



**SUBMISSION TO
SENATE INQUIRY INTO
PALLIATIVE CARE**

Prepared by National Policy Office

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COTA Australia

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INTRODUCTION

COTA Australia is the national policy arm of the eight State and Territory Councils on the Ageing (COTA) in NSW, Queensland, Tasmania, South Australia, Victoria, Western Australia, ACT and the Northern Territory.

COTA Australia has a focus on national policy issues from the perspective of older people as citizens and consumers and seeks to promote, improve and protect the circumstances and wellbeing of older people in Australia.

COTA's policy work is guided by five policy principles:

- maximising the social, economic and political participation of older Australians;
- promoting positive views of ageing, rejecting ageism and challenging negative stereotypes;
- promoting sustainable, fair and responsible policies;
- focusing on protecting against and redressing disadvantage; and
- protecting and extending services and programs that are used and valued by older Australians.

COTA Australia welcomes this Inquiry as palliative care is an issue of great importance to older people and is often raised in forums hosted by COTAs around the country. In the Minister for Ageing's 'Conversations on Ageing' with older people in 2011 around aged care reform it emerged as a key area of concern for many older people. The Minister for Ageing also asked the Expert Reference Group on Ageing for advice on this issue and its advice is in the National Aged Care Alliance (NACA) Aged Care Reform Series paper on palliative care¹. COTA was a leading participant in the development of that paper and endorses its recommendations.

COTA also put out a call for input into its submission from its members in its national ONECOTA magazine and we have received an unprecedented response to that call. Those responses and the issues raised in COTA forums and with the Minister cover a wide range of concerns with palliative care which align with the broad terms of reference for the Inquiry.

COTA endorses the World Health Organisation's definition of palliative care. We would like to emphasise the need for palliative care to include not just the person dying but their family, friends and other support networks and that good palliative care extends beyond the death of the patient in providing grief and bereavement services to those people.

COTA was included in the consultations that informed the development of the 2010 National Palliative Care Strategy and is supportive of that Strategy. It is clear from the issues raised with us that there is no nationally consistent approach to palliative care. We are hopeful that this Inquiry will assist with the process of getting the principles and objectives from the Strategy implemented across Australia to ensure greater consistency and to provide people with the assurance that appropriate palliative care services will be available when they need them.

Our Submission is informed by the input from our members and the broader older population. We would like to thank those people who gave us their stories and agreed to include them in this submission as we know for many of them this was not an easy thing to do.

¹ NACA 2012, Aged Care Reform Series-Palliative Care , www.naca.asn.au/Age_Well/Palliative_care

RESPONSE TO TERMS OF REFERENCE

We do not address all the terms of reference but concentrate on the issues of most concern to the older population.

Access and choice

COTA believes that all Australians should be able to expect to die with dignity and have as much control as possible over the circumstances of their death including being with the people they wish to be present and, whenever possible, in the place of their choice.

There are three issues with regard to access and choice that we want to raise. The first is information, the second is eligibility and the third the location of that care

a) Information

For people to be able to make choices about what services they use they need to know what is available and this is why increasing awareness and understanding of palliative care is one of the four goals of the National Palliative Care Strategy.

Palliative Care Australia through its *Let's chat about dying* and other initiatives has improved significantly the community's awareness of palliative care, what it does and what services are available. However more needs to be done as it is clear that many people do not have a good understanding of the range of palliative care services that could be available and how to access them. This is particularly true of non-cancer patients.

This lack of understanding means that sometimes people do not ask for a referral to a palliative care service and sometimes refuse one when it is suggested. Palliative care is often seen as end-of-life care. People do not want early referrals sometimes because they fear that it means "not everything will be done" and they are not yet ready to give up hope.

COTA believes that there needs to be more effort put into raising awareness in the broader community at the local level amongst people who are not facing the need for services at the moment. There are many models for doing this and one might be a peer education model where older people go out to community groups of older people to talk about the issues. COTA through the State and Territory COTAs runs similar models for *beyondmaturityblues* and the quality use of medicines programs and they have proven successful in getting important health related messages out to the older population. Such sessions could also be useful in providing information about advanced care planning.

Health services and health professionals need to do more to promote the benefits of palliative care by giving individuals and their families information early on in their illness and ensuring they receive an appropriate referral.

b) Eligibility

There has been a tendency in Australia for palliative care to be viewed as only being available for people dying from cancer. It has been seen as time limited and often available only in the last few weeks or months of a person's life. Some of the funding models put time limits, usually no more than three months on services and resources are not available for to support people through longer periods.

COTA believes we need to ensure that palliative care is made available to everybody that has a terminal illness and supports the view that the palliative approach commences at the time of diagnosis or acknowledgement that the condition is terminal. Obviously the intensity of support and care will change with the progression of the disease but it is clear from the stories we have heard that people who make contact with a palliative care services earlier in their illness feel more supported and more able to come to terms with dying.

One correspondent wrote *“My wife had good palliative care. I was very happy with the treatment and believe it is the ‘only way to go’ and it destroyed any fears I had of dying”*²

We believe there cannot be a one size fits all approach to palliative care; the illness and the circumstance of the individual need to be taken into account.

A number of people have commented that they believe people with dementia do not get good access to palliative care. The NACA paper makes the following point “Dementia care as palliative care requires a different approach than palliative care for conditions such as cancer as the process will take place over a longer period of time, involves early engagement in advance care planning, and requires more flexibility than palliative care approaches to other diseases.”³ This view is echoed in Alzheimer’s Australia’s submission to the Inquiry. COTA supports their views and recommendations.

People with other degenerative conditions such as motor neurone disease, multiple sclerosis, emphysema often do not get access to palliative care. The people with the disease and their family and support networks need support and to hopefully establish a longer term relationship which allows families and friends to provide care for longer. As a member from Queensland wrote *“Beryl had emphysema, had several hospital stays over a six month period and was put on to oxygen therapy. Nobody explained the illness and no one mentioned palliative care.”*⁴

This lack of access is in part due to lack of resources. It is clear that if access is to be improved then there will need to be more funding for palliative care. Resource allocation models need to take into account the full burden of disease of people who could benefit from palliative care to ensure adequate resourcing.

It is also due in part to reluctance by some medical professionals to refer people to palliative care, especially non-cancer patients. As the Beryl story indicates we still have a long way to go in getting some medical professionals to discuss the terminal nature of their illness with patients. This reluctance inhibits individuals’ choices of treatment options and often denies them access to the support and care they so desperately need. We support measures to improve training in palliative care for all health professionals to help improve referrals and care for people.

c) Location of care

A consistent theme from our consultations is that everyone wants to choose where they receive palliative care and where they die. There are a number of factors that affect people’s choice of setting and preferences change through the course of their illness and treatment. It is important not to assume that everybody wants to die at home or that everybody who wants to is able to. We need to have care and funding models that support those choices.

² COTA member in South Australia

³ NACA 2012, Aged Care Reform Series-Palliative Care
http://www.naca.asn.au/Age_Well/Palliative%20care.pdf

⁴ COTA Queensland member in correspondence

There are four possible settings for palliative care: at home in the community, a hospice, a hospital or a residential aged care facility. Not all options are available in all locations. In rural and remote areas attracting and retaining staff, especially for the mining states, is an ongoing problem that limits the availability of a number of health services including palliative care.

The information below from COTA ACT illustrates not everybody can access care in their setting of choice even when such services are offered in an area.

In the ACT, people wanting and/or needing palliative care services have frequently been unable to access them in the environment of their choice be it the community, hospices or in aged care facilities. Anecdotal feedback suggests that the current hospice is often full and people are being accommodated in hospital facilities such as sub-acute or intensive care wards. Those people who are able to access the services of Claire Holland House (CHH), the only in-patient hospice in the ACT, generally report very well on their services. However, the bulk of palliative care services are provided in the community. This is supported by the statistics, CHH having only 19 beds and Community Palliative Care having 200 funded places. The latter has been the area of most rapid growth of demand and services, which has been unable to be met.

COTA ACT also makes the point that while the bulk of people who access home based palliative community care receive a very good service, there are others who have been very poorly served because of inadequate resources.

As well as the generic decision about location it is important that we take into account other factors which are important to people. We need to give more consideration to meeting individuals' preferences e.g. wanting a non denominational environment or a particular denominational service provider, convenience of location for family and friends. As a member from Queensland wrote *"The only palliative care place available for Dad was a palliative care service run by a Catholic order. There was a crucifix above the bed. When he asked for it to be removed as he is not a catholic he was told this was not possible. He became very distressed about this and kept asking to be moved."*⁵ This is something which should not happen in a service which is publicly funded and universally available and where the patient was given no choice about the service provider.

COTA supports having a broad group of service providers across all settings to deliver palliative care services. We just need to make sure that the services are delivered in a way that acknowledges the diversity of the people using them. We have to be realistic and accept that not everybody can have their ideal service provider and there needs to be more room for accommodating the needs of individuals

Effectiveness of palliative care arrangements

The National Palliative Care Strategy puts quality and effectiveness together as a goal. COTA's position is that effectiveness needs to look at the effectiveness of the four service types and the effectiveness of the system as whole to deliver good quality palliative care.

It is probably true to say that we do not yet have a national system for palliative care but rather a patchwork of services that do not always connect with the type and quality of services depending very much on where someone lives and how they access palliative care.

The demographic changes with a decrease in the supply of informal carers through increases in women's participation in the paid workforce and a decrease in the birth rate means that there needs

⁵ A COTA Queensland member in correspondence.

to be more dedicated palliative care services and community based services will need to be funded to use paid rather than informal unpaid carers. This may reduce choice for many people and indicates that we need to put more resources to dedicated palliative care facilities, including stand alone hospices, palliative care and hospice type wards in hospitals and residential care.

The story below from a member demonstrates the problems we face in ensuring there is good continuity of care and that people who need palliative care get it.

Brian entered the public teaching hospital (PTH) in June of 2011 with a cut hand after a fall. He had experienced shortness of breath and was being seen by our GP for emphysema who was monitoring this problem. At the hospital he was immediately taken to a care situation for his breathing difficulty. This was a good thing, as he was monitored and looked after in the emergency department. Things deteriorated to such an extent that he was placed in the Thoracic Ward where the family was able to visit him. We were told that he could not survive. The family came over from Sydney with the expectation that he about to die.

Once he was given no hope he was transferred to the eighth floor, a room with 6 or 8 beds (I can't remember the right number) and I could not stay with him as it was a men's ward. I could not even sit down beside him as there was no room. This for a man paying private costs and about to have his last night on this earth.

Thank God for my children, who contacted a Nursing Home attached to a facility where we had intended to have our home? He could get a bed, and we moved him at the first available time for palliative care. We are fortunate that we could afford the fees charged by this facility (God pity the poor people who would not have that good fortune). Within a couple of days Brian had rallied to such an extent, with the wonderful care he was given by his new Doctor and the Nurses, that he could recover.

Within a short period of time we could take him home. We had six months extra time with him to celebrate many family get-togethers and when he finally became too ill to continue, he was taken to the local private hospital where he had such wonderful care as did the family in a room set up for such an unhappy time . The difference between our experience at the PTH and the private hospital was so great that I would not wish anyone to die in the first institution.

How could the end of a life be treated with such inconsideration for a man's right to die with dignity?⁶

This story highlights a number of issues that are important to consumers when looking at effectiveness.

The first is that an acute area of a hospital is often not equipped to deal appropriately with patients needing palliative care. COTA would say that in this case it was also not good end-of-life care either. We received many similar stories with regard to palliative care in hospitals. COTA believes there needs to be more work done to improve the capacity of hospitals to provide palliative care and the referral pathways to move people to a more appropriate setting where possible. The new activity based funding model for hospitals will probably make them more likely to try to place palliative care patients in a sub-acute facility or residential aged which may be a better outcome for many people but not necessarily for all.

⁶ Story provided by COAT member with name of individual and changed and names of hospitals deleted.

The second is that people may need to move across different settings to get the palliative care they need. This man had care in three different facilities; two of which delivered care which the individual and family considered of good quality and met their needs. We assume there was some ongoing community based palliative care and some coordination to ensure when the time came he was moved to a hospital which could provide the appropriate care.

We think more thought needs to be given to palliative care patients' movements between services and the system needs to be joined together. There needs to be more resourcing for good care coordination and management so individuals do not have to find the next appropriate service. This is highlighted in the feedback from COTA ACT below.

The ACT Palliative Care service began as part of the ACT Community Nursing Service and provided a full range of services. The service was sub-contracted to Calvary Health Care in the 1990s, and after some time, the service model was changed to a consultative model, in which the Palliative Care staff act as advisors and referral for other services and the actual nursing of palliative care patients returned to the Community Nursing service of ACT Health. It has been suggested that this may have been due to the inadequacy of the funding of Calvary's Palliative Care service to cater to the growing demand.

For some patients in the community palliative care service, this consultative model is less than satisfactory and it does not meet the standards originally defined for provision of Palliative Care in the ACT. It would be much more straightforward if all services are provided by the one organisation and we (clients and carers) do not have the responsibility of negotiating to get the additional services we require from other organisations (such as the nursing care⁷).

The third is the capacity of residential and community aged care to provide good quality palliative care, clearly an important option for older people. This issue is addressed in the NACA paper which identifies the current barriers and disincentives to this happening and suggests a number of ways these barriers can be reduced or eliminated. We support those recommendations as they highlight the need for improved continuity of care for older people and they would enhance choice, help develop further community based palliative care and ensure adequate funding for aged care services to provide good quality care.

COTA believes health services need to work more cooperatively with aged care services to develop an integrated service for older people so their care follows them as they move between community, hospital and age residential aged care.

The National Palliative Care Strategy identifies consumer involvement in planning and design of palliative care services as one of the key ways to improve quality and effectiveness. Performance against this action is variable and it is one area where COTA would like to see more action. We support the idea of co-design where consumers and their families are included in the design of palliative care services, to identify what they want and where they want it. An important part of that co-design process would be a more systematic collection of feedback from users of palliative care. Of necessity this may come from families and friends after the death of a person. We have found such people are very keen to have their stories heard and to help improve the system; this goodwill and lived experience needs to be harnessed more effectively.

⁷ COTA ACT 2012 Input from COTA ACT Policy Council

Advance Care Planning

Older people have told us repeatedly they want to ensure that their wishes with regard to treatment, particularly at the end of their lives, are respected. They see the introduction of Advanced Care Directives (ACDs) as critical part of that process as it gives them the opportunity to record their wishes.

a) *Communicating care choices*

Many people put in place ACDs before they are sick but for many the realisation that they have a terminal illness provides the impetus to think about what treatments they want and how they want to die. COTA would like to see all palliative care services provide information on ACDs and support people to make decisions about their future care.

The Respecting Patient Choices program is an important initiative that works to encourage people to think about and document their wishes with regard to future treatment. Although the program is rolled out differently in different jurisdictions the basic model of having facilitators who discuss the options with people and help them prepare the necessary documentation to put those wishes into effect appears to be working well. For example COTA ACT gets several enquiries a week from older people who have heard of advance care plans and are seeking assistance and they are able to refer people to the respecting Patient Choices facilitators funded by the ACT government.

However more could be done to actively promote the program and to educate the broader community about the benefits of advance care planning. There needs to be a more systematic approach through hospitals, residential aged care and community aged care services all taking a more active approach to raising ACDs with their patients or at least encouraging them to have a conversation with the respecting Patients Choices facilitator if there is one.

In addition COTA believes there is value in having periodic community education on advance care planning to raise the issue for discussion with the broader community. We raised the possibility of a peer education model in the section on Information on page 2 and we believe it could be extremely helpful in disseminating information about ACDS.

a) *National consistency*

COTA Australia strongly supports the need for a national approach to Advance Care Directives that ensures the rights of all Australians to live well and die with dignity in accord with their personal values. Consumers' main concerns with ACDs are the need to ensure consistency and coherence across jurisdictional boundaries, and the need to raise awareness along with adequate training and support for both consumers and health care professionals in the preparation and use of Advance Care Directives. COTA believes it is imperative to ensure that any material and information developed is linguistically appropriate, culturally sensitive and respects the religious diversity of Australians.

In the COTA Australia submission to the AHMAC consultation process around developing national framework for advanced care directives we argued strongly for a robust national framework⁸. We welcomed the release of the national framework in September 2011⁹ and agree with the objectives for such a framework and the approach taken. The Code for Ethical Practice and the Best Practice Standards if fully implemented should both help to ensure more people know about ACDS, have a greater understanding of what they can be used for and will have more confidence that their wishes will be respected.

In our submission we raised concerns that the draft framework did not contain any performance measures and did not provide information on implementation. The final framework still does not address these issues. Without a robust monitored implementation plan that includes health professional and consumers within an identified national governance regime COTA finds it difficult to see what will drive reform and the adoption of the best practice standards.

COTA believes AHMAC should now develop and publish an implementation plan. As a minimum this plan should have an agreed timetable for mutual recognition of ACDs across jurisdictions and agreement to regular reporting on progress through AHMAC to Health Ministers.

b) Inclusion in personal electronic health records

In line with our desire to ensure people's choices for treatment are respected COTA believes that advanced care directives (ACD) should be included in the personally controlled electronic health record where one exists.

Older people have raised with us their fears that health professionals providing treatment and care will not be aware of their ACD and so they may receive treatment they do not want. In most jurisdictions health staff has to sight the ACD before it can be put into effect and in an emergency it may not be easily available.

Already, ACT residents have the ability to register their advance care plans in their ACT Health personal electronic health records through the Respecting Patient Choices program. Under this system, an alert comes up when a patient is admitted to emergency at the Canberra Hospital when a patient has registered their advanced care plan through the Respecting Patient Choices program. The emergency staff can then access an electronic version of that patient's advanced care plan.

COTA supports this type of system being extended Australia wide. Given that the Respecting Patient Choices is a national program, it would be well worth investigating where else in Australia this is occurring and exploring the potential for using this program as a base for having national advance care plans in personal electronic health records.

⁸ COTA 2010, Submission to the Draft National Framework for Advanced Care Directives, www.cotaaustralia.org.au

⁹ AHMAC 2011, A National Framework for Advanced Care Directives , www.ahmac.gov.au

CONCLUSION

At the moment it is clear that people's access to services is very much dependent on where they live. From the input we received most people were happy with the care they received although most could and did identify ways it could be improved.

COTA is looking for improvements keen to ensure that everybody who needs it has access to good quality palliative care when they need it and preferably where they want to have it. To achieve this COTA makes the following recommendations.

- Publication of an annual report on progress on the action areas identified in the National Palliative Care Strategy to improve accountability and to highlight areas needing more attention.
- Increased funding for a community awareness campaign on palliative care and end of life care to move the campaign to the local level. This would also include encouraging the use of advanced care directives.
- Development of and funding for integrated palliative care services to ensure all people with a terminal illness can access services. Consumers should be included in the design of such services.
- Funding for palliative should not be time limited and should allow for differing intensity of support as the individual's condition changes.
- Funding should be distributed across the various care settings in line with patterns of demand to improve the possibility of people having care in their setting of choice.
- An implementation plan for the national framework on advanced care directives with regular reporting on progress.
- Advanced care directive should be included in personal electronic health records.

COTA would welcome the opportunity to discuss these issues with the Committee and looks forward to seeing the outcomes of the Inquiry in September.