



LEGACY LAW

Protecting the assets in your family tree

9 September 2019

Royal Commission into Aged Care Quality and Safety
GPO Box 1151
ADELAIDE SA 5001

Dear Sir / Madam

A Response to Background Paper 5

We welcome the opportunity to make a submission to the Royal Commission into Aged Care Quality and Safety (the “Commission”).

Introduction

Legacy Law is a personable boutique law firm that specialises in acting for individuals including assisting them with estate planning and succession, estate litigation, and family disputes. Legacy Law’s client base includes elderly citizens who need more time and support.

Our work is largely in New South Wales although we are familiar with other jurisdictions.

Therefore, our submissions are limited to NSW. Further, we only comment on Background Paper 5, “Advance Care Planning in Australia”.

Lastly, we make no comment or wish to denigrate any person’s religious views and hope that the discussion can be respectful of all people.

Advance Care Planning

It is trite to state that Australia’s population is ageing and that the country has not done all it can to plan for this new dawn.

While, individuals should take responsibility for their own affairs, if they have the capacity to do so, it is the responsibility of government to facilitate difficult social dynamics which affect the population and the country.

The interest in end-of-life care, assisted dying and voluntary euthanasia is a sign that a large portion of the population are interested in taking some control over their later years. We applaud that and suggest that acknowledging one’s own mortality is an important and sensible step to be taken in a life.¹

We hope that “Advance Care” planning does not suffer the same fate as “financial” planning did after the recent Commission into Misconduct in the Banking, Superannuation and Financial Services Industry and become a term of abuse.

¹ The author is writing a book called “The Irish Book of Living and Dying”



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Our experience with Advanced Care Planning

We always ask if clients have appointed substituted decision makers and less than 10% have. We ask if they have given advanced care directions and less than 2% have.

Once we point out that they should attend to this, all of our clients agree to appoint substituted decision makers but we do not know how many take the forms we give them to their GP for finalising. Our best estimate is less than 50%.

Most clients will appoint all of their adult children acting jointly and severally to be their enduring guardian if their spouse is unable to act in that role.

The issues and concerns

We suggest the main issues and concerns are:

1. The low rate of participation;
2. The need for NSW legislation;
3. Complexity of the law;
4. The need for a forum to ventilate disputes; and
5. The need for the role of “supporter”.

1 The low rate of participation

We encourage the keeping of registers and putting the onus on people at the point of diagnosis, for example, doctors and aged care centres. This may include greater education about aged care planning, including, at minimum, basic understanding of power of attorney and enduring guardian documents.

Records should be kept also to show which of these institutions are succeeding in getting clients to act and make these directions. It should be systemic. In fact, the community would benefit from it being an opt-out system rather than an opt-in system.

Although advance care plans do not need to be in writing, ideally, a system should be introduced to start these types of conversations with the person at an early stage of contact, with a requirement that these conversations be recorded in writing. There should be a *continuing obligation* on health professionals to work together with their clients towards an outcome.

The focus should be on what the client wants during their life, not a last minute “get your affairs in order” situation. Having these discussions early facilitates this important goal. Unfortunately, as lawyers, we often do not get to have these conversations until clients consider it to be an imperative or it becomes an outstanding, “after-the-fact” issue to be resolved. However, health professionals are in a vital position because they have the opportunity to bring discussions like advanced care plans and directives into the forefront of their minds.

The person’s values and beliefs should be paramount.

The NSW Trustee should have more specially trained people who can assist those who have no-one.

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2 The need for NSW legislation

We suggest that the fact that these directives are made under the common law is not appropriate². A subsequent case could over-rule this case and leave people who made directives on the basis of the case in an unclear and very difficult position.

Further, as mentioned in Background Paper 5, the lack of legislative governance in relation to advance care plans and directives creates an inefficiency in the implementation of them. *“There is evidence suggesting that advance care plans are not always being implemented in accordance with the preferences set out in the document”* due to fear of litigation or conflict with family’s inconsistent directions and confusion about the legal effect of an advance care plan.³

Appropriate legislation can help address these confusions around the legally binding effect of advance care plans, with the view of providing clear guidance on whose instructions prevail where there is conflict between an advanced care plan and a family member’s directions. Education about newly implemented laws should then be given to health professionals, so that they can confidently and competently implement advance care plans without fear of litigation.

It would be an appropriate exercise of Parliament’s legislative mandate to present draft legislation on this topic. We venture that the energy put into assisted dying legislation in Parliaments around the country suggests the population is interested in this area.

3 Complexity of the law

In a country where we are told half the population do not have a simple Will and our experience tells us that perhaps 10% have an appropriate Will, we should not be surprised that most people do not have appropriate substituted decision making and health directives organised.

Compounding the issue are the different laws and names for the documents in different States and Territories. For example, Medical Powers of Attorney (VIC) are known as Appointments of Enduring Guardian in NSW and ‘advance care directives’ (NSW, VIC, TAS, SA and WA) are called ‘advance health directives’ (QLD), ‘advanced personal plans’ (NT) or ‘health directions’ (ACT).

In addition in NSW, where we mainly practice and do not comment on other jurisdictions, one can direct what type of emergency treatment one gets in an ambulance in an ‘Authorised Care Plan’. However, these only remain valid for 12 months and the treating physician is responsible to review and submit a new plan within the 12 months. You can understand why busy doctors, who are well educated and familiar with the system, may also think the system makes work for them.

² Hunter and New England Area Health Service v A [2009] NSWSC 761 (6 August 2009)

³ Commonwealth, Royal Commission into aged Care Quality and Safety, *Background Paper 5* (2019), 6.



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Advance care directives protect a person's right to self-determination. Life-saving medical treatment such as CPR cannot lawfully be given if a competent adult refuses it, and any touching of a person in the absence of consent amounts to a civil battery (and perhaps criminal assault).

It is preferable due to clarity and ease for families for an objection to medical treatment such as CPR to be in writing, with the option to verbally change that written direction. It can be very difficult and upsetting for family members to make that decision on behalf of someone, especially if the family member/s are not close (at that time) and/or have different religious views.

We may want to look towards other states and territories which have codified the common law principles around consent and the validity of advance care directives. Currently, all states and territories in Australia, besides NSW and Tasmania, have enacted such legislation clarifying the legal position of advance care directives.

These laws set out the circumstances in which an advance directive may lawfully not be complied with and set out how advance care directives may be challenged. However, it is noted that advance care directives that are not continuous but are on a once-off or isolated basis, such as in the instance of CPR, are usually so limited and unambiguous that they are not helpful.

Retirement villages are not affected by any statutory schemes unless they provide health care or employ registered health practitioners.

4 The need for a forum to ventilate disputes

We suggest that, given the importance of decisions made, they should be reviewable by the Supreme Court in each state and territory.

Legislation can also cover whether the documents apply in different states and territories in the same way as the Power of Attorney legislation.⁴

Elder abuse is a very real issue. Elder abuse can, and does, occur outside of traditional family relationships. Not only is it common for an adult child to take advantage of their elderly parents or a spouse to take advantage of their partner,⁵ it is also possible for a friend or caregiver to do so too, or at least have the opportunity to do so due to that relationship of trust or dependence.⁶ We have seen an increase in complaints about elderly clients being sent by new spouses to facilities that are inappropriate or far away from other family members.

Elder abuse is also not confined to any single form of abuse and often intersects with broader social issues such as culturally and linguistically diverse people or people with disabilities.⁷ It can range from physical, psychological or emotional, social and financial, or a combination of

⁴ *Power of Attorney Act 2003* (NSW) s 25.

⁵ Australian Law Reform Commission (ALRC), *Elder Abuse*, Issues Paper No 47 (2016), 14-15.

⁶ See e.g. *Johnson v Buttress* (1936) 56 CLR 113 and *Badman v Drake* [2008] NSWSC 1366.

⁷ ALRC, above n 5, 17.



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these.⁸ The result of these types of abusive relationships is an inequality between the two people and an imbalance of power, lending itself to higher risks of advantageous conduct and behaviour by the more dominant person in the relationship.

5 The need for the role of “supporter”

We agree with recommendation 4.3 of the NSW Law Reform Commission Report 145, specifically in relation to the modernisation of terms and the use of the concept of “supporter” for someone who assists a person to make their own decisions.⁹ This serves to delegalize the language surrounding advanced planning and makes it more accessible in plain English.

From our experience, clients are regularly seeking the translation of legalese into plain English for their documents. They do not want complex drafting but ask for simple to understand documents that are clear, but effective.

We have created a role of “Advocate” for clients in certain situations. One example is where a client with a disabled child separates from the father of the child who has little to do with the child after that. The mother enters a new relationship with a person who is a great support for the child. However, as a step-father that person has few rights and less standing to fight for the treatment the child should get if the mother could not act.

Clients recently told us that a hospital did not want to reply on an Appointment of Enduring Guardian to deal with the administration of antibiotics. As a result, we now include references to these in our standard documents for clients so that they can fight all battles for their loved ones.

Examples of Good Practice and Innovative Models

Scandinavia / Japanese Models

Scandinavian countries have long been leaders in providing high quality care to their populations. It can be learned and Japan has adopted many of its learnings. The following is an extract from an article by Caroline Egan.¹⁰

“A ‘Dementia Supporters Program’ teaches children, students, adults – anyone in the community – the basics of dementia care and promotes understanding. One of the most successful features of the Japanese system are the local Dementia Cafes, which create a “relaxed environment” for those living with dementia to meet up with family, to discuss care needs, or simply to have a good time!”

“‘Simulated training programs’ are performed to show people ways to [sic] quickly find people living with dementia who may have walked outside their usual domain. ‘Dementia Working Groups’ are led and run by people living with dementia, and create local platforms where their

⁸ Ibid 13

⁹ New South Wales Law Reform Commission, *Review of the Guardianship Act 1987*, Report No 145 (2018), 29

¹⁰ <https://hellocaremail.com.au/swedens-community-based-aged-care-philosophies-take-hold-world-wide/>



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voices can be heard directly. Community-based Integrated Care Systems have been taken up by more than 11 million people across Japan.”

Compassionate Communities

In February 2017 The GroundSwell Project¹¹ and Palliative Care Australia combined to put on the first Compassionate Communities Symposium in Australia. Health practitioners joined with volunteers, carers, end of life doulas and researchers to explore how more people can get involved in end of life care. A strong community is what people want and of course it is unpaid so also sustainable.

Sub-standard Quality - A personal note

The writer’s father-in-law sadly became ill with mesothelioma in recent years. While his children were appointed as his Enduring Guardians, they still struggled and ultimately failed to get the attention of the Registered Nurse at the facility in order to provide more pain relief.

A previous facility attended by my father-in-law did not have a Registered Nurse available at weekends and we submit that this should be compulsory.

No patient should, in the writer’s personal opinion, suffer pain for the want of pain relief in a terminal situation.

We thank the Commission for the opportunity to make this submission and wish the Commission well in it’s good work.

Yours sincerely

Donal Griffin

¹¹ <https://www.thegroundswellproject.com/national-compassionate-communities-practice-forum>