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To whom it may concern

### **Aged Care Financing Authority Respite Care Consultation**

The availability of appropriate respite care options for people receiving palliative care is an issue of high importance to Palliative Care Australia (PCA) and we are pleased to see specific reference to palliative care within the Respite Care Consultation Paper. PCA is the national peak body for palliative care in Australia, providing leadership on palliative care policy and community engagement. Working closely with consumers, its Member Organisations and the palliative care and broader health workforce, PCA aims to improve the quality of life and death for people with a life-limiting illness, their families and carers.

Palliative care is for people of any age who have a life-limiting illness that cannot be cured. Dying is a normal process with palliative care offering a support system to help people to live their life as fully and as comfortably as possible until death and to help families cope during this illness and in their bereavement. As the Consultation Paper notes, respite care provides support for carers and the people they care for, and therefore should be an integral component of palliative care.

**Unfortunately the current system is not suitable for people receiving palliative care and their specific needs. In general, those receiving palliative care that are eligible for current packages and access requirements can, on paper, receive respite care however in reality the delay in getting access is often time prohibitive and people either die or are too unwell to use it.**

The system for allocating respite bed days to residential care providers places the supply of respite beds with the independent facilities, and as the cost of supplying a respite bed is greater than a non-respite bed, PCA believe this leads to a negative effect on respite bed availability. Demand for accessing respite services is high, and access to emergency respite is very limited. PCA has received advice from palliative care services that planned respite wait lists are untenable, for example in one jurisdiction a person receiving palliative care is unable to receive respite until November 2018.

Emergency access to respite care is extremely difficult to facilitate, and what is available often requires at least two weeks 'notice' in these time sensitive 'emergency' situations. These time delays are compounded by unclear and varying application process across locations, and what is often occurring when a carer is unable to provide care, is a hospital admission or entry into residential care earlier than planned and not in alignment with the wishes of both the person and

their family/carer. The process of entering residential care also have delays which are not acceptable to a person receiving palliative care, where 84 days (AIHW, Aged Care Data) was the average time in 2015-16 between approval and entry into residential care. PCA is often informed of instances where people have died on entry into residential aged care before an Aged Care Funding Instrument assessment has taken place.

On the issue of funding models, information provided to PCA indicates that while there is networking between aged care services and palliative care services, activity-based funding has created a competitive market, territorial practices and limited cross program interactions. While PCA believe the majority of funding within the aged care system should follow the consumer, alternative funding options may be required, and funding of carer support needs should be available to carers directly and not just as a by-product of the package received and controlled by the person they care for.

The emotional cost of the current assessment and process of accessing respite care is often bewildering and confusing for carers whom, by the very nature of requiring access to respite care, are often already extremely tired, stressed or burnt out, compounded by feelings of guilt and loss when their loved one enters respite care. Carers want help that is high-quality, responsive, culturally appropriate, addresses the needs of the person they care for, respects their individuality, is delivered with respect and compassion, and promotes a good quality of life.

The involvement of the carer, where necessary, in the assessment process is essential to recognise and support the role of the carer. PCA highlight that a critical factor in this is a person and their carer/family having a reasonable level of health and system literacy that allows them to understand, access and navigate the system.

PCA supports the Recommendation made in the Legislated Review of Aged Care 2017 Report, in particular the need to ensure adequate supply and equitable access to residential respite care, however, this must be addressed within the context of the specific needs of people receiving palliative care. PCA recommends that a targeted consultation with the palliative care sector be undertaken to assist in informing the future models of respite care, including consideration of:

- Specific funding allocation for the provision of respite care to someone receiving palliative care,
- Specific referral pathways under any package for emergency respite that is provided in a timely manner,
- The complexity of care required which will also determine the discipline/profession of the respite carer,
- Improved access to training, where staff will need to be well trained to deliver appropriate respite care to someone receiving palliative care.
- Adequate resourcing of respite care services to deliver and/or support the delivery of palliative care, which includes access to specialised equipment and materials to manage pain and provide symptom relief.

Caring for someone at the end of life can be a rewarding experience, and needs to be appropriately supported through available and appropriate respite care. If this is not available there is the potential to increase strain on the carer by creating more problems to be coped with after the respite period, such as a decline in the care recipient's condition, decreased likelihood of accessing respite in future and implications related to grief and bereavement. It is also important to note that the provision of respite care alone is not a panacea, where there is a need to develop a package of services that may benefit the carer in their role of supporting a person receiving palliative care.

Please do not hesitate in contacting Kelly Gourlay, National Policy Advisor, if you would like to discuss these issues further at [kelly@palliativecare.org.au](mailto:kelly@palliativecare.org.au)

Kind Regards



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