JOINT SUBMISSION TO

SENATE COMMUNITY AFFAIRS COMMITTEE INQUIRY

INTO

PALLIATIVE CARE IN AUSTRALIA

MARCH 2012

ECH Inc., Eldercare Inc. and Resthaven Inc. are three of South Australia's largest and most experienced providers of residential and community aged care and housing options for older people.

Our combined operations offer a comprehensive range of services and support to frail, older South Australians, including independent retirement living, Home and Community Care (HACC) services, community care packages, Transition Care, health and well-being services, respite and residential aged care. In all, we employ close to 4,000 staff and provide assistance to many thousands of residents and clients each year.

1. Introduction

All Australians should expect to be able to die with dignity, with as much control as possible over the place of their death, the type of care they will receive and the people present. Palliative care is often mistakenly regarded as end of life care, rather than the more holistic view of palliation as adopted by our organisations, which is consistent with the World Health Organisation's definition:

"Palliative care is an approach that improves the quality of life of (residents) and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

As argued by the National Aged Care Alliance (NACA) in its Aged Care Reform Series paper, 'Palliative care is often markedly different from the mainstream medical approach that focuses on curing illness and protecting life as an over-riding priority.'[1]

For providers of residential aged care in particular, palliative care should be 'core business' but all too often, staff are poorly equipped and services under-resourced to provide quality palliative care. The management of chronic and debilitating illnesses can have a serious effect on the ability of the older person to live a quality life. The recognition that older people requiring residential care have palliative care needs must be supported by adequate resourcing and a co-ordinated approach by health services. The situation for community care services and their clients is even more difficult.

[1] http://www.naca.asn.au/Age_Well/Palliative%20care.pdf

2. Access and Choice

Many factors influence access to and choice of appropriate palliative care that meets the needs of older people, among them being:

- older people with dementia becoming more and more limited in their ability to exercise informed choices about their care; and residential care or hospitalisation can become the only options for many;
- lack of staff education and training;
- lack of appropriate equipment;
- poor access to GPs;
- limited or no access to some PBS-subsidised medications;
- lack of coordination between aged care and specialist services;
- hospitalisation often being the default option;
- insufficient and inflexible Federal and State funding;
- limited use of advanced care planning;
- restrictive funding program guidelines (including time limits);
- inappropriate aged care accreditation standards; and
- poor access to specialist consultancy services.

Most older people would prefer to die at home but access to quality home-based palliative care services is difficult. Locum costs are high and after hours access to GPs is poor. As a result, many people present at hospitals, causing significant distress to the person concerned and their family, in the older person's last days. Funding for Home and Community Care and 'packaged' community aged care services does not extend to palliative care. Urban myths about eligibility also contribute to problems with older people getting access to appropriate services, particularly in regional Australia.

3. Funding

Current funding arrangements for aged care are manifestly inadequate for the proper provision of palliative care. The Aged Care Funding Instrument (ACFI) applying to residential aged care has unrealistic requirements for claiming a subsidy payment for palliative care; and community 'packaged' aged care funding makes no such provision whatsoever. In relation to residential care, service providers are very often unable to obtain a clinical pain or palliative care directive from either a medical practitioner or specialist nurse. There is no distinction between palliative care and terminal (or end of life) care with claiming requirements focused entirely on end-of-life care.

The Productivity Commission (PC) has suggested that it might be appropriate for the Australian government to underwrite a significant proportion of the costs of some aged care services, such as palliative care[2]. The PC has specifically recommended that the government should ensure that residential and community aged care providers receive appropriate payments for delivering palliative and end-of-life care; and that the payments should form part of an assessed entitlement determined by a 'Gateway' assessment process.

It further recommended that the government establish an *Australian Aged Care Commission* (AACC) that would, inter alia, assess and recommend scheduled care prices based on the actual cost of care. NACA has taken the recommendation a step further by calling for an independent cost of care study to set the price of care entitlements, pending the establishment of the AACC[3].

The appropriate payment for palliative and end-of-life care should be determined by such a study, and later, by the government on the advice of the AACC in consultation with the National Hospital Pricing Authority. The PC suggested that 'the costs to providers of supporting GPs, geriatricians and other specialist teams (such as palliative care specialists) be taken into account by the proposed AACC when recommending the costs of delivering care'.

One funding model, recommended by Applied Aged Care Solutions P/L, is a 'layered funding model involving a base subsidy varying across low to very high levels of need; together with layered 'supplements' covering specialist areas (e.g. dementia/behaviour/mental health, health/nursing/continence, palliative care, rehabilitation) and 'care support' needs'[4]. A more detailed analysis and recommendations on financing aged care are contained in another NACA Aged Care Reform series paper on 'Financing aged care in Australia', also available on the NACA website[5].

The PC has also made recommendations about the levels of co-contribution for aged care services. It suggests that health services provided as part of aged care should attract the same subsidy in aged care as they do in health care. Such an approach, it says, could see a lower subsidy (higher co-contribution) for basic support (such as transport and home maintenance) and a higher subsidy for personal care, with the highest subsidy for the health care component of aged care (nursing and palliative care).

Whatever the case, a cost of care study is a prerequisite to determining suitable funding options for not only palliative care but aged care more generally.

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[2] Productivity Commission, *Caring for Older Australians* 2011
[3] NACA, *Blueprint for Aged Care Reform* 2012
[4] Productivity Commission 2011
[5] http://www.naca.asn.au/Age_Well/Financing.pdf

4. Resources

Given the strong preference for people to age at home, we support the Productivity Commission's recommendations for the removal of quantity restrictions on the supply of care, thereby allowing a greater variety of services to be delivered in all types of accommodation. In this context, the PC recognised a greater role for the delivery of palliative and end-of-life care in people's own homes as well as 'congregate care settings' such as residential aged care. It concluded that improvements were needed to the interface between aged care and health, 'with a greater focus on in-reach services'. We would also add as a general comment that access to specialist palliative care and bereavement services is inadequate, resulting in less than optimum care for many older people.

In 2009, the National Health and Hospitals Reform Commission recommended reforms to the hospital system that would make better use of aged care services. The reforms were aimed at reducing hospital care to older people that could be provided more appropriately in individuals' homes and in residential aged care services. Along with improved access to primary health care providers and geriatricians for residents of aged care homes, the reforms were intended to strengthen access to specialist palliative care services, with a special emphasis on people living in residential aged care[6].

We urge the government to act on these recommendations, which should result in a better balancing of resources between hospitals and aged care services. Combined with the recommendations by NACA and the PC for the establishment of a Gateway, older people requiring palliative care and their families stand to benefit from greater choice of services, service provider and location, together with greater control of decisions about their care.

Providing palliative care to someone in their own home presents particular difficulties that need to be addressed in a resourcing sense. Besides the obvious need for adequately trained staff and the provision of basic nursing care, are the potential requirements for hospital beds, air mattresses, continence aids and wound dressings. Durable equipment such as beds, air mattresses, walking frames etc. could be made available through an equipment loan scheme. There may also be the need to make some modifications to the home and install aids like grab rails.

The challenge of palliative care resourcing in community packages service delivery has at least three dimensions. They are additional resourcing to deliver:

- more of the same services;
- new services; and
- existing services in a more skilled way.

[6] NHHRC 2009, recommendations 52 and 55

Related to the above is the capacity to dramatically increase services towards the end of a person's life to avoid them having to be moved in their last days.

For many older people we have encountered in our community programs, palliative care means end of life care, which is not easily recognised by them as quality-oriented but rather, care accessed only when one is dying. This attitude creates resistance to accessing beneficial specialised services early in the journey of the life threatening illness.

Carers warrant specific consideration in the palliative care discussion. They play a vital role but are often unsupported. Carers could be assisted through upskilling them to continue their role more effectively; having ready access to respite and wellbeing opportunities; and augmenting that with appropriate service measures in recognition of the increasing needs of the person requiring palliative care. This implies a partnership model between the person requiring care, carer/s and service providers.

The coordination of palliative care in the community requires clarity about whether we want this overseen from a medical perspective or more from a normative/ home life/community services perspective, which includes medical and specialist interventions.

Along these lines, in its 2012 Federal Budget submission, Palliative Care Australia (PCA) has suggested other mechanisms to enhance service provision, including enhanced Medicare items for GPs and specialists to provide services in the community and in residential care[7]. We support such an initiative.

5. Palliative Care Arrangements

We have recommended in submissions to various previous inquiries into and reviews of aged care that the Australian Government should create a single integrated, flexible system of care and entitlements to replace the existing system of discrete programs and funding arrangements.

Assessment arrangements should be co-ordinated between the Gateway and the health system (possibly with the involvement of Medicare Locals) and should include palliative care. Having been assessed as requiring care, it should be a matter of individual choice as to where and in what form the care is to be provided. If a person chose to be cared for at home for example, an equivalent level of resourcing and expertise should be made available as would have been provided in hospital or a specialist hospice.

[7] Palliative Care Australia, *Submission to the Treasurer on Priorities for the 2012 Federal Budget*, January 2012

Any subsequent reassessment of an individual should build on the last, making use of (personally controlled) electronic records. Records should include advance care directives. In this way, services would have access to a case history of care as a basis for care coordination and case management. Where relevant, assessments would include consideration of additional care needs and supports, including specialist palliative and end-of-life care and equipment.

This requires systemic changes to assessment, funding, staffing and equipping of aged care and specialist palliative care services as well as a cultural shift in orientation of the health and aged care sectors. Hospital-based and other specialist care providers would need to work in tandem with community health services, GPs and the aged care sector, keeping the wishes of the older person front of mind.

Sub-acute and transition care are other aspects of the health and aged care system that bear consideration. Sub-acute care can include palliative care and associated pain and wound management, which could be provided in many residential and community care services. However, a multi-disciplinary approach is required across the health and aged care systems to achieve quality palliative care outcomes for older people.

Access to a choice of in-home or residential palliative care, together with specialised nursing and medical teams, GPs and sub-acute care are central to the design of new palliative care arrangements for older Australians.

6. Workforce

As acknowledged by PCA, residential aged care facilities are increasingly becoming palliative care providers. We agree with PCA and the PC that many aged care facilities provide excellent palliative and end-of-life care but that unfortunately it is not always the case.

There are palliative care guides and resource kits that have been developed specifically for residential care facilities and for GPs but they are not a substitute for a well-trained workforce. There is a need to have GPs specialise in geriatric medicine with a high focus on palliative care.

The potential for the role of the Palliative Care Nurse Practitioner in aged care has been recognised by the Department of Health & Ageing, and Resthaven, for example, has established a pilot project to assess the business case implications of the role. It is already well documented that the current Medicare Benefits Schedule items applying to Nurse Practitioners are not adequate to cover all the activities undertaken for specialist palliative care in the community or in aged care by Palliative Care Nurse Practitioners. This of itself presents a barrier to the role being undertaken and for Palliative Care Nurse Practitioners to operate in the NGO sector.

On-the-job training and post employment education play an important role in upskilling the workforce and maintaining professional standards but there needs to be changes to curricula for care worker and nurse training to incorporate palliative care as a basic competency. An alternative is for such training and education to be an elective but, as recommended by PCA, that suitably qualified staff be paid a palliative care loading, funded by government through a palliative care supplement to the ACFI.

In the medium to longer term, the cost of the wages loading would be reflected in the price for care recommended by the AACC.

The Australian Government could also extend existing workforce initiatives to include funding of training places for medical practitioners, nurses and care workers to specialise or enhance their expertise in palliative care. Investment is also required to increase the numbers of professionals with specialist palliative care knowledge and the expertise to train others in palliative care.

7. Quality and Standards

Residential aged care services are required to comply with the Australian government's Aged Care *Accreditation Standards*. The current Standards include an expected outcome, 2.9 Palliative Care – the comfort and dignity of terminally ill residents is maintained. Other expected outcomes under the four Standards are taken to refer indirectly to palliative care as well as directly to the total care of all residents (e.g. 2.5 Specialised nursing care needs; 2.8 Pain management; and 3.6 Privacy and dignity, among others).

Draft Revised Accreditation Standards for Residential Aged Care do make a distinction between palliative and end of life care (by removing reference to 'terminally ill') and recognise that specialist palliative care cannot always be accessed. However, that is the limit of the changes.

Palliative care is not referred to in the *Community Care Common Standards* that govern community aged care services, but there are *Guidelines for a Palliative Approach to Aged Care in a Community Setting*.

Our view is that, subject to the acceptance by government of recommendations regarding funding, resourcing, assessment, education etc., PCA's *Standards for Providing Quality Palliative Care for all Australians* could form the basis of a quality framework for both residential and community care, with key elements incorporated into the existing aged care standards.

8. Advance Care Planning

It goes without saying that aged care services should have staff trained to discuss and develop advance care directives but this is often not the case. Similarly, there is evidence that GPs require additional training to assist older people to formalise their advance care plans.

We believe there is a low level of knowledge and understanding of advance care directives in the community more generally and their use in many aged care services might be limited at best. Community awareness education about advance care planning would be an important step towards improving the potential for better quality palliative care in aged care services.

Aged care providers should be encouraged to have their staff discuss advance care planning with new residents and clients and industry associations should be resourced to provide education and training on the subject.

9. Research

We are long time practitioners of evidence-based approaches to aged care and will continue to support research efforts both through local, self-funded initiatives and grants. Research on the scale required for the development and continuous enhancement of approaches to palliative care across both the health and aged care systems warrants specific funding support by the Australian Government through existing research grant programs and authorities.

10. Summary

- All Australians deserve to die with dignity and most would prefer to die at home (or residential aged care) in the presence of loved ones;
- For providers of residential aged care in particular, palliative care should be core business but staff are often ill equipped and services under-resourced to provide quality palliation. There is no funding currently provided for community aged care services to provided palliative care;
- Aged care services present a potentially more effective, efficient and acceptable form of palliative care, in combination with ready access to specialist advisory and direct care services;
- A skilled workforce is an essential element of a quality palliative care system. Necessary initiatives include changes to worker education and training to ensure a consistent supply of suitably qualified staff, together with improvements in wages for aged care staff;
- The level of knowledge and understanding of Advance Care Planning in the general community is low and requires a specific awareness raising effort;
- Specific research initiatives are needed to improve the quality and effectiveness of palliative care provision across the health and aged care systems.

RECOMMENDATIONS

In summary, we present the following recommendations for the Committee's consideration:

1. The Australian Government should adopt the World Health Organisation definition of palliative care for application to aged care funding and quality standards;
2. Consistent with the PC's recommendations that aged care providers receive appropriate payments for delivering palliative care, the Australian Government should initiate an independent cost of care study pending the establishment of the Australian Aged Care Commission (AACC). The cost of care study should take account of competitive wage requirements for the aged care industry;
3. The ongoing determination of costs and pricing should be based on the advice of the AACC in consultation with the National Hospital Pricing Authority;
4. Co-contributions for palliative care should be determined by the proposed Gateway at the time of assessment of a person's care needs and entitlements;
5. Particular consideration should be given to the needs of carers to ensure their needs are assessed at the same time as the person requiring care, as recommended by the PC;
6. The Australian Government should act on the PC's and NHHRC's recommendations for reform of the hospital and health system and aged care system with a view to improving access to specialist palliative care advisory and direct care services;
7. In view of the rapid ageing of the population, current and future workforce requirements for palliative care need to be determined, including education and training requirements;
8. Subject to the acceptance of other recommendations regarding funding and resourcing, education etc., PCA's *Standards for Providing Quality Palliative Care for all Australians* should form the basis of a quality framework for aged care services, with key elements incorporated into the existing standards and guidelines; and
9. Research authorities and programs, such as the NHMRC's, should support research projects aimed at improving the understanding of and best practice approaches to palliative care for older Australians.

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