

# Submission to the Primary Health Care Advisory Group:

Better Outcomes for People with Chronic and Complex Health Conditions  
through Primary Health Care

September 2015



**PalliativeCare**  
AUSTRALIA

## Recommendations

### Recommendation One – Case Conferencing

- Evaluate methods to improve the uptake of case conferencing by General Practitioners (GP) and test a rigorous evaluation platform to measure the impact of case conferencing initiated by the GP.
- Provide funding to support multi-disciplinary care including case conferencing.

### Recommendation Two – Referral processes

- Develop nationally agreed referral criteria for when palliative care services should be engaged.
- Support the expansion of provision of home-based services (including palliative care services) for people with chronic, progressive disease.

### Recommendation Three – Telehealth

- Prioritise funding to support remote health care delivery including telehealth.
- Invest in the development of apps and other IT tools that connect the patient to their own health record and apps that provide opportunity for the patient to self manage.

### Recommendation Four – Outcomes

- Develop an outcomes measurement framework to assess patient outcomes against the agreed objectives of primary care.

### Recommendation Five – Advance care plans

- Provide funding for the development and maintenance of advance care plans for all people with chronic progressive disease.

### Recommendation Six – Funding

- Ensure that in spite of fragmentation of funding for palliative care services, access to care is seamless and universal to the patient and their family.
- In the short term, provide fee-for-service funding to support GPs involvement development and maintenance of advance care plans, and to provide funded referrals to allied health professionals from specialists for people with chronic, progressive disease.

### Recommendation 7 – Proof-of-concept trials

- Develop one or more proof-of-concept studies based on the examples provided, and implement this study to test options for management of chronic progressive disease.

## Introduction

Palliative Care Australia (PCA) welcomes the opportunity to provide input into the review of primary health care. This submission is the product of widespread consultation with not only PCA member organisations (Palliative Care New South Wales, Palliative Care Victoria, Palliative Care Australian Capital Territory, Palliative Care South Australia, Palliative Care Western Australia, Palliative Care Northern Territory, Palliative Care Queensland, Tasmanian Association for Hospice and Palliative Care and the Australasian and New Zealand Society for Palliative Medicine) but also broader consultation with stakeholders both within and outside the palliative care sector.

The primary health system works well when care is patient-centred, multidisciplinary and coordinated. It must be provided in a way that is seamless to the patient regardless of the organisational structure or funding arrangements that make up the provision of such care. Palliative care is an example of such multi-disciplinary care and is defined by the World Health Organization as: ‘an approach that improves the quality of life of patients 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.’ Palliative care is provided in almost all settings where health care is provided, including neonatal units, paediatric services, acute hospitals, general practices, residential and community aged care services and generalist community services.

The development of the palliative care speciality is the benchmark for provision of person-centred multi-disciplinary care. It takes into account not only the typical medical aspects of care, but also psychosocial and spiritual aspects of care, and care of the person and their family/carers including bereavement support. When palliative care is delivered well, it provides a model of effective coordination of services across the health system, including in primary care. While specialist palliative care has developed with these principles in mind, there is significant fragmentation in the delivery of end-of-life care, and this is an important issue for people with chronic and complex health conditions.

## Effective and Appropriate Care

Extensive research has found that palliative care services contribute to more effective and efficient use of health resources in ways that are consistent with the goals of care expressed by people with a life limiting illness and their families. This includes fewer emergency and hospital admissions, shorter lengths of stay, and the elimination of non-beneficial tests and treatments.<sup>i, ii, iii, iv, v</sup> Importantly, the research also indicates that palliative care improves the quality of life of patients and their families, improves the management of pain and other symptoms, reduces caregiver burden and provides greater emotional support compared with usual care.<sup>vi, vii, viii, ix</sup>

Around half of all Australians die in hospital and a third die in residential care<sup>x</sup>. In spite of the benefits that palliative care has been demonstrated to have with regard to patient and carer outcomes and reduced cost to the health sector, the data below illustrates that even within the hospital setting, many people are not being provided with access to palliative care services:

- In 2012, chronic lower respiratory disease was the fifth leading cause of death in Australia.<sup>xi</sup> In 2013, Chronic Obstructive Pulmonary Disease (COPD) was certified as the

underlying cause of 7,148 deaths in Australia.<sup>xiv</sup> However, there were only 622 palliative-care related hospital separations for people with a principal diagnosis of COPD.<sup>i</sup> This suggests that, at best, less than 9% of people with chronic COPD access palliative care.

- 10,369 people died from Dementia and Alzheimer's disease diseases in Australia in 2012, comprising 7% of all deaths.<sup>xiv</sup> However these diseases did not feature in the top ten non-cancer diagnoses for people who received palliative-care related separations.<sup>i</sup> A recent Australian survey of 783 professional carers and 236 family carers of people with dementia reported difficulties in: accessing hospice care (68%); accessing palliative care specialists (58%); getting sufficient end of life care support in the community (>50%); and in ensuring the person they were caring for received adequate pain relief.<sup>xii</sup>
- In 2013, there were 2,987 deaths in Australia due to diseases of the urinary system (including renal failure).<sup>xiv</sup> However, there were only 708 palliative care-related hospital separations for people with a principal diagnosis of renal failure across Australia.<sup>i</sup> This suggests that, at best, fewer than 24% of people with chronic renal failure access palliative care.

Further, there is inequity of access to palliative care services brought about by fragmentation of care between primary and acute care, fragmentation between public and private care, and geographical issues. For example, people in South Australia in the private hospital system face difficulties with transferring to community-based palliative care services. This is because discharge planners in private hospitals are not able to provide access to equipment, nursing and allied health in the community. People often have to exit the private health system before they can enter the public system and access these services. This lack of interface between public and private providers is a disincentive for people to use private health insurance when they are aged or have a chronic disease.

Lack of access to appropriate services is of greater problem for vulnerable populations. The burden of chronic disease in Indigenous Australians and the provision of care in rural and remote settings remain significant challenges. Building capacity of the primary health care workforce to provide palliative care to rural and remote communities, where access to specialist services is limited will be important in preparing for an ageing population with an increasing burden of chronic disease.

To improve these statistics, there is a need to clearly define the community of care that will enable patients to understand what services are available to them, and to provide the health care team with support to undertake this team-based care. Primary care has a pivotal role to play in good palliative care, but there are barriers. The ability of primary care physicians to deliver high quality care is hindered by the difficulties and reluctance of the medical profession to communicate the prognosis for people with chronic diseases and the risk of dying, and the reluctance of the community to discuss death and dying. Further, there is a need for primary care physician to be able to identify the transition point between chronic complex and chronic progressive disease – the latter should commence initiation of a palliative approach. This should be complemented by all medical specialties that are responsible for care of people with chronic diseases identifying the palliative phase of their care. With these two things in place, primary care physicians will be empowered to be proactive about providing a palliative approach and reaching out to specialist services when

appropriate. However, other barriers remain and can only be addressed by the implementation of an integrated health care system and amendments to funding arrangements. These barriers that prevent clinicians from working at the top of their scope of practice include:

- Fragmentation of the health system.
- Inability to access and link health data in real time, especially advance care plans or advance care directives.
- Lack of funding for non face-to-face care.
- Lack of a standardised approach to allow integration, coordination and person centred care
- Funding mechanisms do not support multi-disciplinary care.
- Access to equipment is difficult making support of patients at their home difficult.

The following details the essential elements of coordinated and person-centred care for people with chronic progressive diseases.

#### Case conferencing

Studies of the Australian health system have demonstrated the benefits of case conferencing<sup>xiii xiv</sup>, with one study finding that a single case conference between a GP and a palliative care specialist can reduce hospital admissions by 26%<sup>xv</sup>. This study looked at case conferences for patients already referred to specialist palliative care. Changing the responsibility for initiation of the case conference to the GP will require primary care physicians to identify the transition point between chronic complex and chronic progressive disease. It is at this junction that incorporation of a palliative approach realises benefit to both resource use and patient and family outcomes. Further research is required to establish the efficacy of case conferencing when initiated by the GP, and its impact on hospital utilisation rates across specialties, particularly at the transition point between chronic complex and chronic progressive disease.

#### **Recommendation One – case conferencing**

- Evaluate methods to improve the uptake of case conferencing by General Practitioners (GP) and test a rigorous evaluation platform to measure the impact of case conferencing initiated by the GP.
- Provide funding to support multi-disciplinary care including case conferencing.

#### Multi-disciplinary care

Team-based care is important due to the spectrum of support people with chronic diseases need at the end of their life. In palliative care a multi-disciplinary team will mean different things to different services. For some it might mean having many specialist palliative care practitioners involved in the services itself e.g. social worker, occupational therapists, bereavement counsellors. For other services multi-disciplinary team may consist of a network of health professionals that work together to provide a holistic and a patient/family-centred approach. In palliative care, these networks have been established by individual health services, but there is no systematic approach for doing this across the country. Their establishment relies on a local champion to bring together the team in spite of fragmented funding arrangements and difficulties in interconnectivity of health data. Services that have achieved a good model could be used to test application of different funding models or service provision pathways, as described later in this paper.

### Home based care

Research conducted by Palliative Care Australia shows that when people are asked where they would like to die, more than 70% say they would like to die in their own homes. There have been studies undertaken internationally that support the economic benefit of provision of care at home. One such study<sup>xvi</sup> suggests that cost savings might be available if community-based support were made more widely available to help people to die in their own homes, where that was their preference.

Silverchain, a not-for-profit organisation delivering community health and care services across Australia, have found reduce hospital and emergency costs of over \$5,000 per patient who accessed their service over those that did not (unpublished data from Silverchain). They also found that patients using Silverchain were three times more likely to die at home for all age groups, and for people under 50 years old, they were 8 times more likely to die at home. In the last financial year 69% of all people who accessed the service were supported to die at home, compared with around 14% nationally.<sup>x</sup>

Another study in the United Kingdom examined whether the home-based nursing service provided by Marie Curie Nursing Service (MCNS) helped more people to die at home, and reduced hospital use and costs at the end of life. The study found that people who received MCNS care were significantly more likely to die at home than those who received 'standard' care, and were less likely to use all forms of hospital care. There were also significant differences between the two groups in the costs of both planned and unplanned hospital care.<sup>xvii</sup> The findings provide evidence of the potential benefits of home-based end of life schemes, such as that operated by MCNS, and support increasing investment in such services so as to improve care for people at the end of life.

### Care plans and the role of patient pathways

Patient pathways can be used to identify the options for provision of care to patients, and can identify triggers for referral to particular parts of the health system. However there is a need to provide flexible, patient-centred care that is based on individual choice. The risk of using patient pathways is that they can be adopted in an inflexible manner, and may not consider or respect patient's individual needs or wishes. An example of this is the implementation of the Liverpool Care Pathway in the UK, which had the unintended consequence of reducing communication with patients and their families. The Independent Review of the Liverpool Care Pathway,<sup>xviii</sup> aptly named "More care, less pathway" recommended a system-wide approach to bring about improvements in care for the dying through measurable and monitored professional practice and provision of care.

However, in spite of the potential risks of implementing rigid patient pathways, there may be benefit in identifying aspects of the pathway that would be applicable to all patients. Such aspects may include holding a case conference and developing an advance care plan. These aspects could be incorporated into an individually tailored patient care plans. Funding could be based on delivery of the care plan, with a small payment on enrolment of the patient, and the majority of funding for delivery of the plan. In order for GPs to take on shared responsibility for developing an advance care plan, there would be a need to educate them as to how and when to hold the conversation, and to educate them on the medico-legal aspects of an advance care plan and advance care directive.

Involving patients and their families/carers in identifying their goals for care, and developing and implementing their plan for care is important. However, the health care team needs to assess the engagement (capacity to engage and willingness to engage) of the patient to assist in determining the extent of delegation of responsibility for health outcomes. There are many structural issues that often inhibit a patient's ability to be responsible for their own health. These issues, known as social and cultural determinants of health, take the form of things like literacy levels, homelessness, unemployment, social isolation and poverty. PCA urges caution in moving to a model of health that places patient responsibility at the core, there are shared responsibilities for health outcomes.

There are, however, ways in which increased patient responsibility for their own health could be achieved, all of which hinge on patient involvement in the development of the care plan which identifies the goals of care for the patient and their family. Other arrangements which could be adopted to support patient engagement in their health include:

- Providing patients with information about options for care and the benefits and risks of each option.
- Providing a menu of services whereby the patient can choose what services they would like to access. The value of the services could be dependent on the complexity of care.
- Supporting patients through development of apps etc that allows them to input their own health data.
- Provision of regular contact with a health professional to discuss their progress against their health management plans.

Once the individual care plan has been developed, implementation of the care plan is required.

Some of the key arrangements needed to implement individual care plans include:

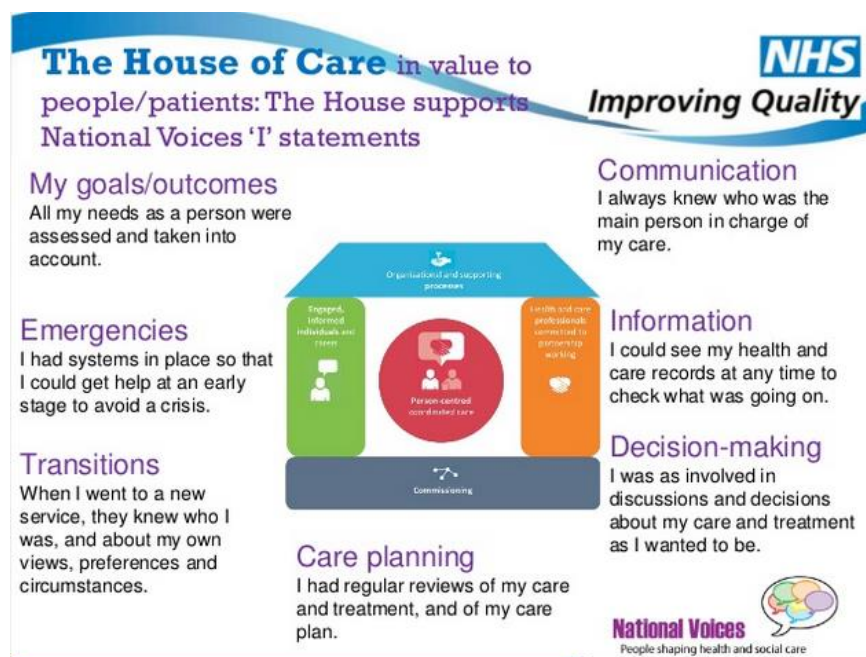
- Development of a partnership agreement between the patient and their health care team which identifies the extent the patient is responsible for self-management, the responsibility and commitments of the health care team and provides information to the patient about how to access integrated care across the whole system (primary, secondary, tertiary and community).
- Sharing of information between care settings.
- Funding access to the agreed and appropriate health services, equipment and support programs (such as bereavement care) to reduce inequity in care.
- Providing of culturally safe and sensitive care provision.
- Educating the entire sector about communicating with patients on sensitive issues including dying and bereavement.
- Implementing strategies to identify psychosocial issues so that interventions can be implemented before having a negative health impact.
- Providing effective 24/7 accessibility (at home, residential care, hospital) to primary care services, to reduce the need for emergency department presentations.
- Supporting ongoing assessment and updating of the care plan.
- Identifying triggers for referral to specialist palliative care to assist in managing complex pain and symptoms and addressing chronic needs.

## Models of seamless, integrated health care

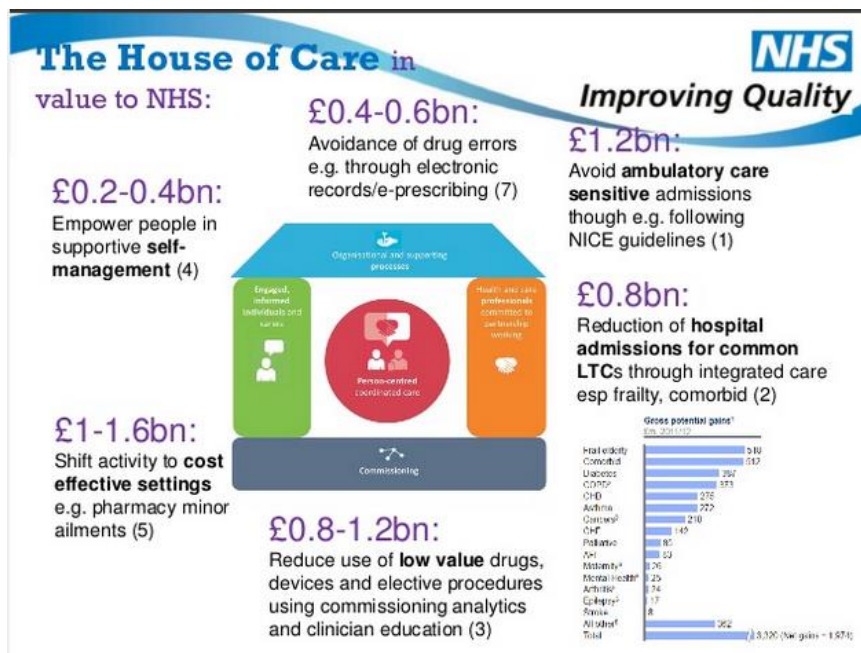
The UK have developed a 'House of Care' model designed to change the way the health system manages people with long term conditions. They found that the greatest barrier to care for people with chronic diseases can be summed up as failure to provide integrated care. The National Voices Program developed a series of 'I' statement that are generic but define what most users are seeking from their health care system. Such a series of statements could be adopted as the intended outcomes of provision of primary care for people with chronic conditions as follows:

- 'All my needs were assessed and taken into account'.
- 'I had systems in place so that I could get help at an early stage to avoid a crisis'.
- 'When I went to a new service, they knew who I was, and about my own views, preferences and circumstances.'
- 'I had regular reviews of my care and treatment and of my care plan'.
- 'I always knew who was the main person in charge of my care'.
- 'I could see my health and care records at any time to check what was going on'.
- 'I was as involved in discussions and decisions about my care and treatment as I wanted to be'.

Infographics describing the 'House of Care' are depicted below.<sup>xix</sup> Palliative Care Australia would support the development and trial of a model of care for end of life care that is based on the House of Care Model. The second figure identifies the significant savings that have been realised through implementation of this approach. Later in this paper, the conduct of proof of concept trials based on existing services is proposed. It may be possible to incorporate aspects of this model into such trials to identify potential savings and benefits to patient outcomes should it be implemented in the Australian context.







## Recommendation Two – referral processes

- Develop nationally agreed referral criteria for when palliative care services should be engaged.
- Support the expansion of provision of home based services (including palliative care services) for people with chronic, progressive disease.

## Increased use of technology

There are a number of ways patients can be involved in management of their own health care using technology. It is important that these are implemented to complement services rather than relying solely on technological solutions as this can create inequity in access to services. For example, the burden of chronic disease in Indigenous Australians and the provision of care in rural and remote settings are significant challenges. There is a degree of technical difficulty in utilising telehealth in remote areas, for example with internet services failing 20km out of Alice Springs.

Some of the ways technology can be used to enhance the delivery of health care services include:

- Performing a self-assessment of their health status more regularly and have the information provided to their health care team (could be achieved through an app). Changes in health status can trigger a booking with their primary care physician, possibly for referral to a specialist (or other allied health service).
- Documenting their medication intake electronically with the information provided to their health care team.
- Holding their e-health record to ensure that their health information is available in all settings.
- Participating in telehealth appointments more regularly without the need to leave their home. This is particularly important as the patient approaches the end of their life if they want to remain in their community.

- Improving their own health literacy, through apps and databases that provide access to high quality information to support their decisions about their health care.

### Recommendation Three – Telehealth

- Prioritise funding to support remote health care delivery including telehealth.
- Invest in the development of apps and other IT tools that connect the patient to their own health record and apps that provide opportunity for the patient to self-manage.

## Outcome measurement

### Quality of Service

The Australian Commission for Safety and Quality in Health Care has published the ‘National Consensus Statement: Essential Elements for Safe and High-quality End-of-life Care’<sup>xx</sup> which identifies principles for high quality provision of end of life care. This will be further enhanced by the inclusion of actions specific to end of life care in version two of the National Safety and Quality Health Service Standards. It is important to measure the provision of service against these Standards.

In addition, the measurement of outcomes is important to enable assessment of the success of the model in enhancing the quality of life and death for people with chronic disease, and also to measure the cost to the health system. The Palliative Care Outcomes Collaborative (PCOC) has been developed to measure patient outcomes in palliative care. The PCOC framework is a dataset designed to provide clinicians with an approach to systematically assess individual patient experiences, define a common clinical language to streamline communication and collect national data to drive quality improvement through reporting and benchmarking. This existing measurement framework could be adopted or adapted to assess patient outcomes under new service provision arrangements.

Other quality measures, which could be incorporated into accreditation for the practice, include:

- Care in the place of choice.
- Death in the place of choice.
- Proportion of patients with an advance care plan
- Speed of decline on a scale.
- Provision of specific services against a scale of need.
- Patient reported quality of life.
- Carer quality of life.
- Post death bereavement surveys.

Cost measures:

- Cost of care.
- Access to emergency departments.
- Hospital admission rates.

## Recommendation Four – Outcomes

- Develop an outcomes measurement framework to assess patient outcomes against the agreed objectives of primary care.

### Funding models

Shifting from a fee-based service model to a blended-funding model (incorporating fee-for-service and capitation payments) would support multi-disciplinary care, remote care and provision of whole of person services such as advance care planning and bereavement support. However the blended model works best where the scale of the health service is sufficiently large to balance the spectrum of needs: that is they have a mix of patients with lower needs to enable absorption of the additional costs for patients with very high needs for their condition. However, there are some services that have managed to work within current funding constraints to deliver high quality palliative care. These existing models of care could be transferable into primary care. This is most often achieved when the state or territory government understands the benefits of providing this care both from a patient outcome perspective and a cost of care perspective. Small investments to facilitate development of care networks can support delivery of palliative care.

An example of where state and territory governments have worked closely with the Commonwealth in terms of shared funding can be found in the Multi Purpose Service (MPS) models, and in the 1990s Healthstreams<sup>xxi</sup> model, adapted from the MPS model in Victoria. Funds from both Commonwealth and state and territory governments were pooled in order to provide a flexible approach to service models and capital funding. In Victoria, for example, MPS is considered to be a service which operates under the Small Rural Health Service (SRHS) model promoting an integrated funding and accountability model across various service types. MPSs function under a Payment Agreement (also referred to as a Tripartite Agreement) between the Commonwealth Department of Health (DOH), the Victorian Department of Health and each MPS agency. In line with Commonwealth requirements, agreements can be a maximum of three years in duration.

In the short term, if funding remains as fee for service, there are a number of changes that would support provision of palliative care to people with chronic progressive disease, including:

- There is no specific Medicare item that GPs can use for providing palliative care. Having a specific item for advance care planning would make the provision of this important service more visible to GPs and would enable greater promotion of the GPs role in advance care planning and management. Advance care planning requires the capacity to follow through on the wishes of patients. Inclusion of item numbers specific (of similar time and value to those items for chronic disease management) to the development and review of advance care plans by GPs would support them in performing this service.
- Provision of palliative care by primary health care could be supported by a review of Medicare payments to improve access to nurse practitioner services. This might provide more flexibility with service provision in the future as nurse practitioners are proving to be very flexible and adaptable to complex care arrangements and working across settings.
- There is a need to identify funding for non-face-to-face care. This would include patient follow up, coordination of care with specialist and allied health services, participation in case conferences and telehealth (or similar).

- Where patients face significant out-of-pocket costs for out-of-hospital services, the Medicare Safety Net picks up 80% of these costs once certain thresholds are reached. Primary palliative care should be a normal out-of-hospital service.

#### Recommendation Five – Advance care plans

- Provide funding for the development and maintenance of advance care plans for all people with chronic progressive disease.

If funding moves to capitation (or a blended model):

- It may be necessary to stratify patients based on risk, such as using the HARP model. If this is not done, the risk model may not be acceptable to many GPs and complex patients may be turned away.
- It will be very important to measure what is considered quality care. There is a risk that patients will demand more than is appropriate, or that physicians will provide less than is appropriate in order to save costs. This may be particularly true for those complex patients, or those approaching the end of their life, where the cost of providing services is higher.
- Home and Community Care (HACC) guidelines must acknowledge end of life care to ensure that service providers continue their support alongside specialist palliative care services or general palliative care services when necessary.

#### Private health insurers

Palliative care is very poorly covered by private health insurance. Privately insured patients have an expectation their private insurance will cover them through all aspects of their illness journey, and not cease when curative treatment is no longer appropriate. However, many private health insurers do not offer rebates for access to privately funded palliative care services, resulting in people not being able to afford access to community based palliative care. This means that private patients may be receiving more expensive, and at times, aggressive treatment in the final stages of life in a private acute hospital which may not be the best place of care on many fronts<sup>xxii</sup>. For example in Victoria, Cabrini Health Service is the only service that offers community palliative care funded via private health insurance. Recently, there has been some anecdotal evidence that private health insurers are willing to commence conversations about providing coverage for palliative care. This has been demonstrated in the United States (US), with the health insurer Medicare (US) commencing coverage for some palliative care services. PCA is very keen to engage in discussions with Australian private health insurers about coverage for palliative care.

Should the role of private health insurers expand, there is a need to ensure no erosion of universality. PCA does not support the development of a two-tiered health system in primary care. However, there are opportunities to improve services by better linkages between privately and publicly funded services. One option may be to enable public health providers to purchase services from private providers. This would achieve seamless care from the patient's perspective while still providing access to the full suite of services available, many of which may result in better health management and lower health expenditure. Should private health care providers reap benefits by offering customers health prevention and management programs, there is a need to ensure these are available to those without private health insurance, and that those that do have private insurance reap financial benefits rather than pay additional funds brought about by the health insurer selling access to these services as an additional benefit.

### Recommendation Six – Funding

- Ensure that in spite of fragmentation of funding for palliative care services, access to care is seamless and universal to the patient and their family.
- In the short term, provide fee-for-service funding to support GPs involvement development and maintenance of advance care plans, and to provide funded referrals to allied health professionals from specialists for people with chronic, progressive disease.

### Short-term demonstration pilots

There are a number of services across Australia that deliver high quality, multi-disciplinary palliative care services that incorporate or are based on primary health care. It is recommended that one or more of these could be amended and studied as a proof of concept trial to test options for management of chronic progressive disease. The advantage of testing an existing model is that the service is already established with patients using that service. This means that the trial could start in a timely manner and would not result in the removal of services on cessation of the trial. The trial would enable assessment of different funding mechanisms, which could be achieved either through actual amendment of funding during the trials, or through shadow funding arrangements, where the impact of various funding models could be assessed. The trial could also test different referral models and different models for delivering care to regional and remote areas and different governance arrangements.

Three options for proof of concept trials were identified during discussions with Dr Hambleton as having strong potential to provide data on the risks and benefits in the identification of a long term model for primary care provision. These are described below. These and/or other approaches could be tested to identify the benefits, risks and barriers to broader implementation. Palliative Care Australia would welcome the opportunity to work with the Australian Government and stakeholders to further develop and coordinate proof of concept studies.

### Recommendation 7 – Proof of concept trials

- Develop one or more proof of concept studies based on the examples provided, and implement this study to test options for management of chronic progressive disease.

### Option 1: The Silverchain model

Silverchain are Western Australia's largest provider of palliative care in the community. Silverchain are a not-for-profit provider of care that has been able to achieve good outcomes in a cost effective way. One of the factors contributing to the success of their model is scale. Due to their large size, Silverchain are able to deliver different tiers of service depending on patient need. This is a similar model to the Marie Curie Nursing Service in the UK (previously referenced), which provides four models of care depending on need. The model hinges on a collaborative network with hospitals and GPs and other health care providers in Perth. However, there is opportunity to improve these networks further, including through enhance IT systems.

Silverchain offer hospital in the home palliative care services as well as a priority response team with nurses active 24/7. The current Silverchain model is currently based on care provided predominately in the last three months of life, and predominately for people with a cancer diagnosis (80% of patients accessing Silverchain have a cancer diagnosis). There is opportunity to develop and test a model building on the current Silverchain service model to provide earlier access to palliative care,

and to enhance the partnership with the GP and other primary care providers. This would better meet the needs of people with chronic progressive diseases where the disease trajectory may be over a greater timeframe, but where consultative access to palliative care services would support the person to better live with their disease and would facilitate transition to palliative care when the disease progresses sufficiently to require transition to full palliative care in the future.

It is proposed that this study would test a prognostic tool to support GPs in determining when to make a referral to a palliative care service. Such tool could be the Prognostic Indicator Guideline (PIG) which was developed as part of the Gold Standards Framework in the United Kingdom<sup>xxiii</sup>. The PIG is based around the question ‘Would you be surprised if the patient were to die in the next year’?

The proof of concept study could shadow different funding arrangements for provision of this service. For example, a model for blended payment could be tested. In this model, the responsibility for governance and oversight rests with the organisation, which is overseen by a skills-based Board.

#### Aim

1. Test the prognostic tool to support referral from GPs to consultative palliative care services
2. To test whether earlier access to community based pall care provides benefit to patients and the health care system.
3. To shadow different funding arrangements over an existing model for the provision of community based palliative care.

## **Option 2: Integrated care model**

Calvary Health Care Bethlehem (CHCB) was funded by the Department of Health and Human Services (DHHS) to develop a state-wide model of care for people with progressive neurological diseases (PNDs). To this end, CHCB worked with the Department of Health and Human Services (DHHS) to develop an innovative and sustainable Model of Care (MOC) that integrated CHCB’s role as a state-wide provider of progressive neurological services as well as its local role as a specialist palliative care service. The model seeks to care for people closer to home and is based on an integrated care model with strong networks between primary and specialist care (including specialist palliative care and other clinical specialties).

The model utilised regular case conferencing, telehealth and emphasises the specialist service role in providing secondary consultation advice and education and training as required. Part of this project involved the development of a ‘red flag’ tool to identify the people with PNDs who require this model of care and at what stage in their illness they should access that model of care. This provided a tool to trigger referral from the primary health team to specialist care.

Part of this project involved development of an evaluation framework which considered both the efficacy of the model, and patient and carer outcomes. This evaluation framework could be utilised should a proof of concept study be supported for other chronic, progressive diseases.

CHCB has operationalised the model in this health service. This has involved establishing operational management, governance and ongoing development of the service. Current work is underway to implement the model more widely across the state.

With the ageing of the population, the forecast growth in chronic disease and increased demand for health services, in particular acute health services there may be value in testing this model in other chronic non-malignant conditions. This model should be evaluated for: reduction of burden on the acute sector; improvement of outcomes for patients with complex, chronic disease; and facilitation of the transition to palliative care services.

Aim:

1. Pilot this model to assess its applicability to other chronic, non-malignant disease using the established evaluation framework.

### **Option 3: Proactive model of Palliative Care service delivery in Residential Aged Care**

Clare Holland House, operated by Calvary Health Care in Canberra, have developed an integrated model of specialist palliative care partnering with residential aged care facilities to implement the Palliative Approach (PA) Toolkit with two additions: Palliative Care Needs Rounds (PCNR) at the pilot sites that also provided education about the palliative approach and identified residents suitable for case conferencing, and the implementation of a goals of care discussion. Results of the trial found a 45% reduction in overall length of hospital stays and hospital deaths were reduced by 10%.<sup>xxiv</sup> Of the residents who had known preferred place of death, 100% died in their preferred place of death.

It is proposed that this model could be adopted to assess the efficacy of the approach in delivering efficient and high quality care for older adults with chronic and complex diseases.

Aim:

1. Test whether the model of proactive service delivery can be adapted to support older adults with chronic disease within and beyond residential aged care facilities.
2. Report the health economics outcomes of the model as applied to chronic disease in elder care.

## References

- <sup>i</sup> World Health Organization, 2011, *Palliative care for older people: better practices*, WHO, P13
- <sup>ii</sup> Worldwide Palliative Care Alliance, 2014, *Global Atlas of Palliative Care at the End of Life*, P91.
- <sup>iii</sup> Albanese T, et al, 2013, Assessing the Financial Impact of an Inpatient Acute Palliative Care Unit in a Tertiary Teaching Hospital, *Journal of Palliative Medicine*, Vol 16, Number 3, 2013, P293.
- <sup>iv</sup> Canadian Hospice Palliative Care Association, Cost-Effectiveness of Palliative Care: A Review of the Literature, P12 <http://www.hpcintegration.ca/media/36290/TWF-Economics-report-Eng-final-webmar7.pdf> (accessed 20 May 2014)
- <sup>v</sup> Starks H, et al, 2013, Cost Savings Vary by Length of Stay for Inpatients Receiving Palliative Care Consultation Services, *Journal of Palliative Medicine*, Vol 16, Number 10, 2013, P1215.
- <sup>vi</sup> Lorenz et al, 2008, reported in Rand Europe and the National Audit Office, 2008, *The Potential Cost Savings of Greater Use of Home and Hospice-Based End of Life Care in England*, National Audit Office, 2008.
- <sup>vii</sup> Casarett, D; Pichard, A; Bailey, F A; Ritchie, C; Furman, C; Rosenfeld, K; Shreve, S; Chen, Z; Shea, J A; 2008 “Do Palliative Care Consultations Improve Patient Outcomes?” *Journal of the American Geriatric Society*, 2008 No 56 pp593-599
- <sup>viii</sup> Morrison, R S; Penrod, J D; Cassel, B; Litke, Ann; Spragens, L; Meier, D E, 2008, “Cost Savings Associated with US Hospital Palliative Care Consultation Programs”, *Archives of Internal Medicine* 168, No 16 (2008) p1786
- <sup>ix</sup> Le, B; Watt, J, 2010, “Care of the Dying in Australia’s Busiest Hospital: Benefits of Palliative Care Consultation and Methods to Enhance Access”, *Journal of Palliative Medicine* Vol 13, No 7, 2010, pp855-860.
- <sup>x</sup> Swerissen H. and Duckett S. (2014). *Dying Well*. Grattan Institute. Australia.
- <sup>xi</sup> Australian Bureau of Statistics, *Causes of Death, Australia, 2012*  
<http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/3303.0main+features100002012> (accessed 16 May 2014).
- <sup>xii</sup> Alzheimer’s Australia, 2014, *End of Life Care for People with Dementia: Survey Report February 2014: Executive Summary*, Pp3-14,  
[http://www.fightdementia.org.au/common/files/NAT/EOI\\_ExecSummary\\_Web\\_Version.pdf](http://www.fightdementia.org.au/common/files/NAT/EOI_ExecSummary_Web_Version.pdf)
- <sup>xiii</sup> Mitchell G, Cherry M, Kennedy R, et al 2005. General practitioner, specialist providers case conferences in palliative care—lessons learned from 56 case conferences. *Aust Fam Physician*. May;34(5):389-92.
- <sup>xiv</sup> Mitchell GK, Del Mar CB, O'Rourke PK, Clavarino AM. 2008. . Do case conferences between general practitioners and specialist palliative care services improve quality of life? A randomised controlled trial *Palliat Med*. 2008 Dec;22(8):904-12.
- <sup>xv</sup> Abemethy A. P., Currow D. C. Shelby-Janes B. et al (2013), ‘Delivery Strategies to Optimize Resource Utilization and Performance Status for Patients with Advanced Life-Limiting Illness: Results From the “Palliative Care Trial”’. *Journal of Pain and Symptom Management* Mar 45(3).
- <sup>xvi</sup> <http://www.nuffieldtrust.org.uk/publications/exploring-cost-care-end-life>
- <sup>xvii</sup> <http://www.nuffieldtrust.org.uk/publications/marie-curie-nursing>
- <sup>xviii</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/212450/Liverpool\\_Care\\_Pathway.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf)
- <sup>xix</sup> Callow L. & Lockhart J. (2014) *Long Term Conditions Improvement Program Your Local House*. LTC Year of Care Commissioning Early Implementer Sites Workshop UK NHS <http://www.slideshare.net/NHSIQ/ltc-yearofcarecommissioningearlyimplementersitesworkshop> Downloaded 31 August 2015.
- <sup>xx</sup> Australian Commission on Safety and Quality in Health Care (2015). *National Consensus Statement: Essential Elements for Safe and High-quality End-of-life Care*. Commonwealth of Australia.
- <sup>xxi</sup> <http://catalogue.nla.gov.au/Record/307542>
- <sup>xxii</sup> N Sullivan, H Walker, J Brooker A Framework for the Delivery of Comprehensive Palliative Care Services in the Australian Private Sector Prepared for the Australian Centre for Health Research by Cabrini Health
- <sup>xxiii</sup> Thomas K. (2011). Prognostic Indicator Guidance (PIG). 4<sup>th</sup> Ed. The Gold Standards Framework in End of Life. <http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf> Downloaded 3 September 2015.
- <sup>xxiv</sup> Johnston N., Chapmen M., Liu W. and Lovell C. (2015) Effect of a Proactive Model of Palliative Care Service Delivery in Residential Aged Care Facilities on Hospitalisation and Location of Death, *Oral presentation to the Palliative Care Australia Conference*. Melbourne, Victoria.