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NSW Department of Health

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Dear Ms Letts,

Carers NSW welcomes the opportunity to comment on the Conflict Resolution in End of Life Settings (CRELS) Project Working Group Report.

This submission will provide some feedback on the Report.

About Carers NSW

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

The core work of Carers NSW is to:

- Be the voice for carers in NSW
- Undertake research, policy development and advocacy
- Provide carer services and programs
- Provide education and training for carers and services providers
- Build capacity in the sector.

Carers NSW vision is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by their communities and by governments.

The goal of all of the work Carers NSW undertakes is for carers in NSW to have improved opportunities and access to services that meet their needs regardless of their age, gender, circumstances, location or cultural and linguistic backgrounds.

Who Carers NSW represents

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful. Across NSW there is an estimated 750,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

Key statistics about caring in NSW

According to statistics on carers from the Australian Bureau of Statistics 2003 Survey of Disability, Ageing and Carers (SDAC):

- Approximately one third of all carers in Australia live in NSW
- 40 per cent of primary¹ carers cared for a partner, 29 per cent for a child, 32 per cent for other (eg sibling, parent)
- Women aged 45-54 years were the largest single group of carers
- 45 per cent of primary carers provided 40 hours or more care per week on average
- 78 per cent of primary carers lived with the person they supported
- 75 per cent of carers were of workforce age although 45 per cent were not in the workforce
- 55 per cent of primary carers relied on a government allowance or pension as their principal source of income²
- 4 per cent of all people under 25 (90 200) in NSW are young carers.

Carers NSW comments on the CRELS Project Working Group Report

Carers NSW is pleased that the CRELS Project Working Group Report recognises the importance of communicating better with families to avoid and resolve conflicts in end of life settings. However, Carers NSW is disappointed that the Report demonstrates so little consideration of the role and needs of carers in particular, instead only referring to 'families'. It is concerning that the lack of consideration given specifically to carers in the report may be reflected in its outcomes. While carers and families interests often coincide, the experience of caring is unique and has implications for the interaction of the patient and the carer in the health system, including in end of life settings. Carers NSW believes that the Report and its recommendations could have better recognised carers and caring relationships, and supported the acceptance of carers as partners in care, as per the NSW Carers Action Plan 2007 – 2012 and the NSW Carers Charter from the NSW Carers (Recognition) Bill 2010.

The Report makes recommendations which require long-term cultural and systemic changes. This is a valuable opportunity to also support the long-term cultural and systemic changes required for the better recognition and support of carers, while effectively addressing the specific goals of the Working Group. Ensuring that carers are recognised, respected, valued and supported, and that carers are partners in care, would have benefits both within end of life settings and across the health system.

Carer recognition

Carers NSW is pleased that the Report recognises the importance of working with families, and that it has identified a comprehensive range of approaches to facilitate this. It is also gratifying to see recognition of the different needs of Aboriginal and Torres Strait Islander families and of families from culturally and linguistically diverse backgrounds.

The Report defines family as:

¹ A primary carer is someone who takes on the main caring responsibilities of a care recipient. Australian Bureau of Statistics defines a primary carer as a person who provides the most informal assistance on an ongoing basis, to another person who is restricted by one or more core activities in the areas of communication, mobility and self care. A secondary carer provides informal care in a supporting role where either another family member or formal services provide the majority of care.

² ABS (2004) Survey of Disability, Ageing and Carers (SDAC) Summary of Findings, Australian Bureau of Statistics, Canberra

“...those closest to the person in knowledge, care and affection. This includes the immediate biological family; the family of acquisition (related by marriage/contract); and the family of choice and friends (not related biologically or by marriage/contract). It may include the ‘person responsible’, other relatives, partner (including same sex and de facto partners), or close friends according to any expressed wish of the patient...”

Although carers would meet this definition of family, Carers NSW believes that this definition should explicitly recognise that often one (or more) of the patient’s family will be their carer, and differentiate between the experience of a carer, and a family member who is not a carer. The definition should recognise the distinct role played by a carer, and the expertise, experience and impacts that the caring role entails.

Carers NSW also feels that the definition of family should include acknowledgement of the diversity in age that may exist in families, and the role that children and young people may play as carers. This is an issue that will need to be addressed in relation to family conferences and decision-making in end of life settings, as discussed below.

Recommendation 1: That carers are explicitly recognised, valued and respected in all policy and training implemented for better conflict resolution in end of life settings.

Carers are partners in care

While in some cases it is acceptable to reference and address ‘families’ only (if the definition of family is changed as above to explicitly recognise carers), at times it will be necessary for policy or training regarding conflict resolution in end of life settings to specifically address carers and their role as partners in care. For example, discussion of quality of life judgements by health professionals (section 4.4.4), and any initiatives to address this issue must include recognition that many patients with chronic, degenerative disease and disability have carers, who have valuable insight into such judgements and should be partners in care in end of life settings, as in all care settings. As the NSW Government has recognised in the NSW Carers Action Plan 2007 – 2012,

“Carers play a crucial role as care partners. They are often experts in the care of the person requiring care and can assist with care planning and delivery, with the agreement of the care recipient.”

Carers are partners in care is a Priority for Action under the NSW Carers Action Plan 2007 – 2012, and could be better implemented through the recommendations of the Working Group, to the benefit of conflict resolution in end of life settings. For example, the best practice advice on how to plan for and run effective end of life family conferences recommended in Recommendation 5.2.1 should include recognition of carers and of their role, to ensure their inclusion in end of life family conferences. The communication skills programs recommended in 5.6.1 and 5.6.2 must also recognise carers, and support the Priority for Action Carers are partners in care. It is vital that doctors, nurses and allied health professionals are aware of the role of carers and of the importance of working with carers, and that they are equipped with communication skills that enable them to work effectively with carers, as well as with other family members without caring responsibilities.

Recommendation 2: That greater consideration is given to the role of carers as partners in care in initiatives relating to conflict resolution in end of life settings, particularly in those relating to communication skills development.

Young carers and family members

Carers NSW is concerned that the Report makes no mention of the involvement of young carers (carers aged under 26) or young family members in end of life settings. It is possible that this has not been a factor contributing to conflict in end of life settings to date, perhaps because children and young adults are not often involved in decision-making in end of life settings or indeed in other health care settings. There exists a strong cultural expectation that children are care recipients, not the providers of care. As a result young carers are often ignored by health and medical professionals, despite the detailed knowledge and expertise they may have of the patient's needs and quality of life, and the implications treatment decisions may have for their caring responsibilities³.

Carers NSW believes that in light of the critical contribution of young carers to the care of the patient, their expertise, and the serious implications that treatment decisions can have on their caring responsibilities and wellbeing, the recommendations of the Working Group should address the role of young carers in end of life settings. Greater awareness of young carers is vital to ensure that; their expertise and opinions are valued and respected, their support needs are met, and they are not burdened with inappropriate levels of care or responsibility. The best practice advice for end of life conferences recommended in 5.2.1 should include advice for the appropriate and respectful involvement of young carers and family members.

Recommendation 3: That best practice advice for end of life conferences include advice for the appropriate and respectful involvement of young carers and family members.

Gay, lesbian, bisexual, transgender and intersex (GLBTI) carers

It was pleasing to note that the recognition of same sex relationships in the definition of family used in the Report, despite there being no specific discussion of the involvement of GLBTI people in family conferences or end of life settings. A recent study by Alzheimer's Australia suggests that at times the 'family of origin' of a patient may not accept their sexuality or gender identification, and may exclude the partner or carer of the patient from decision-making relating to their care⁴. Many GLBTI people, particularly older people, are estranged from their parents and siblings and have closer relationships with their friends and partners on whom they rely upon for care and support⁵. Carers NSW recommends that the best practice advice regarding end of life conferences ensure that it is those who are truly 'closest to the person in knowledge, care and affection' who are included in family conferences and decision-making and that the caring relationships of GLBTI people are recognised.

Although the Report did not include in-depth discussion of the issues relating to substitute decision-makers, Carers NSW is pleased to see the focus on improving identification of appropriate substitute decision-makers. It is important that any tools developed to improve substitute decision-maker identification do not discriminate against same-sex relationships. In end-of-life settings and after death same-sex partners are sometimes excluded from decision-making by the 'family of origin' of the patient⁶. Initiatives to improve identification of substitute decision-makers need to take into account the needs of GLBTI people and recognise the different caring relationships that GLBTI people may have, which include same-sex partnerships and informal friendship networks.

³ FaCHSIA 2009, Young carers in Australia: understanding the advantages and disadvantages of their care giving, Canberra.

⁴ Alzheimers Australia 2009, Dementia, Lesbians and Gay Men, Melbourne.

⁵ ACON 2006, Ageing Disgracefully: ACON's healthy GLBT ageing strategy 2006 – 2009, Sydney.

⁶ Alzheimers Australia 2009, Dementia, Lesbians and Gay Men, Melbourne.

Recommendation 4: That best practice advice for family conferences ensures that those closest to the patient in knowledge, care and affection are included, irrespective of sexuality or gender.

Recommendation 5: That tools developed to identify substitute decision-makers do not discriminate against GLBTI people.

Key recommendations

Recommendation 1: That carers are explicitly recognised, valued and respected in all policy and training implemented for better conflict resolution in end of life settings.

Recommendation 2: That greater consideration is given to the role of carers as partners in care in initiatives relating to conflict resolution in end of life settings, particularly in those relating to communication skills development.

Recommendation 3: That best practice advice for end of life conferences include advice for the appropriate and respectful involvement of young carers and family members.

Recommendation 4: That best practice advice for family conferences ensures that those closest to the patient in knowledge, care and affection are included, irrespective of sexuality or gender.

Recommendation 5: That tools developed to identify substitute decision-makers do not discriminate against GLBTI people.

Conclusion

Carers NSW thanks NSW Department of Health for the opportunity to comment on the Conflict Resolution in End of Life Settings Project Working Group Report.

If you require any further information about Carers NSW response to the policy, please contact Alison Parkinson on 02 9280 4744 or email alisonp@carersnsw.asn.au.

Yours sincerely,



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Carers NSW