What’s stopping us?

Why people don’t plan for a safe older age: a literature review

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Acknowledgements

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1. Executive Summary

When people don't plan for older age, they leave important decisions about their futures in the hands of other people – people who may not know, understand, care about, or respect their values.

Planning for older age – or "future planning" – empowers people to think deeply about their priorities, retain dignity and control over their lives, and make legally binding decisions about their futures. Future planning can play an important role in safeguarding older people against elder abuse.

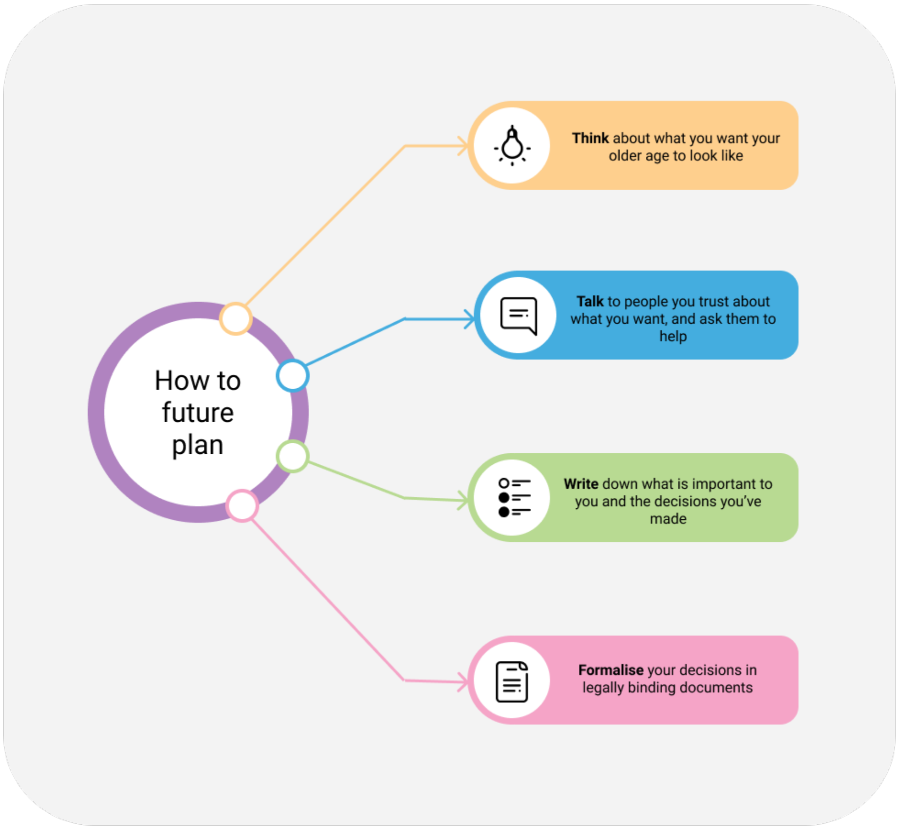
It is relatively well known that a lot of people don't plan for older age at all, or only start planning when a crisis hits, but there is little consolidated research into *why* people don't future plan.

This literature review intends to shine a light on what prevents people from planning for their older age in Australia. By understanding the answer to this question, we will be better equipped to empower more people to future plan – and ultimately, to help prevent elder abuse.

What is future planning?

Future planning is planning for older age. It includes planning who would make decisions for someone if they couldn't anymore, if they lost capacity to due to cognitive decline or illness, and what a person would want to happen if they faced changes in future due to getting older. Decisions often include what would happen if someone's home was no longer suitable or if there was a health decision to be made, or who would pay the bills.

Future planning can be seen as a four step process: **thinking** about what we want our older age to look like, **talking** to people we trust about what we want and asking for their help, **writing** down what is important to us and any specific decisions we've made, and **formalising** our decisions in legally binding documents.



This literature review is focused on **what prevents people from taking the final step: formalising decisions in legally binding documents**. We took this approach to sensibly limit the scope of the literature review, and because there are fewer studies that are relevant to the first three steps of future planning.

Formalising future planning decisions in legally binding documents includes:

- **Appointing substitute decision makers**, that is, a person giving someone else the legal power to make decisions on their behalf about their finances, medical treatment, or other personal matters
- **Appointing supportive decision makers**, that is, a person giving someone else the legal power to help them with their decision-making and giving effect to their decisions in relation to finances, medical treatment, or other personal matters, and
- **Making legally binding plans for the future** about healthcare and other personal matters.

For more information about types of future planning, **see page 6.**

Our approach

The literature considered for this review includes peer-reviewed articles, government reports, studies, surveys and articles that identified barriers to future planning, spanning the period 2006 to 2021. The review primarily focused on Australian studies, but regard was had to some relevant international sources.

We analysed literature relevant to a broad section of Australian society, including culturally and linguistically diverse (CALD) communities and people who identify as lesbian, gay, bisexual, transgender, intersex, or queer (LGBTIQA+). We also sought to find literature that focused on people who are ageing alone (without support from family or an intimate partner) but we did not identify anything with that particular focus. We wanted to capture these specific cohorts of people because typically they face barriers above and beyond those faced by the broader public.

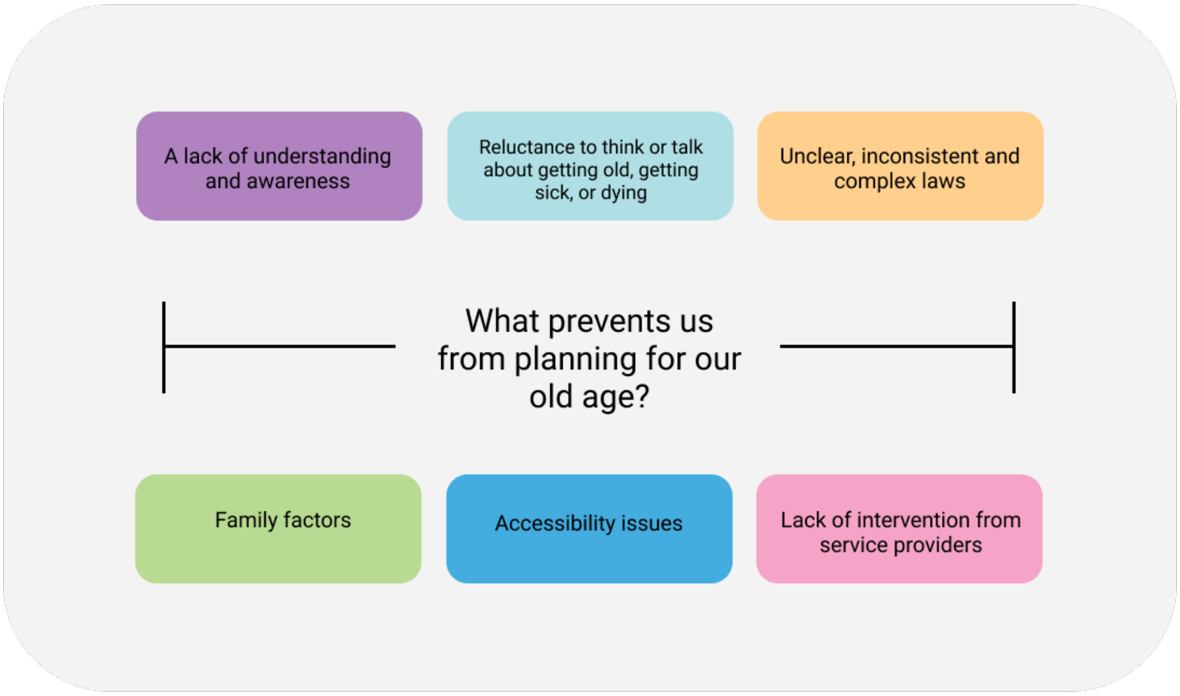
We found there was much more literature focused on the barriers to medical future planning, with comparatively fewer sources that considered barriers to financial future planning. Only one source specifically considered barriers to personal planning (and its particular focus was on family agreements, which are described on page 8).

The focus was on literature that considers future planning from a legal perspective. This is an important limitation to keep in mind, because it means we did not necessarily capture studies into people's attitudes to future planning more broadly – for example, in relation to having informal conversations with loved ones, or taking important practical steps such as engaging service providers for support (although these matters may nonetheless be covered in some of the literature).

Due to the limited literature on these topics in Australia, the literature we reviewed (particularly peer-reviewed literature reviews, government reports and studies) often cross referenced one another. This led to the same, or similar, barriers and recommendations being identified by these resources.

What prevents people from future planning?

The key barriers to future planning that we have identified in this literature review are outlined briefly below.



- **A lack of understanding and awareness**
  - Many people are not aware of future planning, don't know what it involves, or don't know how to do it. This is due to a whole host of reasons. For example, it is sometimes assumed that future planning is done in a will, or that it is someone else's responsibility – such as a doctor or a lawyer - to raise the issue of future planning with their patients or clients. In addition, there are not enough accessible educational materials (including culturally appropriate materials) and not enough avenues to seek advice. **See page 8 for more detail.**
- **Reluctance to think or talk about getting old, getting sick or dying**
  - People are reluctant to think or talk about getting old, getting sick or dying. If we don't think or talk about these issues, we cannot plan for our futures. This is a significant barrier to future planning. Interestingly, the reasons behind our reluctance to grapple with these issues vary depending on the individual or community. For example, some people are reluctant to talk about getting sick due to spiritual or cultural beliefs that it is bad luck; others believe they are in good health and that it is unnecessary to talk about such things; some people believe we should 'live for today' and not worry about tomorrow. **See page 10 for more detail.**
- **Unclear, inconsistent, and complex laws**
  - The inconsistency in future planning laws between states and territories in Australia is often cited as a big factor that prevents a greater uptake of future planning. For example, studies indicate that aged care facilities would be more likely to support more residents with medical future planning if there was a consistent national legal framework. **See page 11 for more detail.**
- **Family factors**
  - People's trust in their families – and belief that their families will take care of them and know what they want – is another factor that prevents people from future planning. There is a common belief that family members will know what to do in future, even if a conversation has never been had about it. **See page 12 for more detail.**
- **Accessibility issues**

  - There are a range of accessibility issues that prevent people from future planning. For example, older people might struggle to access legal services due to the high cost of service or insufficient expertise of lawyers in relevant areas; people from CALD communities may have limited access to culturally appropriate services; and some people who identify as LGBTIQA+ are hesitant to seek support with future planning due to a fear of discrimination. **See page 13 for more detail.**
- **A lack of interventions from service providers**
  - Finally, the lack of assistance and intervention from service providers is another factor that prevents people from future planning. For example, studies show that doctors are uncomfortable discussing future planning with their patients because they don't have adequate time during appointments, are not sufficiently trained, and don't know how to approach such sensitive topics. In addition, there is confusion among professionals as to who is responsible for talking to clients or patients about future planning. **See page 13 for more detail.**

What is elder abuse?

Content warning: some readers may find the description of elder abuse distressing, although there are (deliberately) no graphic descriptions used in this document.

Elder abuse is "a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person".[1] Elder abuse can have a devastating impact, including physical and psychological trauma, injury, and a fracturing of family relationships.

An "older person" is typically defined as someone aged 60 years and older. A relationship where there is an expectation of trust can include a relationship with a family member, neighbour, friend, carer, or intimate partner. Elder abuse is most commonly perpetrated by adult children against their older parents.[2]

Elder abuse takes many forms. It includes financial, psychological or emotional, physical, and sexual abuse, violence and neglect. Recent Victorian research indicates that the most common form of elder abuse is psychological or emotional abuse, followed by financial abuse.[3]

There are many different things that put older people at risk of elder abuse, including family conflict, co-habitation with the perpetrator of the abuse, poor physical health, and a lack of information about rights.[4]

Elder abuse is not always clear cut or obvious. Victims of elder abuse often don't characterise their experience as elder abuse, and perpetrators are often unaware that their actions would constitute abuse.

It is estimated that up to one in seven older people experience elder abuse,[5] but it is under-recognised and underreported. Many people expect the actual figures to be much higher.[6] For example, in 2021 it was estimated that physical and sexual abuse in aged care in Australia is up to eight times higher than the reported numbers.[7]

How can future planning help prevent elder abuse?

Future planning can be an empowering experience. It can help people understand their rights to have a say over their own lives and to decide what they want their futures to be like, and it can help people understand how the law works to protect their autonomy and independence.

Future planning enables people to make legally binding decisions that others, by law, must abide by. This helps safeguard against abuse or exploitation. It can also help ensure that the people around an older person – including family members and loved ones – respect that person's decisions and support them in living the life that they want to live – not the life that someone else thinks is best for them.

Future planning will not on its own prevent all forms or instances of elder abuse, but it is one important tool that can help safeguard against elder abuse by making it harder for people to abuse, exploit, or take advantage of an older person. It allows people to retain dignity and control over their lives in older age.

2. Types of future planning

The types of future planning that we have focused on in this literature review are outlined, with case studies, below.

Medical future planning

Medical future planning is planning done by a person about their future medical treatment and healthcare as they age. Legal options for medical future planning include:

- **appointing substitute medical decision makers** (that is, people who have legal power to make decisions about someone else's medical treatment on that other person's behalf);
- **appointing supportive medical decision makers** (that is, people who have legal power to support someone else to make, communicate, and act on their decisions – for example, by requesting someone else's personal information from a doctor or health organisation); and
- **completing planning documents** (often called 'advance care planning'), that outline the medical treatments a person would want to receive if they couldn't communicate or make their own decisions at the time, for example at end of life. Advance care planning generally occurs in consultation with medical practitioners.

Case Study 1: Suyin is 64 and lives in Tullamarine in Victoria. Suyin's husband Cheng was diagnosed with cancer a few years ago and couldn't communicate in the last few weeks of his life. Doctors asked Suyin to make medical decisions for Cheng.. Suyin and Cheng had never discussed Cheng's healthcare and Suyin didn't know what he wanted – neither did Cheng's doctor. It was a very stressful experience for Suyin.

Because of that experience, Suyin is now determined to make sure she is in control of her own healthcare. She talked with her doctor and completed an advance care plan, where she wrote down what medical treatments she wants and doesn't want, and what is important to her. Suyin feels relieved

Financial future planning

Financial future planning is planning done by someone in relation to their financial management and decision making as they age. Legal options for financial future planning include:

- **appointing substitute financial decision makers** (that is, people who have legal power to access and make decisions about someone else's money on that other person's behalf); and
- **appointing supportive financial decision makers** (that is, people who have legal power to support someone else to make, communicate, and act on their decisions – for example, by requesting someone else's personal information from a bank).

Case Study 2: Josie is 54 and lives in Prahran in Victoria. When she was diagnosed with early onset dementia, she gave her partner Charlotte the legal power to manage her finances in the future, when she can't make her own decisions anymore, under a power of attorney (financial).

Josie doesn't want Charlotte to manage her finances yet - but she has noticed that it's becoming harder to do herself. Charlotte helps her, but sometimes the banks and other businesses won't speak to Charlotte because she doesn't have authority to speak on behalf of Josie.

Josie sees a lawyer who explains that Charlotte can be given legal authority to help Josie with her finances now, without having full control of them under a supportive power of attorney. The lawyer helps Josie fill out a form that appoints Charlotte as her supportive attorney. This gives Charlotte authority to support Josie with her financial management.

Personal future planning

Personal future planning is planning done by someone in relation to their living arrangements, care and other personal needs as they age. Legal options for personal future planning includes:

- **appointing substitute personal decision makers** (that is, people who have legal power to make decisions about someone else's personal matters - for example, what support they get at home & where they live);
- **appointing supportive personal decision makers** (that is, people who have legal power to support someone else to make, communicate, and act on their decisions – for example, by requesting someone else's personal information from a service provider); and
- **entering legal agreements regarding living arrangements** (for example, legal contracts known as 'family agreements' or 'granny flat agreements' under which a family member promises to provide care for an older person in return for receiving a valuable asset from them).

Case study 3: Christos and his wife Sophia live in Brunswick East in Victoria. They have a granny flat in their garden that they plan to move into when they get older. Their daughter Kat and her husband Tom tell them that they will be happy to take care of them when the time comes.. Sophia suggests that, in return, Kat and Tom could live in the house. Everyone agrees.

Christos and Sophie go to a lawyer to get a contract to formalise their agreement (called a 'family agreement'). Everyone checks that they agree with what the document says, and signs it. Christos and Sophia also both give Kat the legal power to make personal decisions for them in future if they can't make their own decisions anymore, by appointing her as their attorney under a Power of Attorney (personal). They each talk to Kat about what is important to them. They feel confident that she will respect their wishes.

3. Our findings: key barriers to future planning

The key barriers to future planning as identified in this literature review are detailed below.

Lack of understanding and awareness

1. A key barrier to future planning is a lack of awareness about future planning, what it consists of, and how to do it.[8]

2. This lack of awareness and understanding of future planning (both financial and medical) has been found to be the result of a variety of factors, including:

   - an assumption that healthcare or legal professionals bear the responsibility for broaching the topic with their patients and clients about creating future planning documents;[9]
   - a lack of understanding of the cost of creating future planning documents, which often leads to an overestimation of the cost;[10]
   - in CALD communities, cultural norms and language barriers;[11]
   - a (perceived or actual) lack of avenues for advice;[12]
   - a lack of understanding of the factors that contribute to elder abuse within both formal and informal care relationships;[13]
   - a misunderstanding of the relevant laws (particularly associated with advance care planning), which is exacerbated by different laws applying in different states and territories in Australia;[14]
   - a belief that information relevant to future planning is contained in a will, and therefore nothing else is required;[15]
   - a lack of educational resources or materials that are fit for purpose.[16]

3. In relation to the last point, White et al. (2018) found that awareness of the laws surrounding advance care planning promotes uptake.[17] The paper highlighted that, for many, this awareness is supplemented by health resources such as webpages, brochures, booklets, manuals, reports, information sheets and forms.[18] However, although this information has been designed to assist older people, it may at times act as a barrier if it is poorly designed or contains inconsistent or inaccurate content.

4. In an analysis of existing information, White et al. (2018) found that a number of resources on end of life care support contained language in the titles and headings which is not commonly known or understood to laypersons.[19] Further, few of the resources incorporated visual design features (such as flow-charts and tables). Such graphics could assist to explain the future planning process and to depict legal structures to broader audiences.[20] A further barrier was identified in relation to accessing online resources.

5. Sellars et al. (2021) found that, out of more than 1,000 Australians surveyed, only 33% reported that they knew there are laws in Australia that permit the appointment of a healthcare substitute decision maker.[21]

6. Boddy et al. (2013), found in their discussions with medical practitioners from hospitals, that the lack of patients' knowledge was the biggest barrier to advance care planning. A common misconception among patients, according to the medical practitioners, was that all necessary information was contained in the patient's will and therefore they did not need to engage in medical or financial future planning.[22]

7. Recognising the importance of advance care planning, Cartwright et al. (2014) explored barriers NSW medical practitioners experienced in discussing advance care planning with older patients. Although patient wishes were largely respected in relation to advance directives, a postal survey of 1,000 medical practitioners found many practitioners lacked understanding of key terminologies and systems supporting future care planning for elder persons.[23] Interestingly, while many medical practitioners were aware of and had experience with enduring powers of attorney, they did not routinely discuss these with their patients.[24] Cartwright et al. (2014) concluded that medical practitioners require a better understanding of which advance care planning options apply to each patient's situation.[25]

8. Despite the perceived ethical, personal and health benefits of advance care planning, the extent to which older and seriously ill inpatients in Australia have considered future health decisions remains uncertain according to Waller et al. (2019). In its study of inpatients Waller et al (2019) found many older people had not considered the importance of future planning, with some unaware of the concept.[26] Of the inpatients who had not engaged in future planning, the study found many already felt that their family or doctors were aware of their future care arrangements or were simply not interested in the process.[27]

9. People from CALD groups are more likely to have a limited understanding and awareness of future planning, according to a number of studies. For example:

   - The Ethnic and Community Council of Victoria (2015), whose study focused on Filipino and Macedonian communities in Victoria, found that there was a common misunderstanding of what advance care planning involves, and a belief that it is the same as creating a will or doing other financial planning for retirement;[28]

   - Tilse et al. (2019) found that those born in Australia, as well as those who spoke English as a first language, were more likely to have advance care planning discussions with their family compared to those born overseas, or who spoke English as a second language;[29]

   - Wainer et al. (2011) found that 19% of Vietnamese participants in their project had appointed an Enduring Power of Attorney to manage their finances if they became unwell, compared to 50% of Italian participants and 63% of Greek participants. By contrast, 69% of English speaking participants in an earlier study had appointed an Enduring Power of Attorney (financial);[30] and

   - Sinclair et al. (2021), explored the associations between birth region, sociodemographic predictors, and advance care planning uptake and found that those born overseas were less likely to complete an advance care plan compared to those born in Australia.[31]

10. In addition to the lack of general knowledge about future planning, a New Zealand study found that there is widespread ambivalence about the existence of enduring documents, even among those who are aware of them. This operates as a separate and additional barrier to those listed above.[32]

11. Pachana et al. (2014) identified various factors which create barriers to the establishment of enduring powers of attorney.[33]

12. Samis et al. (2011) identified barriers including lack of community knowledge and strong, trusting relationships with general practitioners and other health professionals.[34]

13. Hughes et al. (2012) conducted a study of 19 service providers, 6 community members and 25 LGBTIQA+ individuals in New South Wales. The study found that a major impediment to end of life planning was that many people did not know that their same-sex partner had a right to act as Responsible Person for their medical decisions, should they lack decision-making capacity. Not only did the individuals lack awareness of their rights, but health care professionals often also lacked awareness of the rights of same-sex individuals. This meant that LGBTIQA+ individuals who were unaware of the right to have a same-sex partner make decisions on their behalf, were sometimes denied that option.[35]

14. Hughes et al. (2014) found, in their study of more than 300 people in the LGBTIQA+ community in New South Wales, that while the majority of participants were aware of future planning options available to them, only 13 per cent of participants had discussed end of life issues with their general practitioner. Importantly, participants were unaware of future planning and legal protections that are specifically relevant to the LGBTIQA+ community.[36]

Reluctance to think or talk about getting old, getting sick or dying

15. Another barrier to future planning is a general reluctance by people to think about or plan for illness, dying or death. The reasons behind the reluctance to talk about illness, death, and dying vary, from spiritual beliefs and cultural taboos, to avoidance, denial and fear.

16. A survey conducted by Samsi et al. (2011) found the reluctance to engage in medical and personal planning may sometimes be explained by carefree attitudes and religious beliefs. They found, amongst some respondents, a 'live only for today' attitude and unwillingness to interfere in 'God's will'. Whilst some older people acknowledged the importance of advance care planning, a large proportion sought to postpone health and future care planning for later in life or when their health deteriorated.[37]

17. According to Fowler et al. (2009), general community attitudes which value 'living in the moment' can act as a barrier to future planning because people may be inclined to wait until there is 'an actual and concrete need' before engaging in planning activities.[38]

18. Gerber et al. (2020) reviewed peer-reviewed articles for the period 2008 to 2018 addressing end of life preferences, attitudes, values and beliefs amongst first generation migrants over the age of 50 in Australia. The authors found that a general reluctance to talk about death and dying was one factor that impacted the likelihood of completing medical future planning. [39] Some key findings of their review included:

    18.1. People’s cultural background influenced the level of avoidance in discussing and planning for the end of life.

    18.2. In certain cultures, superstitious fears existed that talking about death might bring it closer.

    18.3. The concept of filial piety (which is a principle which refers to respect and dedication for one's elders) was an important barrier as many older people simply assumed that their children would know their end of life wishes (even though they had never been discussed) and children felt that they needed to shield their older relatives from confronting information, which led to avoidance of future planning on both sides. This was a particular problem among some people who didn’t speak English and relied on their family to translate medical information.[40]

19. Scott et al. (2013) identified that amongst the chief barriers contributing to the slow uptake of advance care planning was the personal and social taboo associated with death and the dying process. This included clinicians who found it difficult to think and talk about dying.[41]

20. A similar societal reluctance to discuss end of life issues was identified by Rhee et al (2012) to be a barrier to advance care planning. In that study, a qualitative, descriptive survey was conducted through semi-structured telephone interviews. The transcripts of these interviews were coded and analysed to identify participants' views on the major issues and problems affecting advance care planning in Australia.[42]

21. Ries (2016) found that a belief that one is in good health and a reluctance to think about future illness and dying resulted in a lower uptake of advance care planning.[43]

22. Tran et al. (2018) found that patients were unwilling to carry out advance care planning with their medical practitioners as they were reluctant to communicate end of life issues, particularly if they were healthy. Some patients regarded death as a matter of fate and therefore believed that advance care plans were unnecessary and irrelevant.[44]

23. White et al. (2018) conducted a telephone survey in three Australian states in relation to the prevalence of advance care planning and factors for and against their completion. Among other things, they found that avoiding consideration of mortality and ill-health was one of a number of factors that explained the lower prevalence of medical future planning when compared to financial future planning.[45]

24. The Ethnic Communities Council of Victoria (2015) found, in discussions with the Filipino community, that a fear of talking about death or dying (i.e. something beyond a general reluctance to talk about death or dying) was a barrier to future planning. Participants believed that thinking about issues such as death, illness and loss of mental ability was bad luck and could increase the likelihood of those things occurring.[46]

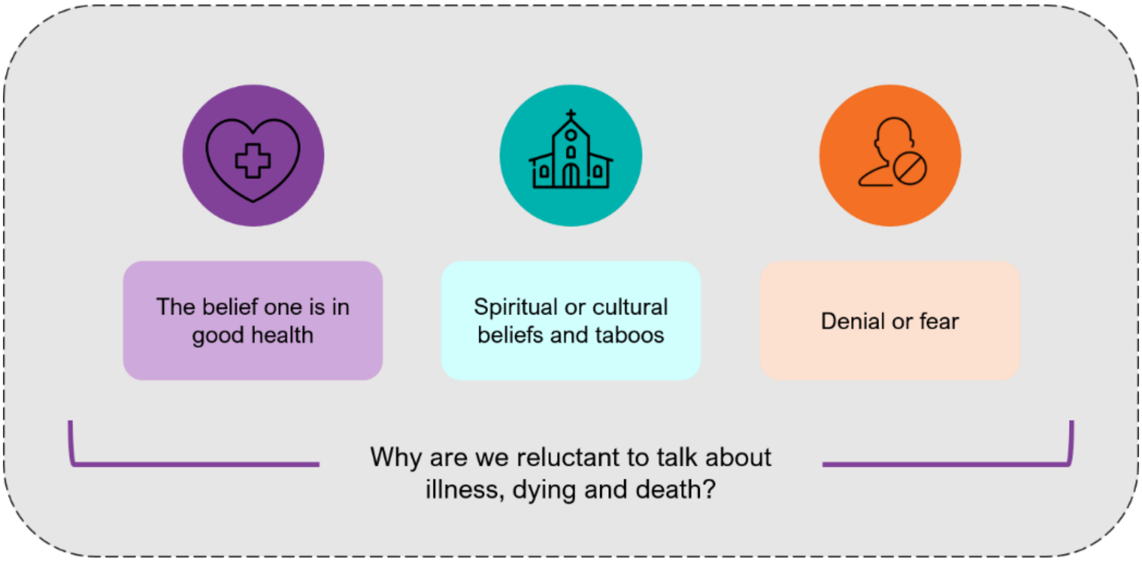
25. The Victorian Law Reform Commission (2010) also identified a number of so-called psychological barriers to financial future planning (specifically, entering into power of attorneys in relation to finances) including a fear of death, disability and dying.[47]

26. Hughes and Cartwright (2014) in their study of more than 300 people in the LGBTIQA+ community in New South Wales, found that (among other things):

    - only 13% of participants had discussed end of life issues with their general practitioner[48]
    - participants who identified as transgender, or did not identify as male or female, were much less likely to feel comfortable having end of life discussions with medical practitioners than other LGBTIQA+ participants in their study. The authors considered that this may be because of difficulties transgender and intersex people continue to have in engaging with health care professions.[49]

27. Hughes et al. (2012) found that 'not wanting to think about or plan for the end of life' was a major impediment to advance care planning. For some individuals, this resulted from a fear or denial of death arising as a legacy of the HIV epidemic, for others the taboo surrounding death was reinforced by the perceived emphasis placed on youth and beauty in the gay male community – 'the Peter Pan syndrome' among gay men. This was mirrored by individuals who felt that older gay men can become socially isolated and alienated from the LGBTIQA+ community.[50]

28. In a review of the experiences and preferences of LGBTIQA+ people in end of life care, Harding et al. (2012) identified several barriers and noted sexuality disclosure played an important role in facilitating advance care planning discussions with some patients less likely to disclose sexuality, thereby limiting the effectiveness of some advance care plans. Further, if medical practitioners failed to engage in an open discussion with their patients about sexuality, patients were less likely to reveal their sexuality and express wishes about future plans. LGBTIQA+ people may also experience barriers in developing advance care plans due to the involvement of family, who may seek to override the wishes of the patient and their partner. [51]



The belief one is in good health

Spiritual or cultural beliefs and taboos

Denial or fear

Why are we reluctant to talk about illness, dying and death?

Unclear, inconsistent and complex laws

29. Another barrier to future planning is the complexity of the legal process and existence of inconsistent laws throughout Australia.

30. Batchelor et al (2019) found that uncertainty in legislation was a major barrier to the development of advance care plans in Australian residential and community aged care settings and that there was significant differences between states and territories in the rights, responsibilities and processes surrounding advance care planning.[52]

31. Kaspiew et al. (2016) found, amongst other issues, an absence of a consistent approach to elder abuse over time, and that there is a need to consider how elder abuse and neglect should be conceptualised, and why elder abuse raises questions of public policy that are not adequately addressed within existing private and public law frameworks.[53]

32. White et al (2014) noted that the low uptake of advance care plans in Australia was partly due to a lack of standardised form in Australia.[54] They found that there were many forms of advance care plans that varied significantly between the States and Territories, and that this affected community awareness and acceptance.[55]

33. Tilse et al. (2019) found that participants in their study did not fully or accurately understand their rights and responsibilities associated with advance care planning. The different legislative schemes used across states and territories and the inconsistent rights and responsibilities therein was found to be a significant cause of this misunderstanding. This study highlighted the different sources from which people derived their understanding of advance care plans, including the media, friends and family, personal professional knowledge and the Internet.[56]

34. Batchelor et. al (2019) examined both the facilitators and barriers to implementing advance care plans in Australian residential and community aged care settings. One factor cited as a barrier preventing health care professionals from assisting in the preparation of advance care plans was uncertainty about applicable laws, given the significant differences between relevant state and territory legislation.

35. Rhee et al. (2012) found that the low uptake of advance care planning in Australia was a result of inadequate awareness of advance care planning, as well as difficulties accessing advance care planning documentation, difficulties interpreting advance care plans and difficulties making binding decisions for future unpredictable situations.

36. Inconsistency in legislation is also considered to be a barrier to financial future planning, including enduring power of attorney documents in relation to finances.[57]

Family factors

37. People's family dynamics, and beliefs and attitudes about their families, are also factors that can act as barriers to future planning.

38. The Victorian Law Reform Commission (2010) identified family dynamics as one factor that prevented people from financial future planning – specifically, from entering into powers of attorney in relation to finances. The authors noted that some people trust their family to manage their affairs in their best interests; and some people - particularly from certain CALD communities - assume that younger generations of family members will take on this responsibility.[58]

39. Similarly, Wainer et al. (2010) in their survey of English-speaking people aged over 65 found that participants demonstrated great faith in family members taking care of them, and knowing 'what is expected of them', and that this was particularly true of participants with lower incomes.[59]

40. Wainer et al. (2011) found that Vietnamese and Italian participants believed that their children would take care of them, such that they did not need to make financial plans for the future. Greek participants were more wary, but still held a strong expectation that their children would care for them.[60]

41. The belief that a person's family will know what they want also arose in the research undertaken by Tran et al. (2018) which found that patients were not willing to carry out advance care planning with medical practitioners as they assumed their family and doctors already knew their preferences.[61]

Accessibility issues

42. Accessibility issues act as another barrier to medical and financial future planning.

43. The House of Representatives Standing Committee on Legal and Constitutional Affairs (2007) inquired in into the barriers to older people in Australia accessing legal services. The following barriers were identified in relation to accessing legal assistance, including but not limited to legal assistance for powers of attorney and medical future planning:[62]

- cost, leading to a reliance on free services offered by community legal practices. which generally have limited resources and funding, and strict eligibility requirements;
- complexity of some contracts relating to future living arrangements which have a correspondingly high legal cost (e.g. retirement village contracts);
- importance of a relationship of trust being built before an older person is willing to discuss and formalise arrangements. These relationships take time to develop, at a corresponding cost. Relatedly, community legal services lack the resources or capacity to spend the time required to build such a relationship;
- reliance on lawyers to anticipate the needs of older people, increasing the amount of time taken to identify or explain relevant issues, thereby increasing the cost of services; and
- insufficient expertise of lawyers in legal issues affecting older people.

44. The Standing Committee also found that social and cultural factors prevented older people from seeking legal advice and noted that many older people were unaware of the importance of legal documents (and receiving legal advice) and lacked the confidence to enforce their legal rights for fear of reprisal.[63]

45. Multiple studies have identified that the complexity of future planning, including enduring powers of attorney, as something that prevents people from future planning.

46. The Victorian Law Reform Commission (2010) found that having multiple different forms and the use of legal terminology made entering into a power of attorney too complex.[64] It also identified a "psychological" barrier, being the fear of lawyers and legal documents.

47. Boddy et al. (2013) found that, according to medical practitioners in hospitals, difficulty in accessing forms, difficulty in understanding the content of those forms, and the inconvenience of completing forms, prevented patients from completing medical and financial future planning documents. In addition, confusion surrounding the process of advance care planning – including whether a lawyer needs to be involved – was identified as a barrier.[65]

48. Another barrier to financial future planning, as identified by King et al. (2011), is the limited use of professional services by people from some CALD communities.[66]

49. Hughes and Cartwright (2014) found that many LGBTIQA+ individuals actively avoided advance care planning due to actual experiences of discrimination and abuse as well as fears of such treatment. Community members and health care providers noted that a failure to provide LGBTIQA+-friendly environments for care delivery had the result that LGBTIQA+ people were less likely to seek routine healthcare. For example, healthcare providers in small towns noted that LGBTIQA+ clients who could access services locally (which could also be a point of access for advance care planning) chose not to do so, for fear of discrimination.[67]

50. This fear of discrimination was mirrored in the study completed by Lawton et al (2014), which found that fear of mistreatment stemming from sexual orientation could prevent LGBTIQA+ individuals from seeking medical assistance to prepare end of life planning.[68]

Lack of assistance from service providers

51. One barrier to medical future planning identified in the literature we reviewed was a lack of assistance, or insufficient intervention, by medical practitioners and other care providers.

52. Detering et al. (2019), in their study involving more than 2,000 Australian participants, found that people in residential aged care facilities were significantly more likely to have completed an advance care plan than people in hospital or people attending general practice. They stated “the low prevalence in hospitals and very low prevalence in general practices suggests that further efforts are needed to increase uptake of advance care planning in these settings, and to understand barriers to this occurring”.[69]

53. They noted the following as barriers preventing medical practitioners from helping their patients with advance care planning:

- the fact that the conversations are time consuming and cannot ordinarily be completed in a single visit;
- lack of suitable or adequate remuneration for medical practitioners; and
- lack of training and support for medical practitioners to have these types of conversations.[70]

54. Tran et al. (2018) explored the barriers to general practitioners helping their patients with advance care plans, and found a lower uptake in CALD communities. General practitioners felt discouraged from discussing advance care planning with patients on the basis of:[71]

- a belief that an advance care planning discussion would damage the doctor/patient relationship and be seen as depriving the patient of hope;
- trepidation about changing patients' preferences;
- a view that they lacked adequate training to produce an advance care plan;
- concerns with workload relative to the time required to produce an advance care plan;
- fragmentation of the healthcare system; and
- doctors or substitute decision makers disregarding or feeling incapable of enacting the express wishes of a patient

55. Similar findings were made by Ries et al. (2016) who noted that medical practitioners reported that they did not initiate advance care planning discussions with patients because they do not feel confident of their knowledge and skills in this space, they are concerned about upsetting patients, they have competing work demands and they do not believe advance care planning is their responsibility.[72]

56. According to Sellars et al. (2015), advance care planning could successfully be carried out by staff who implement home care packages, since as older people who access such packages are likely to be in better mental or physical health than older people who are in care facilities.[73] Despite this apparent opportunity, advance care planning is rarely carried out in the context of a home care package. In their study, which explored the current attitudes of home care service providers and case managers towards advance care planning, Sellers at al. found that:

- advance care planning was only provided occasionally;
- of the home care providers surveyed, 36% did not provide any advance care planning;
- of those providers that did undertake advance care planning, only 24% offered this service to all of their clients, whilst the majority provided advance care planning to only certain clients, apparently without any particular rationale for which clients were selected.

57. Sellers at al. reported the following were factors cited by case managers as reasons for the limited provision of advance care planning support or services to home care clients:

- lack of training (52%) and subsequent lack of advance care planning skills (45%);
- lack of formal advance care planning policies and procedures (69%);
- insufficient time and resources (10%), with the majority of managers dissatisfied with the time allowed to undertake advance care planning (65%) and only a minority (36%) believing they had sufficient time in their workload to complete advance care planning;

- belief that clients were more comfortable discussing advance care planning in their own homes (78%) rather than at the provider's offices;
- interestingly, most case managers disagreed that discussing death was a barrier to undertaking advance care planning (55%) and reported feeling confident discussing death and dying with their clients (57%).[74]

58. Scott et al. (2013) in their review of advance care planning implementation, noting that medical practitioners avoided responsibility for helping clients with advance care planning. In addition, the authors found there was a lack of standardised procedures for recording and retrieving advance care planning documentation, which meant that there was slow acceptance and operationalisation of advance care planning.[75]

59. Following discussions with medical practitioners in hospitals, Boddy et al. (2013) identified the following practitioner-centred barriers to medical future planning:

- lack of knowledge, including a lack of understanding of the meaning and scope of advance care planning and lack of understanding of associated administrative processes;
- practitioner sensitivity, including a reluctance to engage in discussions around advance care planning with patients admitted to hospital (including, potentially due to the practitioners' own discomfort relating to death and dying);
- legal barriers, including confusion about when a person can make an advance care plan if there are capacity issues; and
- confusion around who is responsible for advance care planning within a hospital and whose role it is to help hospitalised patients with advance care planning.[76]

60. Rhee et al. (2012), through interviews with medical practitioners and representatives of key stakeholder organisations, identified two barriers to documenting advance care plans, being:

- inadequate involvement of medical practitioners in the advance care planning process; and
- paternalistic attitudes of medical practitioners and families of patients.

61. The former acts as a barrier by reducing the chance of medical practitioners starting conversations about advance care planning with their patients. The latter acts as a barrier by making older people assume that the issue of advance care planning will be brought to their attention by others, which has the effect of preventing older people speaking up and expressing their own wishes proactively.[77]

62. Hughes et al. (2014) found, in a study involving more than 300 LGBTIQA+ people in New South Wales, that medical practitioners need more training in how to communicate effectively and raise issues with LGBTIQA+ patients.[78]

Real or perceived tax consequences

63. One barrier to personal future planning (specifically entering family agreements) that has been identified in the literature is the possible tax implication of entering such agreements.

64. A review conducted by the Australian Board of Taxation (2019) examined the tax barriers to creating formal, written family arrangements (also known as granny flat agreements) and mechanisms to removing these barriers by providing capital gains tax exemptions and increasing public education and awareness.[79]

65. The review found the primary barrier to the execution of such agreements were the real or perceived tax consequences to a formal written agreement and wanting to maintain eligibility for the age pension.[80]

4. Conclusion

If we understand why people don’t future plan, we will be better equipped to design ways to increase future planning –enabling more people to retain dignity and control as they age and helping safeguard against elder abuse.

This literature review shows us that there are many things that prevent people from future planning – from a lack of support from service providers, to being unaware that future planning is even an option.

It also shows us that different individuals and communities may experience different barriers, and for different reasons. For example, although many of the studies show that there is a general reluctance among the community to think or talk about ageing, getting sick or dying, the reasons for this reluctance vary greatly – from spiritual or cultural beliefs among some CALD groups; to fear of discrimination among some in the LGBTIQA+ community ; to a belief that we should live for today and that it is not necessary to think about what might happen in the future.

This reminds us that we need to come up with tailored responses and ways to address barriers; a one-size-fits-all approach to encourage and enable future planning is unlikely to work.

Although a fair amount of research has been done in Australia about what prevents people from medical future planning, this literature review demonstrates there is a paucity of research into what prevents people from financial or personal future planning (and in particular, from appointing substitute decision makers and supportive decision makers under enduring documents). In addition, there is not enough research into the enablers of future planning – that is, what are the things that help, encourage and lead people to future plan? These are significant gaps that merit consideration, discussion and attention.

We hope that this literature review will be another step towards preventing elder abuse in Australia.

5. The Safeguarding Now, Preventing Future Abuse Project

This literature review has been undertaken as part of the Safeguarding Now, Preventing Future Abuse Project, an elder abuse prevention project which is aiming to understand what prevents people from future planning and design & implement ways to empower more people to future plan.

The project is focused on the following groups in Melbourne:

- CALD communities (particularly Italian, Greek, Vietnamese and Chinese communities),
- people who identify as LGBTIQA+, and
- people who are ageing alone.

The project is led by Justice Connect in collaboration with cohealth and others including MinterEllison, who generously developed this literature review on a pro bono basis in partnership with Justice Connect. The project is generously funded by Perpetual.

Justice Connect and cohealth have a longstanding Health Justice Partnership in which lawyers from Justice Connect are located at cohealth sites and offer free legal services to older cohealth clients.

6. Glossary

- **Advance care planning -** describes the process of planning and setting out the medical treatment a person would like to receive (or not) in the event that they were unable to communicate those decisions. It is a broad concept that may take the form of a formal or informal conversation with friends, family and/or medical practitioners. It may or may not result in written documents, but ideally leads to a written advance care plan.
- **Advance Care Directive** – a formal written document that records the medical treatment a person would like to receive (or not) in the event that they were unable to communicate those decisions, as well as information about the person's values, goals, and what is important to them in life. Also known as an Advance Health Directive in Queensland, a Health Direction in the Australian Capital Territory, and an Advance Personal Plan in the Northern Territory.
- **Advance care plan** – a written document about the medical treatment a person would like to receive (or not) in the event that they were unable to communicate those decisions, which may take the form of a more formal document like an Advance Care Directive or an instrument appointing a substitute decision-maker.
- **Advance Health Directive** – see Advance Care Directive.
- **Advance Personal Plan** – see Advance Care Directive.
- **Capacity or decision-making capacity** – someone has capacity if they are able to make decisions for themselves, including being able to understand relevant information, remember it long enough to inform their decision, weigh up relevant information in the decision-making process, and communicate their decision. There are various legal definitions of capacity that apply in different circumstances.
- **Enduring document and enduring appointment -** An enduring document is a document under which a principal appoints a substitute decision-maker (giving them legal power to make decisions on the principal's behalf), or a supportive decision-maker (to support the principal to make decisions). An enduring document often comes into effect immediately upon the principal no longer having capacity to make their own decisions, or at such other time chosen by the principal, unless the principal:
  - revokes it (while they still have capacity) or the enduring power is otherwise automatically revoked;
  - the appointed person resigns, dies or is unable to carry out the role; or
  - the appointment is changed or revoked by a Tribunal or Court.
- **Enduring Power of Attorney** – a document under which a substitute decision-maker can be appointed.
- **Enduring Power of Guardianship** – a document under which a substitute decision-maker (medical or personal) is appointed in New South Wales, Western Australia, and Tasmania.
- **Family Agreement** (also known as a "granny flat agreement" or asset-for-care arrangement) - while they can take many forms, family agreements generally involve "an older person transferring title to their property, or proceeds from the sale of their property, or other assets, to a trusted person (or persons) in exchange for the trusted person promising to provide ongoing care, support and housing."[81]
- **Home Care Packages** – funding provided by the Commonwealth Government to eligible older Australian, which is used to fund tailored care services at home.
- **Medical Treatment Decision Maker** – the name for a substitute decision-maker (medical) in Victoria.
- **Health Direction** – see Advance Care Directive.

- **Principal** – in the context of enduring documents or enduring appointments, means the person who appoints a substitute decision-maker or a supportive decision-maker under an enduring document. Jurisdictions outside of Victoria use different terminology.
- **Substitute Decision Maker** – someone who has the legal power to make decisions on someone else's behalf.
- **Supportive Decision Maker** – someone who has the legal power to support someone else with their decision making in relation to health, financial and personal matters.

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