

24 August 2016

Australian Commission on Safety and Quality in Health Care  
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To whom it may concern

**Consultation on the draft *National consensus statement: Essential elements for safe and high-quality paediatric end-of-life care***

Thank you for the opportunity to comment on the draft *National consensus statement: Essential elements for safe and high-quality paediatric end-of-life care*.

PCA supports the development of a statement specific to the care of children with life-limiting illnesses. PCA has been provided opportunity to give feedback on previous iterations of this document, with many of these suggestions being incorporated into this version of the document. We have provided the consultation draft to our members, and have the following feedback for your consideration:

- Reference to and recognition that services may be required for children who are in detention whether that be corrective serves or as a refugee, as well as to children that may be in the protection of children's services and the challenges this can bring
- The language in relation to "boyfriends and girlfriends" doesn't feel that contemporary and probably leans into a wider issue which is the recognition of needs of LGBTI children.
- Stronger support for clinicians in relation to the very real challenges around confidentiality particularly when working with adolescent children.
- As per our previous comments, there remains reference to the death of a child as being rare. This may be uncomfortable to read for people who have experienced a child's death.
- The definition of interdisciplinary team refers to hospital volunteers, but volunteers are not mentioned elsewhere in the document. It is suggested that this is changed to 'volunteers' rather than 'hospital volunteers' as the volunteers may be part of a community service. It would also be good to mention volunteers in the list of partners in paragraph one on page two.

PCA looks forward to continuing to working with the Commission. If you have any queries about the content of this submission please direct them to Philippa Kirkpatrick, National Policy Manager on [philippa@palliativecare.org.au](mailto:philippa@palliativecare.org.au) or phone 02 6232 0705.

Yours sincerely

A handwritten signature in black ink, appearing to be 'Liz Callaghan', with a horizontal line extending to the right.

Liz Callaghan  
Chief Executive Officer  
**Palliative Care Australia**