the older person and their family and education about survival rates following cardiopulmonary resuscitation
9. Older persons with cognitive impairment require timely advance care planning. They benefit from a timely diagnosis and a prioritisation of appointing a substitute decision maker. They should be actively assessed for their decision-making capacity and if they can participate in the process, they should be encouraged to do so.
10. The heterogeneity of older persons in residential aged care facilities underlines the need for a patient-centred approach
11. Further research and resource development is required for culturally and linguistically diverse groups.
12. Effective, consistent communication between healthcare settings, from general practice to residential aged care to hospital settings, should be emphasised to underline the dynamic nature of advance care planning and the multi-disciplinary approach

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Background

Definition of Advance Care Planning

"Advance care planning is a process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known; so that they can guide decision-making at a future time when that person cannot make or communicate his or her decisions."[1]

An Advance Care Plan may incorporate a combination of a written document, such as an Advance Care Directive or documentation in medical records, the appointment of substitute decision maker, such as an Enduring Power of

Attorney, or a verbal instruction or communication. [1, 2].

Due to the wide spectrum in terminology, we will consistently use the term 'Advance Care Directive' to incorporate Health Directive, Statement of Wishes, Anticipatory Direction, Advance Care Statement, Advance Personal Plan, Living Will and other similar terms; unless otherwise stated. We will use the term 'substitute decision maker' to incorporate enduring medical power of attorney, enduring power of attorney and appointed decision maker and other similar terms; unless otherwise stated. It is important to be aware of the relevant terminology in your region.

History

The concept of advance care planning has been in existence internationally since the 1970s [3, 4]. It gained prominence in Australia in the 1980s. The first state based legislation regarding Advance Health Directives was in South Australia's Natural Death Act (1983) [5] followed by Victoria's Medical Treatment Act (1988) which gave patients the right to refuse treatment and appoint a substitute decision maker [6].

In the early international literature, health professionals did not seem to believe that their patients were able to participate in end of life decisions with only one third of health professionals believing that their patients understood their health issues [7]. These same professionals, however, felt that a competent person should have the right to refuse life supportive treatment even if this resulted in death. This perhaps signalled a shift in attitude from an earlier study, which, in exploring the attitudes of health professionals towards Advance Care Directives, showed that even in the presence of a clear advance care directive; doctors would choose to override the patient's wishes [8].

Studies in the early 2000s acknowledged that patients preferred to have some control over decision making at the end of life [9, 10] but that in practice, this was difficult when factors such as cognitive impairment impacted on decision making ability [11, 12] which led to health professionals making unilateral decisions about resuscitation orders [10]. Family members were sometimes called upon to help guide decision making on medical treatment at the end of life, even though the literature suggests that most family members are not able to predict an older person's

preferences [11, 12] and tended to overestimate the benefits of resuscitation [10].

Advance care planning, at this time, followed a "legal transactional approach" which prioritised the formal documentation of an Advance Care Directive and appointment of a substitute decision maker [4, 13]. Since that time, there has been a move towards prioritising the advance care planning conversation via a "communications approach" and away from the legal transactional approach [4, 11]. This communication-centred approach is more reflective of the definition used in this position statement.

Principles of Advance Care Planning

It has been established that advance care planning can improve the quality of end of life care for the person, improve satisfaction with care, improve the likelihood that the person's wishes are followed, and can help reduce distress and anxiety in family members [14, 15]. This emphasises a key goal of the Advance Care Plan in allowing people's autonomy to be respected even at a time when they cannot directly participate in the decision-making process because of a loss in capacity [1, 11, 16, 17]. As such, the planning process must also remain a voluntary undertaking which should not be forced [1, 18].

Despite these benefits, prevalence of Advance Care Directives among older people in Australia remains low and in the order of around 5-8%. [19, 20]. In a study on residential aged care facilities in the Illawarra region, the median prevalence of Advance Care Directives amongst residents was 5% [21]. In a national survey, 14% of community dwelling adults over the age of 18 had an Advance Care Directive, compared to 30% who had a financial enduring power of attorney [22]. In a small survey of clinical records kept by general practitioners, 1% had documented evidence of an advance care planning discussion. The same study found that only 10% of surveyed adults knew about Advance Care Directives but 70% were keen to know more [23].

The ethical considerations of advance care planning should also be considered. Health professionals should be clear in their minds that the goal of advance care planning is not to reduce costs for the health system [24]. In discussing avoidance of unnecessary emergency department presentations, we must be conscious of the interplay between our well-meaning paternalism and the older

person's autonomy. In providing older persons with information about their health status, we must also be conscious of the influence we have in an older person's decision-making based on how we present information [25]. The solution, is to ask the older person what they want to know rather than making an assumption [26] and identify their willingness to engage [27].

Several barriers that have been identified that lower engagement with advance care planning from the community's perspective. These include a lack of awareness of the availability, goals and utility of advance care planning, fears that decisions cannot be revised and fears that appropriate care will be withheld [1, 11, 18, 24, 28]. From the health professional's perspective, barriers include time constraints, discomfort in discussing prognosis, progressive disease and dying with patients, a lack of confidence in the legal framework around advance care planning and the lack of a centralised registry [1, 18, 29-32]

There is a cognitive process that occurs which facilitates advance care planning. A 5 step process described in detail by Sudore et al. [27], based on Prochaska's Stages of Change model [33], involves pre-contemplation, where there is no desire to engage, followed by the contemplation phase where the person understands the relevance of advance care planning and takes steps to engage. This is then followed by a transition phase of preparation and values clarification before the action phase where the person commences discussions with their family and health providers, which leads to some form of documentation. This phase is followed by a maintenance phase where the person reflects on their decisions and reviews them based on their changing health status. How a person moves through these steps is individual and dynamic [27, 34].

From the health professional's perspective, organisational policy and legal framework need to be taken into account so that once the person reaches the "action" phase [27], the subsequent processes involve clarification of the person's understanding of their health status, communication and documentation, identification of a substitute decision maker and ensuring the documentation is available to relevant parties [14, 35, 36].

Advance Care Planning in Australia and New Zealand

One of challenges of providing a national, let alone a Trans-Tasman, framework for advance care planning is that while the law in New Zealand and each Australian state and territory broadly recognises the right of the competent individual to make an Advance Care Directive and to appoint a substitute decision maker, there are differences in the legal standing of the Advance Care Directive; differences in the inclusions and exclusions of the Advance Care Plan; differences in the powers afforded to the substitute decisions maker, and differences in the requirements for validity [1, 22, 37-39].

New Zealand and all Australian states and territories have statutory laws allowing the appointment of substitute decision makers [1, 38-40]. Queensland has a legally binding statutory Advance Health Directive [38, 41]. New Zealand, Tasmania and New South Wales have common law Advance Care Directives that are legally binding [38, 42, 43]. Australian Capital Territory [44], Northern Territory [45], South Australia [46] and Western Australia [47] have both common law and statutory Advance Care Directives which are both legally binding [38]. The statutory Advance Care Directive in the Australian Capital Territory, Northern Territory, South Australia and Western Australia are called the Health Direction, Advance Personal Plan and Advance Health Directive respectively. Victoria [6] has a legally binding statutory Refusal of Treatment Certificate, but a common law Advance Care Directive which may not be legally binding [38].

To highlight differences in the inclusions and exclusions of the Advance Care Directive, in Victoria, a statutory Refusal of Treatment Certificate can only apply to a current condition of a patient [6] whereas, in the Northern Territory, an advance consent decision, which is most similar to Victoria's Refusal of Treatment certificate, has no restriction on whether the directive needs to be based on a current illness [45]. Each country, state and territory has their own prescribed Advance Care Directive form but some also accept other forms of communication, both written and verbal. It is no doubt easier to ascertain the validity of an Advance Care Directive if it is written on a standardised form, compared to a verbal discussion between a person and their family and so it should be recommended that discussions are documented, reviewed regularly and communicated to relevant parties [40]. While there are provisions in legislation and common law regarding the recognition of interstate Advance Care Plans, there are

jurisdictional differences and limitations [48]. When there is doubt or dispute about the validity of an Advance Care Plan, an application for judicial review is recommended [49].

Although there has been clear support for enshrining Advance Care Directives in legislation, it is also clear that the common law recognises that Advance Care Directives must be followed provided that the directive has been made by a competent adult, is valid, and applies to the situation at hand [38, 50]. Doctors are protected from prosecution where they have acted in good faith based on a valid Advance Care Directive under common law, but they may be subject to criminal and civil liability if they provide treatment that contravenes a known, valid Advance Care Directive [1, 5, 29, 38]. It is also recognised in common law that doctors are not obliged to provide treatment that is deemed futile even if requested by the patient or substitute decision maker [49].

The law is still evolving and in view of the legal complexities, the need for national approaches were recognised both in Australia and New Zealand with formation of the National Advance Care Planning Cooperative in New Zealand and the publication of a guide for the New Zealand health care workforce [40] and the publication of the National Framework in Australia [1]. Ultimately, until such time as consistency is achieved, health professionals should familiarise themselves with their own region's legislation, processes and documentation[51].

The Role of the Geriatrician

There is some evidence that older persons are reluctant to talk about end of life care plans at the start of a life-threatening illness, but are instead, willing to discuss their values and beliefs [11]. However, in studies involving older persons on haemodialysis, only a small percentage reported ever having discussed their end of life wishes with their Nephrologists although the majority already had views on their wishes [52]. Clinicians that frequently treat older persons with progressive chronic illnesses or multiple comorbidities, should advocate for patient autonomy by raising awareness of advance care planning [32] and should ensure that older persons understand their illness, its trajectory, the available treatments and prognosis [26].

There is conflicting evidence on the stability of Advance Care Directives of older persons over time [53]. Barrio et al. found that lower education levels, the loss of a loved one and an increase in morbidity were associated with changes in preferences but that hospitalisation did not influence preference change [53]. However, Danis et al found that at times of stress, such as during an acute illness or hospitalisation, older persons may prefer more intensive treatment [54]. This highlights the importance of reviewing Advance Care Plans with patients on a regular basis, particularly when there are changes in health status and underlines that advance care planning is a dynamic process [27, 53]. Geriatricians should initiate the conversation to ensure that older persons are aware of advance care planning and should facilitate an older person's cognitive shift from the pre-contemplative phase to the action phase [27, 34, 55, 56].

A report released by the Cognitive Decline Partnership Centre outlined seven key recommendations for approaching advance care planning in those with cognitive impairment [57]. Clinicians that frequently treat older persons who have lost the capacity to make health care decisions, either temporarily through delirium or permanently through dementia, must be aware of the complexity and urgency of raising the issue with older persons while they still have a choice to engage with advance care planning [32, 57, 58]. In a systematic review of the effectiveness of advance care planning in those with dementia, all the studies were done in residential aged care facilities where only 36% of the participants retained the capacity to participate in advance care planning [59]. For older persons with cognitive impairment, there should be an active assessment and documentation of decision-making capacity and if they are still able to participate in the process, they should be encouraged to do so [57, 58]. The appointment of a substitute decision maker is of particular importance in this group [57]. In the situation where the older person is no longer able to communicate their wishes, there should be active engagement with the substitute decision maker to establish if there was a written or verbal Advance Care Directive that could help guide future decision making and effective handover of the Advance Care Plan between healthcare settings [57].

A key demographic that Geriatricians are involved with are older persons living in residential aged care facilities. It could be suggested that only a small proportion of older

people living in residential care have the capacity to participate in the advance care planning process, and that by that time, it is too late to start [59]. However, while it is estimated that 25% of older people in residential care die within 12 months of admission, around 20% live in care for over 5 years reflecting the heterogeneous nature of residential care residents [60]. This highlights that the need for an individualised approach to advance care planning is still crucial [61]. Barriers identified have included variability in the documentation [62, 63], lack of experience on the part of the residential facility staff in having discussions about advance care planning [62, 64], lack of guidance for residents and families on how to complete the documents [65] and difficulty in accessing and interpreting the document by those that were not involved in its completion [35]. Work is in progress in some areas to address these barriers and develop a consistently used Advance Care Directive template in residential aged care facilities [35]. A key role for Geriatricians would be to raise awareness and facilitate discussion in residential aged care facilities, clarify misconceptions about health status and assist in the advance care planning process.

An area of focus is in the provision of culturally and linguistically sensitive advance care planning to a diverse population, which includes access to trained interpreters. A limitation of many Australian studies is that non-English speaking older persons are excluded or they are not mentioned as a subgroup [14, 19, 66]. One study based in Western Australia discussed the different decision making styles of first generation Dutch and Italian migrants [67]. Another study in New South Wales found particularly low rates of awareness of advance care planning amongst older Mediterranean, Eastern European and Asia/Pacific people [68]. A resource guide for advance care planning with Aboriginals and Torres Strait Islanders was developed as part of the Respecting Patient Choices Programme which is accessible to all health professionals [69]. Within the New Zealand context, the process of patient-centred advance care planning needs to take into account involvement of family/whānau in decision-making and engage with health professionals of Māori and Pacific Island descent to conduct further research and develop resources [70].

Many health services and residential aged care facilities mandate that all persons

admitted should have a resuscitation order [20, 71]. In some cases, this may be the first conversation an older person has about their health status. One of the challenges is the unrealistic expectations that older people and their families may have about survival rates from cardiopulmonary resuscitation (CPR), but other barriers include doctors' failure to communicate with the patients and families, doctors' failure to discuss resuscitation orders prior to critical clinical deterioration and discordance between the health professional's recommendation and the older person's preference [10, 28, 72, 73]. While health professionals are in a better position to predict outcomes based on knowledge of cohort survival outcomes, the values and beliefs of the older person, along with their acceptance of an intervention, must be considered in establishing if an attempt at invasive resuscitation should be considered [20]. Ideally, the model for ethical CPR decision making should be used in consultation with an informed older person with shared responsibility for the decisions [10, 74]. One proposed approach is using a "Goals of Patient Care" (GOPC) form which aligns treatment decisions to goals such as curative, life-prolonging with limitations, primarily non-burdensome treatment or comfort during dying rather than according to the intervention itself [20]. In this approach, the GOPC form uses a default of curative treatment but allows for the provision of limitations based on the patient's current medical condition, their prognosis and potential clinical outcomes. It prompts the identification of those patients who may benefit more from a palliative approach and those who may be entering the terminal stage of life so that appropriate treatments can be instituted. The GOPC form remains a medically initiated order, like widely used versions of the Not for Resuscitation form, however, it prompts a more holistic discussion between the doctor, patient and substitute decision makers about what would be clinically appropriate rather than a mere discussion about a checklist of medical interventions [20, 75]. Completion of the GOPC form, unlike advance care planning, is not reliant on the capacity of the patient. The discussion and planning can be undertaken with the patient's substitute medical decision-maker should the patient lack capacity to be involved.

The Role of Education and Communication Skills

To improve uptake of advance care planning, raising awareness and educating older

persons and their families is crucial [22]. Raising awareness alone has been shown to increase uptake of advance care planning [56]. Written material is often insufficient in communicating abstract concepts about healthcare [12, 65]. Older persons and families report greater understanding and satisfaction and reduced anxiety if written material was accompanied by individualised explanations by a trained facilitator [65].

Effective, consistent communication between healthcare settings, from general practice to residential aged care to hospital settings, should be emphasised to underline the dynamic nature of advance care planning and the multi-disciplinary approach [1, 63]. This could be better served by consistency in documentation that could be transferred across different health care systems [35]. One proposed approach in Australia, is through centralised documentation on My Health Record, though this is not yet widely utilised [76]. Another approach would be to utilise centralised documentation on a health network's Electronic Medical Record, though, depending on the health network, this may only improve communication within the hospital setting.

The role of effective communication skills on the part of health professionals cannot be overemphasised in advance care planning and education in this area should be included in training curriculums. This includes both proficiency in communicating prognosis, clinical course and treatment options and knowledge of the law of advance care planning [14, 51]. Using trained facilitators and educating staff improves compliance, uptake and satisfaction in advance care planning [14, 77]. In order to bridge the gap in communication skills, attendance at Advance Care Planning education workshops [78] should be encouraged for all involved staff, along with utilisation of resources such as the Advance Care Planning Australia website [79], the Advance Care Planning New Zealand website [80], the End of Life Law in Australia website [38], familiarity with government policy [1, 40], and familiarity with the local legal aspects of advance care planning [39, 51].

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