

2015-16 Federal Pre -Budget Submission

January
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PalliativeCare
AUSTRALIA

Introduction

Palliative Care Australia (PCA) is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life. Our mission is to influence, foster and promote the delivery of quality care at the end of life through ongoing policy and advocacy, education, and developing collaborative relationships in Australia and internationally.

We believe that palliative care must be available regardless of location, age, income, diagnosis or prognosis, social and cultural background, to support Australians to live well at the end of life. However we remain a very long way from achieving our goals. In 2011, nearly 147,000 Australians died and around 70% would have benefitted from access to palliative care services, yet only 30-50% did.

The National Palliative Care Strategy endorsed by the Australian Government in 2010 signaled the combined commitments of the Commonwealth, State and Territory Governments to the development and implementation of palliative care policies, strategies and services that are driven by standards and consistent across Australia. This sent a clear message that in order for Australians to live well at the end of life, its implementation is necessary for Australia to continue to provide first class palliative care services.

The World Health Organization (WHO) defines palliative care as:

...an approach that improves the quality of life of patients and their families facing the problems 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.¹

Palliative care will affect all of us at some stage in our lives whether as a patient, carer, family member, neighbour or friend. When an illness cannot be cured, the focus of care changes to supporting and assisting patients to have the best quality of life possible while managing their symptoms. Palliative care maintains quality of life by addressing physical symptoms, such as pain or nausea, as well as helping with emotional, spiritual and social needs and providing bereavement support. The aim of palliative care is to achieve a “partnership of care”, providing the best possible quality of life for the individual patient, their carers and families.

Palliative care is a good health investment

An investment in palliative care is an investment in the future sustainability of the health care system. There are costs associated with dying and these can be addressed through the savings offered by palliative care, and by encouraging the health care system to see palliative care as an integral part of service delivery. International studies have found that the healthcare costs of people who are dying are extremely high, particularly in the last year of life, and there is growing

¹ World Health Organisation, *WHO definition of Palliative Care*, 2008.
<http://www.who.int/cancer/palliative/definition/en/>, Accessed 20 August 2014

evidence that inpatient and in-home hospice palliative care service can reduce these costs.² These studies have examined the ageing population and changes in social and demographic structures, which raise issues around the future of healthcare and how it is funded, including the significant amount of healthcare resources used at the end of life.^{3,4}

The *Global Atlas of Palliative Care at the End of Life*⁵, produced by the Worldwide Palliative Care Alliance (WPCA), of which PCA is a member, included in its analysis of global palliative care need, a literature summary of hospice program cost-effectiveness. Sixteen articles from North America were reviewed. The overall findings were that both hospital-based programs and in-home hospice and palliative care services significantly reduced the cost of care and provided equal if not better care. Cost savings were due to reductions in the use of medical services, hospital costs, laboratory and intensive care unit costs, and decreases in hospital and nursing home admissions, emergency department visits, and the use of outpatient consultation services. The findings of these international studies are transferrable to the Australian setting.

The vast majority of Australians currently die in a hospital setting. As PCA highlighted in the submission to the National Commission of Audit⁶, it is possible to reduce costs and improve care by facilitating a change for acute inpatients from a high intervention pathway to a palliative care management plan, even if care needs to continue in an acute facility.

While no data is currently available to determine the nature of savings in Australia, a 2013 inquiry into palliative and community care by a Queensland Parliamentary Committee, reported that:

The committee believes that an investment in specialist palliative care services to provide consultation services and support home-based care could be offset by a reduction in acute hospital costs from unnecessary and unwanted hospital admissions.⁷

From a social perspective, palliative care improves the quality of life of people dying from a terminal illness, and their carers, family members and loved ones. It addresses pain and suffering and distress in relation to physical, psychological, spiritual and other problems from the point of diagnosis until the end of life, thereby minimising potential flow-on healthcare costs.

The key feature of a palliative care approach is that multidisciplinary teams provide individualised, needs based, evidence based, holistic care to a person with a life limiting

² Palliative Care Australia, *Submission to the National Commission of Audit*, January 2014

³ Shugarman I, Decker S & Bercovitz A, "Demographics and social characteristics and spending at the end of life" *Journal of Pain and Symptom Management*, 2009; 38(1):15-26.

⁴ Fassbender K, Fainsinger RL, Carson M, Finegan B, "Cost Trajectories at the End of Life: the Canadian Experience" *Journal of Pain and Symptom Management*, 2009;38(1):75-80

⁵ Worldwide Palliative Care Alliance, *Global Atlas of Palliative Care at the End of Life*, 2014

⁶ Palliative Care Australia, *Submission to the National Commission of Audit*, January 2014

⁷ Queensland Parliament, *Palliative and Community Care in Queensland: Towards Person-Centred Care*, Report No. 22, Health and Community Services Committee, May 2013, p xli

condition. It is concerned with the care needs and quality of life for people, along with the care and support of their families and friends.

Traditionally, palliative care in Australia has been offered most often to people suffering from malignant cancer. This is partly because the course of the disease has been more predictable, and easier to recognise and plan for the needs of patients and their families. However, the emerging needs of people living with serious chronic disease, together with new evidence for the effectiveness of palliative care, means that it should now be offered more widely and integrated more broadly across the health care sector. A range of different health condition groups are now calling on palliative care to be provided and early on in diagnosis, including Chronic Kidney Disease and End Stage Kidney Disease, dementia and neurological conditions.

The need for efficient and effective palliative care

Some of the reasons why efficient and effective palliative care, that is an integral part of the health system, is required are:

- Australia's ageing population is placing increasing pressure on palliative care services and the health care budget which means Australia will have to urgently address the aged care agenda, as set out in the Productivity Commission report *Caring for Older Australians*.⁸
- An under-resourced palliative care workforce with less than optimum training in palliative care means poorer quality palliative care.
- Low levels of awareness and general discussion in the community about death and dying means people's wishes to die in a place of their own choosing and with the desired type of care, will not be fulfilled.
- People's wishes to die at home are not being met, which means inappropriate referral to acute care settings is adding to the cost of care.
- Inequitable resource distribution and access problems in palliative care means a significant proportion of the Australian population misses out on quality palliative care, including Aboriginal and Torres Strait Islander, Culturally and Linguistically Diverse (CALD), rural and remote communities and other diverse needs groups.

These issues need to be addressed to ensure that every Australian has the opportunity to live well until they die, with their carers and loved ones also receiving appropriate support. We also need to ensure that people's wishes about where they want to die, whether this is at home, in a hospice or in an acute setting, are respected and listened to by family, loved ones and health professionals.

⁸ Productivity Commission, *Caring for Older Australians*, Australian Government, accessed from <http://www.pc.gov.au/projects/inquiry/aged-care/report>

The 2015-16 Budget

A considered and thorough approach to palliative care service provision is required in Australia. While Australia is recognised internationally as being at the forefront of palliative care research, the commitment supporting this research and applying this knowledge on the ground to deliver quality services is short of demand. PCA acknowledges the 2014 announcement of \$52 million over three years for the National Palliative Care Program and that this represents an increase of 25% from the last triennium. PCA has previously sought identified funding for palliative care, including an absolute increase in the level of funding nationally. The 2015-16 Budget should build on these foundations and create a system that is sufficiently resourced and managed to enable all Australians with life-limiting conditions to live well.

Recommendations

This submission presents five recommendations for progressing palliative care in Australia and the associated costs.

<i>Palliative Care Workforce strategy</i>	Cost
That a Palliative Care Workforce Strategy be developed and implemented which identifies workforce resources required across all service types consultations and which embeds palliative care into the education and training of all health professionals across their careers.	\$80,000 (with consultation forums)
<i>Palliative Care Awareness Campaign</i>	
That funding is provided for a comprehensive palliative care awareness campaign, incorporating a communications strategy to build on National Palliative Care Week, and enable PCA to lead a national discussion on palliative care, end of life care and advance care planning.	\$481,100
<i>Advance care planning</i>	
That the Australian Government and states and territories work together to develop and implement a single common legislative requirement regarding advance care planning across Australia.	No/low cost
<i>Feasibility study for community-based palliative care packages</i>	
That a feasibility study be conducted to examine establishing and providing community-based palliative care packages to support people who want to die at home.	\$180,000 (conducted by a consultant)
<i>Joint Kidney Health Australia and PCA proposal</i>	
A collaboratively developed website between PCA and Kidney Health Australia to facilitate more accessible information and education for health professionals, patients, their family and carers on palliative care and kidney disease.	\$143,500

Palliative Care Workforce Strategy

At a time when the demand for palliative care services is growing, the medical specialist workforce is decreasing, including for palliative medical specialists. The health workforce is also ageing, creating problems for ongoing sustainability. Data from the Australian Institute for Health and Welfare (AIHW) has shown that there are 737,400 workers in health services industries in 2010, up from 599,000 in 2005, and employment grew faster in this sector than total employment for the same period. However, on average workers in health occupations were older than for other occupations, and the proportion aged 55 years or older rose from 15% in 2005 to 19% in 2010.⁹

The AIHW *Palliative Care Services in Australia 2013*¹⁰ collates information on specialist palliative medicine physicians from the AIHW Medical Labour Force Surveys 2007 to 2009 and the Medical Workforce Survey 2010 and 2011. Specialist palliative medicine physicians made up nearly 4 in every 1,000 (0.38%) employed medical specialists in Australia, with an estimated 92 working in Australia in 2011. There were 71 vocational trainees under the Australian Chapter of Palliative Medicine's 3-year training program and 44 physician adult medicine advanced trainees undertaking training in palliative care with the Royal Australasian College of Physicians.

Nationally, there were 0.4 full-time-equivalent (FTE) specialist palliative medicine physicians per 100,000 of the population in 2011. The number of FTE specialist palliative medicine physicians per 100,000 of the population for the states and territories were 0.3 in Victoria and Western Australia; 0.5 for New South Wales and South Australia; and none recorded in the Northern Territory. During 2011 Almost 9 out of 10 (85.9%) FTE specialist palliative medicine physicians worked in the major cities. Once population sizes for each remoteness area were taken into account, the FTE specialist palliative medicine physicians per 100,000 of the population was highest for major cities (0.5), followed by outer regional (0.3) and inner regional (0.2) areas.¹¹

*Palliative Care Services in Australia 2012*¹² in addition to medical practitioners, included information on nurses specialising in palliative care through the AIHW Nursing and Midwifery Labour Force Survey. Of the almost 277,000 nurses employed in Australia in 2009, about 1 in 50 (5,173; 1.9%) worked principally in the area of palliative care nursing. Nurses working in palliative care were not evenly distributed among the states and territories or the regions of Australia. There were 20.5 FTE palliative care nurses per 100,000 of the population in Australia, with Tasmania and Victoria reporting the highest rates of 31.0 and 30.3 FTE per 100,000 of the population, respectively.

For nurses who reported information on the location of their main job, the number of FTE palliative care nurses per 100,000 population was highest in inner regional areas (26.1 FTE per 100,000 population in 2009) and in outer regional areas (21.2 FTE per 100,000 population). Major

⁹ Australian Institute of Health and Welfare, *Australia's Health 2012: The Thirteenth Biennial Health Report of the Australian Institute of Health and Welfare*, Canberra: AIHW

¹⁰ Australian Institute of Health and Welfare, *Palliative Care Services in Australia 2013*, Canberra: AIHW

¹¹ Ibid.

¹² Australian Institute of Health and Welfare, *Palliative Care Services in Australia 2012*, Canberra: AIHW

cities, remote and very remote regions had lower rates than the national rate of 20.5 FTE per 100,000 of the population (16.1 and 11.8 FTE per 100,000 of the population, respectively).¹³

PCA believes that a comprehensive plan is needed to look at the sustainability of the palliative care workforce, and to highlight that all health professionals should receive training in palliative care. The strategy should include the role of specialist palliative care in supporting and building capacity in the generalist health workforce, and acknowledge that they will deal with more complex patients. A broad based workforce response is also required to address the difficulties in delivering and accessing palliative care services to people outside of metropolitan areas.

There is a need for a comprehensive workforce strategy which embeds palliative care as a core part of the curriculum across all undergraduate, postgraduate and continuing education courses. This includes key aspects such as education on triggers for referral to palliative care for chronic disease groups, and communicating effectively with patients about care and end of life issues. The workforce should also be accessible and well distributed to allow equitable access for all Australians, including for people in regional, rural and remote areas, and specific population groups such as Aboriginal and Torres Strait Islander people and in paediatrics.

With an ageing population and workforce, developing a strategy which identifies the key issues, areas of need and steps for the future is important. A clear and comprehensive strategy for addressing future palliative care workforce challenges is needed to ensure we plan and direct resources effectively and efficiently.

Recommendation

That a Palliative Care Workforce Strategy be developed and implemented which identifies workforce resources required across all service types and which embeds palliative care into the education and training of all health professionals across their careers.

This recommendation would be no/low-cost as it can be developed within existing departmental resources or through the Health Productivity Agency, which is to include the functions of Health Workforce Australia. This is assuming that the development of the strategy is aligned with existing programs and will be a priority area of work. There would potentially be a reassessment of program priorities and a redirection of resources.

The development of the strategy could involve consultation with the sector to determine priorities. This could be through consultation sessions or forums undertaken in each state and territory. This addition of consultations session or forums would involve an additional cost.

The proposed total cost of this recommendation is \$80,000.00 if consultation forums are included and undertaken in each state and territory capital city.

Benefits: increased resource availability, improved patient, carer and health professional outcomes, improved resource allocation and distribution.

Savings: limited initially, but in the longer term there would be cost savings through improved efficiencies.

¹³ Australian Institute for Health and Welfare, *Palliative care services in Australia 2012*, Canberra: AIHW

Palliative Care Awareness Campaign

Funding from the Department of Health is used by PCA for the development and distribution of resources in English and 21 community languages and to run National Palliative Care Week. National Palliative Care Week, held in the last week in May each year, has proven a successful means of raising community awareness about palliative and end-of-life care. However, a more extensive community awareness and education campaign would allow for an increased level of community activity, resources and reinforcement of the key messages.

The community must be able to openly discuss their end-of-life wishes, in particular the type of care they want to receive and where and how it should be delivered. Being able to talk openly about our wishes with family and friends should be an empowering experience. PCA wants to develop the resources and provide the support to enable this discussion to empower people.

PCA believes that there is a need for an appropriately funded, consumer focussed communication program, including advance care planning and leading a national discussion on death and dying. While the research shows Australians would prefer to die at home, there is an unwillingness to discuss the issue with carers, family and friends which makes realising this wish difficult. A communication program is needed that assists people in having this discussion and supports them to discuss this wish with their General Practitioner, other health professionals and loved ones.

With the ageing of the population and the growing need for palliative care in the community, the challenge to meet growing information needs continues to grow. In the twelve months to February 2013, PCA distributed in excess of 205,000 copies of resources. This represents a significant need for an information and education program targeting the general public, patients, carers and family members of patients. This further increased for 2014, where from the period of 4 April 2014 to 30 May 2014 there were 1,353 orders made (CALD and English brochures) and 355,453 individual brochures distributed.

The Grattan Institute report *Dying Well* commissioned an indicative plan of costs and strategies for a national public education campaign, focusing on encouraging people to discuss preferences and choices for end-of-life care with their families and health professionals. A 12 to 18 month campaign including mass and digital media, public relations, direct marketing and education was estimated to cost \$10 million.¹⁴ PCA would see an awareness campaign and a national communications strategy building on the success of National Palliative Care Week.

PCA has previously called for comparable funding to that of DonateLife Week, which included \$463,000 in 2014 for community awareness grants. A national communications strategy, along with a strong community grants program, would enable ongoing communications on palliative care, advance care planning and other end-of-life issues throughout the year, and a more in-depth focus on grass-roots, community based programs and conversations.

¹⁴ Swerissen, H and Duckett, S., *Dying Well*, Grattan Institute 2014

Recommendation

That funding is provided for a comprehensive palliative care communications strategy to build on National Palliative Care Week, and enable PCA to lead a national discussion on palliative care, end-of-life care and advance care planning. The communications strategy and awareness campaign includes the following key components:

Community awareness grants	\$300,000
Advertising campaign	\$100,000
Staffing (including salary, on-costs and overheads)	\$81,100

The proposed total cost of this recommendation is \$481,100.00

The additional staffing component would allow the development of ongoing community awareness campaigns where priorities for these campaigns would be determined and developed in consultation with PCA members and the sector. The staffing would also allow for the administration of the community awareness grants.

The advertising campaign could include the engagement of expertise to develop the campaign materials; advertising such as billboards in high exposure/traffic areas (for example airports) and bus shelters; and promotional posters. Newspapers and other print media options would also be considered and any free media opportunities, such as television community service advertisements.

Benefits: increased awareness of palliative care generally, increased uptake of palliative care and palliative approaches, improved patient and carer outcomes and quality of life, and increase in awareness of end of life issues.

Savings: reduced demand on acute care will free resources in that sector, which are higher in cost than palliative care in hospital settings and in-home or community palliative care options, and through more appropriate treatments at the end of life.

Advance Care Planning

While the majority of Australians would prefer to die at home, the unwillingness of people to discuss the issue with carers, family and friends makes realising this desire difficult. People not only need to be assisted in having this discussion with loved ones and medical professionals, but to have processes in place to allow them to easily record this information and have it respected. Two key issues with regards to this are how advance care plans are recorded, and the need for consistent processes and legislation in each jurisdiction on advance care plans.

Advance care planning should be applied and promoted across the health sector. Facilitating end of life discussions and supporting and engaging in advance care planning is the responsibility of the whole health care system, and should engage all members of the care team. Healthcare workers across all levels of the health system should be skilled and educated to engage in end-of-life discussions and advance care planning with patients, their families and carers. For this to

happen, it is vital that palliative care information and advance care plans be available to all treating health professionals.

The Personally Controlled Electronic Health Record (PCEHR) under development by the Australian Government, should have the capacity to include palliative care information, including advance care plans. This is one way of providing a central point of recording advance care plans that should, in time, be available to the majority of consumers and health professionals.

Advance care planning is used in all Australian states and territories, however there is no nationally consistent legislation. States and territories have different provisions and terminology, meaning that it is difficult for one jurisdiction to recognise the advance care plan or directive from another, and for healthcare professionals to know their rights and responsibilities in this area. This also makes it difficult for families or carers who may live in a different jurisdiction to their loved one, to have an understanding of the wishes and ensure they are respected.

Most Australian jurisdictions have passed laws that empower various kinds of substitute decision makers, though these are not nationally consistent. Anecdotal evidence suggests that legislative inconsistencies across Australian jurisdictions are part of the reason for the failure to uphold advance care directives and in confusion amongst treating staff about rights and responsibilities in relation to directives. There is a need to achieve national consistency for advance care planning to address these issues and create certainty for health professionals, patients, carers and families.

Recommendation

That the Australian Government and states and territories work together to develop and implement a single common legislative requirement regarding advance care planning across Australia.

That advance care plans be made an integral part of electronic health records, whether this is the national Personally Controlled Electronic Health Record, or any localised version. It is recognised that this would involve costs for each jurisdiction which cannot be factored into this recommendation.

This recommendation is based on developing nationally consistent legislation. This would be no cost/low cost as it can be developed within existing departmental resources. There would be costs for each jurisdiction to develop and undertake this work such as resourcing, staffing and other related costs, as has been the case with other such legislative processes such as for nationally consistent occupational health and safety legislation. It is difficult to put an estimate on these costs for each jurisdiction, which will be influenced by factors related to, for example, the extent of cooperation required from jurisdictions.

The proposed total cost of this recommendation is no/low cost.

Benefits: improved patient, carer and family outcomes, increased understanding of advance care planning with health professionals, and reduction in administration across all health sectors.

Savings: increased efficiency in administration and reduced instances of unnecessary health interventions.

Feasibility study for community-based palliative care packages

The healthcare costs of people who are dying are high and there is growing evidence that inpatient and in-home hospice palliative care services can reduce these costs. The majority of Australians indicate a wish to remain at home as long as possible, and in many cases to die at home. Services are currently provided through community based palliative care in people's own homes, however the availability of community based services are impacted by where people live and the range of services available. There are also differences between jurisdictions in funding directed to community based care.

The report of the Senate Community Affairs References Committee Inquiry into Palliative Care in Australia¹⁵ included a recommendation that the Australian government consider changing the eligibility to Home and Community Care (HACC) to include palliative care patients or carers of such patients, regardless of their age. The Committee noted that as the HACC program was linked to funding and funding agreements, and that the Australian government consider this recommendation in the context of considering changes to the funding model for palliative care.

The Grattan Institute report *Dying Well* proposed that HACC funding be extended to provide community-based palliative care packages to support people of any age who want to die at home. In particular, support should focus on the last three months of life. The existing guidelines and procedures for allocating home and community care funding were in place through HACC and could be modified to support people dying at home with community-based palliative care packages.¹⁶

The analysis in the report with regards to this recommendation, noted that in 2010-11, 4,655 people who died were supported by a Commonwealth funded home and community care package. It was estimated that \$6,000 would be an average cost to provide a comprehensive, home-based palliative care package for the last three month of life. Extending community based packages to enable 30 per cent of deaths to occur at home would require an additional investment of \$237 million. Increasing home and community care would reduce demand on hospital and residential aged care, with an estimated reduction in costs of \$33million and \$200million respectively for people who would otherwise be in residential aged care or hospital. Therefore this \$233million could offset the additional investment cost, leading to a total amount of \$4million required.¹⁷

PCA supports the recommendations of the Senate Report and *Dying Well*. PCA recognises that the inclusion of palliative care patients in the HACC program would create challenges for service delivery, including the need to respond quickly to changing needs.

The key issue with including community based palliative care packages in HACC, is that the HACC Program, along with the National Respite for Carers Program, the Day Therapy Centres Program and possibly the Assistance with Care and Housing for the Aged Program, will come under one

¹⁵ The Senate, Community Affairs References Committee, Palliative care in Australia, October 2012

¹⁶ Swerissen, H and Duckett, S., *Dying Well*, Grattan Institute, 2014

¹⁷ Ibid.

program from 1 July 2015 in the Commonwealth Home Support Program (CHSP). Details around eligibility requirements are still being finalised, and there is a focus on reablement and providing basic supports in the CHSP.

Therefore any changes to HACC to include palliative care would need to take into account the impacts on service delivery, the changes to the structure of the HACC program and the CHSP, the funding required to support any changes, and the appropriateness of incorporating palliative care into the CHSP.

Recommendation

That a feasibility study is conducted to examine establishing and providing community-based palliative care packages to support people who want to die at home, through the structure of the Home and Community Care (HACC) program. That this feasibility study be conducted either when the changes under the Commonwealth Home Support Program (CHSP) are finalised or after 1 July 2015. This would allow for the feasibility study to determine if and how under the new CHSP structure, incorporating community based palliative care packages would be appropriate.

The study could be undertaken under the auspices of the Department of Health, ideally by an independent consultant to evaluate the impact of including palliative care packages and how this would operate and impact on services. The Terms of Reference for the study should include an examination of the process and timing of the packages being phased into the CHSP.

This recommendation would be no/low cost if undertaken within existing departmental capacity. If undertaken by a consultant there would be a cost involved. The timeframe for the study would need to be determined, however it is envisaged it would take approximately 6 months. The start date would need to factor in if an evaluation of the CHSP was required before commencing this study.

The proposed total cost of this recommendation is:

Within existing department capacity no/low cost

By a consultant \$180,000 (at \$1500 for 120 days)

Benefits: improved efficiency in delivering home and community-based palliative care, reduced regional variations in quality of and access to palliative care services, and a reduced reliance on acute and residential aged care services.

Savings: reduced reliance on higher cost acute and residential aged care services.



Joint Kidney Health Australia and PCA proposal - Collaborative Web-based Education Resource

In Australia kidney failure (as a principal or additional diagnosis) is the third most common cause of palliative care related hospital separations (behind secondary cancer and lung cancer), and kidney failure as the principal diagnosis accounts for 36% of all palliative care patient deaths.¹⁸ Patients with Chronic Kidney Disease (CKD) and End Stage Kidney Disease (ESKD) experience an average of seven symptoms affecting their daily life.¹⁹ Symptoms can include itching, fatigue, depression, constipation, insomnia, nausea, vomiting, shortness of breath and pain.²⁰ These symptoms are frequently under-diagnosed or inadequately treated which reduces a person's quality of life.

The highest incidence rates of CKD and ESKD in Australia occur within remote, regional and Aboriginal and Torres Strait Islander communities. Although not all groups are affected equally by ESKD, there are some communities where the rates are approximately twenty times higher than the national figure.²¹ Access to specialist palliative care services and information about palliative care in rural and remote communities is limited for both patients and health professionals.²² Palliative care in rural and remote areas is generally delivered by primary care physicians and community nurses and not palliative care specialists. The limited support, education and information provided to these health professionals make the management of palliative care and renal support difficult.

To achieve the best quality of life for a person with CKD/ESKD, health care professionals need to communicate with and properly inform, understand and support the patient, their families and carers. By raising awareness and providing information and support, the patient, their families and carers will be able to make informed decisions on their future care, including dialysis withdrawal while being aware of, and having access to relevant support networks. Additionally symptom management should be improved.

¹⁸ Australian Institute of Health and Welfare, "Palliative care services in Australia" HWI 123, Canberra: AIHW; 2013.

¹⁹ Murphy, E., Murtagh, F., Carey, I., Sheerin N. "Understanding Symptoms in Patients with Advanced Chronic Kidney Disease Managed without Dialysis: Use of a Short Patient-Completed Assessment Tool" *Nephron Clinical Practice* 2009;111 pp. 74–80

²⁰ Phipps, L. et al "Educational Needs in Supportive and End-of-life Care" *Nephrology*

²¹ Sajiv, Cherian "Cultural Considerations when providing care to Aboriginal and Torres Strait Islanders option for conservative care" in "ANZSN Renal Supportive Care Guidelines 2013" *Nephrology* 18 pp.401-454 p.430

²² May, Stephen "Issues and Models of Renal Supportive care in Rural Areas" in "ANZSN Renal Supportive Care Guidelines 2013" *Nephrology* 18 pp.401-454 p.435

PCA and Kidney Health Australia developed a joint position statement on palliative care and CKD/ESKD²³ which drew attention to the need for health professionals, patients, families and carers to be provided with accurate information and education about palliative care and renal disease. It called for a central national resource point for written, digital information and education for patients, families, carers and health professionals on palliative care associated with kidney disease; and for more accessible information and education for health professionals, patients, their families and carers on palliative care and kidney disease.

Education resources are limited for people with ESKD and those that are available are not widely marketed. One central national resource point for written, digital information and education for patients, carers and health professionals on palliative care associated with kidney disease would bridge this gap. A collaboratively developed website between PCA and Kidney Health Australia would ensure more accessible information and education for health professionals, patients, families and carers on palliative care, and kidney disease including symptom management and dialysis withdrawal. Centralising resources would also allow for the identification of gaps in existing materials and future standardisation.

A website would support the up-skilling of specialist doctors or nurse practitioners to improve access to treatment and palliative care services for remote, rural and regional patients, particularly for Aboriginal and Torres Strait Islander people including the promotion of advance care planning. A website could host education and ongoing support for renal specialists, renal medicine trainees and general practitioners by palliative care specialists on the benefits and practical delivery of a palliative approach for people with CKD/ESKD, their families and carers.

Resourcing and Timelines:

It is estimated that developing the website would be a 6 month project, with existing website developers for Kidney Health Australia conducting the work. There would be ongoing costs for maintaining the website and its content. The website would operate like the Kidney Cancer site²⁴ accessed via the Kidney Health Australia website, which presents extensive information on Kidney Cancer via a special site to support those with kidney cancer, their families, carers and health professionals – but with strong links and branding to the primary Kidney Health Australia and PCA websites.

The main components of the project would be:

Staffing (including senior lead by existing PCA and Kidney Health Australia staff, project officer (based with Kidney Health Australia), website developer, and salary and overhead on-costs	\$119,500
Stakeholder group establishment and meetings	\$10,000

²³<http://www.palliativecare.org.au/Portals/46/Position%20Statements/WEB%20Palliative%20Care%20CKD%20Position%20Statement.pdf>

²⁴ <http://www.kidney.org.au/KidneyCancer/tabid/799/Default.aspx>

Consumer group (volunteers) for testing	\$5,000
Website promotional materials to be sent to all renal units, palliative care services and other relevant health services	\$9,000

The proposed total project cost is \$143,500

Benefits: improved access to authoritative information on palliative care options for CKD/ESKD and particularly end-of-life kidney disease patients, families and health providers, with particular benefits to remote and regional communities.

Savings: Limited direct budget savings but significant community savings are anticipated through improved understanding and use of palliative care by health professionals, patients and carers, leading to a reduction in unnecessary medical interventions.