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ACD Framework Consultation Project
Attention: Geoff Bloom
C/- HWL Ebsworth Lawyers

Dear Mr Bloom

National Seniors' comments on the Draft National Framework for Advance Care Directives in Australia

National Seniors Australia (NSA) is the largest organisation representing Australians aged 50 and over with some 280,000 individual members. Our members are from metropolitan, regional and rural areas across all states and territories, and are broadly representative of the three key ageing cohorts: those aged 50-65; those aged 65-75; and those aged 75 +.

National Seniors does not claim legal or medical expertise to inform its comments on the Draft National Framework for Advance Care Directives. We appreciate the efforts made to bring cohesion and consistency to Advance Care Directives (ACDs) from a legal and medical perspective. In drafting its comments, National Seniors has sought responses to the Draft National Framework for Advance Care Directives from members with a policy interest in advance care directives, palliative care and euthanasia.

ACDs care directives continue to be linked in many people's minds with euthanasia. Our members appear to be divided on the subject of euthanasia in a polarised way to the extent that those who oppose the legalisation of euthanasia are distrustful of ACDs.

The members who responded to the document of the Draft National Framework for Advance Care Directives in Australia essentially raised three issues:

- The need for the framework to be explained to healthcare consumers;
- The need for ACDs to focus on quality-of-life outcomes;
- The need for ACDs to be part of healthcare consumers' medical file.

ACD framework and healthcare consumers

The draft ACD document states that it "is primarily intended to inform policy-makers of the key ethical and practical aspects of ACDs and so is not aimed at the general public."

Members commented that it was just as important for healthcare consumers to be informed in this regard. Some of the case studies told of ACDs containing instructions that were plainly irrelevant in the circumstances in which the ACDs were consulted. Healthcare consumer awareness of, particularly, the practical aspects of ACDs could have prevented this from happening.

Members thought that, on completion of the consultation process, the ACD framework should be the subject of a public education campaign.

ACD framework and quality-of-life outcomes

Members commented on the need for ACDs to specify, in positive or negative terms, the quality-of-life outcomes at the end or as part of medical treatment. It was felt that many people who draft an ACD

focus on the medical treatment itself, substituting in their minds medical treatment with medical/quality-of-life outcomes.

There was even suggestion of ACDs being limited to specifying quality-of-life outcomes. The example was given of one of the case studies in the document where an ACD specified that the person on no account wanted intubation, where the specification should have read that the person did not want medical treatment at the end of which they would find themselves in high level care in a nursing home. The point about quality-of-life outcomes also highlights the need for public education.

Members, however, also commented that it may seem straightforward to say what is and what is not tolerable, but that nothing can prepare anyone for how they will feel when their instructions in their ACD are about to be followed.

ACDs and medical files

Members were very concerned that their wishes documented in an ACD might be ignored simply because the ACD was not available when needed.

Members appreciated the practical difficulties in setting up effective registers and also noted that people's medical records tend to be dispersed among a myriad of medical practitioners. However, members noted the development of electronic medical files and the ability to centralise medical records in that way. The suggestion was that ACDs could be appended to or form part of a person's medical records, so that it would be more likely than not be on hand when needed.

Yours sincerely



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Paul Versteege
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National Seniors Australia

21st October 2010