



To:
Committee Secretary
Senate Standing Committees on
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Dear Committee Secretary

Cancer Voices SA is pleased to offer a submission to the Inquiry into Palliative Care in Australia, referred to the Senate Community Affairs Committees on 23 November 2011 for inquiry and report.

Our submission is primarily a series of comments and concerns raised by people affected by cancer, reflecting the confusion and misunderstandings around what palliative care is, what it does mean or should mean to receive care with palliative intent, what services are available, how to access services, and issues around poor coordination of services and the intersection with cancer care, palliative care and aged care:-

1. There is **poor understanding in the community of what 'palliative care' means** and it is generally interpreted as meaning '*end of life care*', eg. "nobody walks out of that door once they go in". Palliative care is a term feared by many.
2. The cost (financial, physical, emotional) around palliative care is often borne by a carer who is in poor health themselves. The personal cost appears inequitably borne by those on a low income. This can be due to limited information of options and supports that may be available.
3. Palliative care often involves **disconnected services that don't fit together well**, even if you know what all the pieces of the puzzle are that are available! Perhaps people in roles as 'Palliative Care Coordinators' or Navigators could assist the process to be more streamlined? Is there a Palliative care system or are there multiple different systems run out of different hospitals, local areas, regions and states?
4. 'Patient centred care' is needed with options for funds to address the person's needs, rather than trying to fit the patient into a fixed 'care package'. 'Patient centred' should also mean that the patient has some say in decisions, rather than a 'patient centred' solution being chosen for them.
5. Problems arise when people have an aged care package and then require additional services for palliative care. It seems you can't mix aged and palliative services to achieve a seamless transition as the patient's condition deteriorates.
6. Problems arise for younger people re: accessing age appropriate palliative care.

7. What is available for people with behavioural problems arising from their condition eg young people with a brain tumour causing aggressive outbursts. They can be young, fit and strong, and be too difficult to manage at home around a young family.
8. During 'Cancer Conversations', many Aboriginal people reported their relatives dying from cancer in excruciating pain. It is a concern that adequate access to palliative care services failed these people.
9. For many consumers, there is **no clarity around the referral criteria or referral process**. In order to get 'assessed', consumers often don't know the right words to trigger understanding of what they are asking for. Who can refer? When to refer? How to refer? What can a client or relative do? What can a GP, district nurse or domiciliary care worker organise?
10. There may be many different health professionals involved in a patients care, but no one seems sure who has 'key responsibility' for that persons care or who can refer.
11. Palliative care is primarily activated for the last 2-6 months of life, but how do you know if you're there yet? Even in cancer, where the trajectory of deterioration and decline to death is more predictable, this can be difficult to judge.
 - 11.1. - there appears to be limited numbers of palliative care 'places' and getting a palliative care facility place at the time you need it seems to rely on 'who you know' . In addition to the stress and upset that a family member has reached the point of needing assistance with 'end of life' care needs, families are faced with personally having to try and navigate a confusing system to try and put together a 'care solution'. No-one seems to have the role to coordinate or help families navigate or access the services they need at this time! How does a person without close family support get by?
 - 11.2. - respite care places, palliative care places, aged care places .- these all seem to have separate assessment processes and clumsy criteria that doesn't assist transitions.
12. Particularly for family members guiding a loved one through palliative care, even the 'little things' can become lasting issues of regret during the final days of life. It can be astonishing that palliative care staff cannot be more helpful or capable of putting themselves in the shoes of others eg. where family has to ask for an air-bed to relieve pressure sores, ask for a nebuliser to moisten the mouth and airways of a patient parched by a continuous oxygen mask. Families 'don't know what they don't know', are new to the palliative care setting, and often don't know where to find information they need to make their loved one as comfortable as possible in their final period of life. You only get one chance to get it right for your loved one to have 'as good a death as possible'.
13. Facilities are under so much funding pressure that family often only have a very short time interval (e.g. 2 hours) in which to empty a room after being notified that the patient has died, before the next occupant moves into the room.
14. Complementary therapies can be very helpful in palliative care, but accessing reputable services can be challenging. Credentialing of practitioners and the myriad schools of complementary therapies would help ensure minimum standards for this unregulated group of services.
15. Holistic palliative care needs to take account the physical symptoms and psycho-social issues. The medicalisation of palliative care ensures that physical symptoms are heavily weighted as the criteria for referral into Palliative care services.

16. Psychological support services appear to be scarce in Palliative Care, with heavy reliance on religious counseling. Is this a funding or workforce issue, or combination of both?
17. We recognise that family as well as the patient needs are being taken into account. It can be a difficult balancing act for medical staff to keep someone alive while the family comes to terms with the situation and are ready to 'let go'.
18. Consistent use of tools such as the Carers' Support Needs Assessment Tool could help assist carers needs to be identified and addressed.
19. Timely access to Respite Care for the patient or the carer is often not easy to achieve currently. Respite can be 'time limited', leaving families without options if ongoing care or transfer to higher level ongoing care is required after the 'respite' limit has expired and no alternative care places are available. This is especially a problem in rural areas.
20. Finally, there are some good palliative care information resources available e.g. CareSearch (<http://www.caresearch.com.au>) and maintaining these are important for consumers and health professionals. Involvement in the development process as well as the use of the final resource product has achieved better shared understanding between groups who don't often get the chance to collaborate.

Cancer Voices SA is an **independent**, not-for-profit, **100% volunteer organisation**, formed in 2007. We are **'raising a voice for those affected by cancer'** through **advocacy, involvement, awareness and information**. We cover all types and stage of cancers across all ages, social circumstances, gender and locality. Our focus is on wellness and not just illness.

Membership is free and open to all South Australians eg cancer patients, their partner, carers, family, friends, neighbours, colleagues and supporters because 'Cancer doesn't affect one person, it affects the entire community around them'. Having cancer is not a pre-requisite for membership.

The Cancer Voices SA membership continues to grow and has now reached about 800. The organisation is led by a 10 member Executive Team.

We aim to be representative, responsive and respectful of the diversity of our grassroots members background and experiences, and we try hard to hear those views. We have regular engagement and interaction via our websites (www.cancervoicessa.org.au and www.cvsacyclingteam.org.au), events, social media ([Twitter @CancerVoicesSA](#), [FaceBook – CancerVoicesSA](#), [YouTube](#)), and physical activity initiatives.

Thank you for the opportunity to contribute to this inquiry.

Yours sincerely

Julie Marker
Deputy Chair, Cancer Voices South Australia. 23 March 2012