

To the Department of Health and Human Services

RE: Carers Victoria feedback on the 'Simplifying medical treatment decision making and advance care planning' position paper

Thank you for the opportunity to provide feedback on the planning and implementation of the government's proposed legislative changes.

Unpaid (mostly family) carers play a key role in medical treatment decision making, yet Carers Victoria is regularly contacted by carers like 'Helen' expressing a great deal of distress about health practitioners' lack of involvement of them or their relative in significant medical treatment decision making. Helen's story follows:

'Helen' cared for her mother at home for 10 years. When her mother had a fall at home, she was taken to hospital by ambulance. Helen recalls the doctors informed her they would not treat her mother although this was at odds with her mother's stated desire to receive all necessary treatment. She also recalls a nurse telling her on a number of occasions her mother was going to die within earshot of her mother. This was extremely upsetting as her mother wanted to live. Helen held a Medical Enduring Power of Attorney, but says her wishes to access medical treatment for her mother were not respected. She recalls the last thing her mother told her was 'darling, please don't let me die'. Helen reported her mother ultimately died of a severe infection.¹

Parents and foster carers of children with severe disabilities have also reported their child's hospital medical records have been marked 'Not for Resuscitation' without their knowledge or consent.

Recognition and respect for the role of carers

Carers Victoria supports the government's overall approach to simplifying medical treatment decision making and advance care planning. Carers Victoria believes this approach will help address carer's concerns about their recognition by health practitioners as substitute decision makers and as supporters of people making significant medical treatment decisions. Importantly, the proposed changes take into account and include safeguards for situations where people care for someone with a severe disability who may never have been able to express their values and preferences, or have ever had decision making capacity.

Carers frequently report they find themselves in the position of making medical treatment decisions under time and emotional pressure on behalf of a person who may never have expressed a coherent view about the relevant treatment decision, or where meaningful conversations about future medical treatments have not taken place. Legal recognition of advance care plans will therefore help provide carers with a firm foundation for decision making

¹ 'Helen' (name changed to protect identity) contacted Carers Victoria in 2015 for advice and support on making a complaint to the hospital where her mother died.

consistent with their relative or friend's preferences, values and rights, and recognise the role of carers in supporting decision-making in the context of a care relationship.

Community awareness and workforce development

As identified in the position paper, a legal framework ensuring advance care plans are respected will only be effective if more people take up the option of completing a legally binding directive. Substantial community awareness and education will be required and will need to be targeted towards both people who want to ensure their treatment wishes are respected and people who anticipate giving effect to the values and wishes of a relative or friend. The framework will need to be supported by ongoing professional and workforce development to assist health and allied health practitioners to initiate, conduct and document advance care planning discussions with health consumers and their carers.

Emphasis on preferences and values

People in care relationships know through their lived experience that the health status of both the person receiving care and the carer can change rapidly and many future conditions and/or their medical treatment may not be anticipated. Carers Victoria supports the distinction between instructional directives and values directives, and the emphasis on preparation over time in consultation with health practitioners, family and friends. Carers Victoria recommends the proposed legislation should state; where people are involved in a care relationship, carers should always be involved in the preparation of an advanced care directive, except where the person receiving care explicitly requests they are not involved. This will help to ensure carers are in the best position to act in accordance with their relative or friend's values and preferences, regardless of whether they have also been appointed as a decision-maker or supporter.

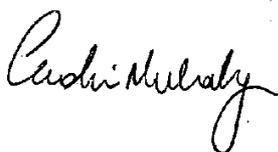
Medical treatment decision-maker hierarchy

In relation to the proposed medical treatment decision-maker hierarchy listing 'the primary provider of care and support (excluding paid care providers)', Carers Victoria recommends it should instead list 'the primary carer (person providing the most assistance within a care relationship)' in order to be consistent with the Victorian Carers Recognition Act 2012 and the Australian Carer Recognition Act 2010. The exclusion of paid care workers should be included in the introductory statement regarding 'the first of the following with a close and continuing relationship with the person (excluding paid care providers)'.

Carers Victoria seeks to reduce the enduring negative emotional impact of medical treatment decisions on carers like 'Helen' where their caring role and relationship have not been respected. We support the proposed legislation in the expectation this will benefit many of the 774,000 carers across Victoria when they too are faced with making the most difficult decisions.

Please do not hesitate to contact me for any further information.

Yours sincerely



Caroline Mulcahy
Chief Executive Officer