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CENTRE FOR HEALTH ECONOMICS  
RESEARCH AND EVALUATION



# PALLIATIVE CARE IN COMMUNITY CARE

Identifying and Funding  
Palliative Care Needs in  
Australia

APRIL 2018

THINK.CHANGE.DO



## About CHERE

CHERE is an independent research unit affiliated with the University of Technology Sydney. It has been established since 1991 and has a strong reputation for excellence in research and teaching in health economics and for providing timely and high-quality policy advice and support. Its research program is policy-relevant and concerned with issues at the forefront of health economics.

CHERE has extensive experience in evaluating health services and programs and in assessing the effectiveness of policy initiatives. The Centre provides policy support to all levels of the health care system, through both formal and informal involvement in working parties, committees, and by undertaking commissioned projects. For further details on our work, see [www.chere.uts.edu.au](http://www.chere.uts.edu.au).

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As an input to: End of Life Directions for Aged Care (ELDAC) project***

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# 1. INTRODUCTION AND BACKGROUND

## PURPOSE OF THIS PAPER

This paper explores the interface between palliative care and community aged care in Australia. In particular it addresses the identification of need for, and funding of, palliative care to recipients of aged care services via the Commonwealth Home Support Programme (CHSP) or the Home Care Packages Programme (HCPP). A companion paper explores the interface between palliative care and residential aged care.

The two papers have been commissioned by Palliative Care Australia as inputs to the Policy Enablers work stream of the End of Life Directions for Aged Care (ELDAC) project.

## DEMOGRAPHIC CHANGE

Older Australians aged 65 and over currently account for approximately 15 percent of the Australian population (Australian Bureau of Statistics, 2017). Of those, about 32 percent access services provided through 'aged care' programmes (financially subsidised services and/or case management assistance), either within their own home or in residential aged care facilities (ACFA, July 2017).

The proportion of older people is projected to increase to 22 percent of the population by 2061 (Australian Bureau of Statistics, 2013). This changing demographic structure, coupled with an increasing number of elderly people who become frail, have a diagnosis of dementia or live with multiple chronic conditions, will inevitably lead to a larger number of older people requiring health and personal care and other services. The need for palliative care, including end of life care, will similarly grow. In most cases the elderly directly access these services in the same manner as other people – either through community-wide government supported programmes (such as for medical and pharmaceutical services) or directly from the market (such as many allied health services, personal care and home maintenance services). In a lesser number of cases some of the elderly will require to access the services they require.

## AGED CARE SERVICES AND COSTS

The Australian Government subsidises a range of services for the elderly (aged 50 or older if they are an Aboriginal or Torres Strait Islander person or 65 or older otherwise), depending on an assessment of their needs and their capacity to make a financial contribution. The level of the subsidy is determined on the basis of their income (and in certain circumstances, their assets). The services which are subsidised under aged care programmes include:

- **Commonwealth Home Support Programme (CHSP):** Entry level services such as meals, transport, domestic assistance, personal care etc.

- **Home Care Packages Programme (HCPP):** Home care is provided at 4 levels of intensity depending on need, and includes services such as personal care, meals, telehealth, transport, nursing, allied health etc.
- **Residential Care:** Personal care and nursing services with the level of services determined by provider assessments using the Aged Care Funding Instrument (ACFI).
- **Respite care:** Respite care is available via CHSP including flexible respite, cottage respite and centre-based respite. Respite care is available in residential aged care facilities for up to 63 days in the financial year and gives those receiving it the same services as those receiving permanent residential aged care.
- **Flexible Care:** Offers other alternatives to the mainstream residential and home care as described above. Includes Transition Care, Short Term Restorative Care (STRC), Multi-purpose Services, Innovative Care and the National Aboriginal and Torres Strait Islander Flexible Aged Care Programme.

In 2016/17 the Australian Government spent around \$17.1 billion on aged care service subsidies and supplements (including accommodation supplements) (Australian Government Department of Health, 2017).

In 2014 it was estimated that by 2050 more than 3.5 million people will receive aged care services, compared to the current 1 million (Australian Government Department of Social Services, 2014). The aged care programmes need to be designed in a way that optimally responds to the changing demographics while ensuring the quality of care for those in need, the fiscal sustainability of the government's outlays and the financial stability of the sector. It is equally important that other government supported programmes that the elderly may require, as well as services sourced directly from the market, operate efficiently and effectively in catering for this expanding demographic.

## AGED CARE POLICY

### Productivity Commission report

In 2011, the Productivity Commission's Report - Caring for Older Australians - raised some key concerns surrounding the organisation and delivery of aged care services in Australia. Specifically, it highlighted the need for a more consumer led care system, the promotion of independence and choice, as well as improved fairness and quality of care. One of the key principles it proposed was that the aged care system should aim to:

"be consumer-directed, allowing older Australians to have choice and control over their lives and to die well" (Productivity Commission 2011 p.95)

Following the Report, the Aged Care (Living Longer Living Better) Act 2013 (LLLLB) introduced several amendments to the Aged Care Act 1997 and initiated a series of reforms. Most notably, the My Aged Care website was introduced in 2013 and further expanded in 2014 and 2015. The platform provides information for consumers on the various types of subsidised aged care services that are available, as well as information on assessments of need and of the level of funding contributions that would be required. Changes were made to the income and asset tests to assess the contributions payable (if any) for persons assessed as being eligible for community and residential care, to improve the financial sustainability of aged care. Measures were introduced to improve transparency and choice of the standard of accommodation for consumers in residential aged care. Moreover, the number of available Home Care Packages was expanded. Overall, the changes have moved aged care services in Australia towards a more flexible model with increased consumer choice and control.

### **Legislated Review of Aged Care**

In 2017, an independent legislated review of the implementation of the LLLB reforms was conducted to evaluate their impact and effectiveness, as well as to suggest recommendations for future reforms to the sector (Tune, 2017). The review recognised that the reforms have had a positive impact on moving the aged care sector towards a more demand driven and sustainable system. However, it also highlighted that further reforms will be necessary to create a truly consumer centred system.

### **PALLIATIVE CARE SERVICES**

Palliative care, as defined by the World Health Organisation (WHO), is “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” (WHO, 2018). Palliative care can be provided in any setting including in hospital, by attending a medical or other health practice, or by a general practitioner or other health practitioner attending a person in the community or in a residential aged care facility (RACF). Commonly, a distinction is made between palliative care which is provided in health specific facilities (hospitals, palliative care wards, hospices) and those provided in the community setting (including the person’s home or in a RACF) (AIHW, 2017).

As the population ages and there is an increase in the incidence of life limiting chronic illnesses, a growing number of older people receiving aged care will also require some form of palliative care that is not necessarily the traditional ‘end of life’ care but where their symptoms require ongoing effective management. Further, most people (about 70%) say their preferred place of death would be at home, yet only about 14% achieve their preference (New South Wales Health, 2017). Thus, there is an increasing need and desire for palliative care to be provided to those in RACFs or in their own homes in conjunction with any aged care subsidised services they may be receiving.

## **PALLIATIVE CARE POLICY**

While the 2017 Tune Review on LLLB implementation explicitly set aside the issue of palliative care, its importance and its nexus with aged care was established in the Productivity Commission's 2011 report. In addition to stating that the aged care system should aim to allow people to die well, the 2011 report pointed out that under the current system, the palliative care needs of many older people are not being met due to a lack of funding for these services. The report also acknowledged the likelihood of an increased number of older people who will require palliative care services in the future as the population ages. Under Recommendation 10.3, the report proposed that residential and community care services should receive appropriate payments in order to deliver palliative care. This would happen via an entitlement assessment to be carried out through the My Aged Care Gateway. Thus far, this recommendation has not been implemented. Indeed, the palliative care agenda seems to have developed largely in parallel to the aged care agenda and with less policy attention.

### **2010 National Palliative Care Strategy**

In 2010, the Australian Government Department of Health released the National Palliative Care Strategy, building on the first national strategy in 2000. The 2010 Strategy provides a national framework to enhance the work that is taking place at the State and Territory level, to ensure that all jurisdictions are working towards an agreed set of palliative care goals. Those goals are: awareness and understanding; appropriateness and effectiveness; leadership and governance; and capacity and capability.

### **2012 Senate Community Affairs References Committee Inquiry**

In 2012 the Senate Community Affairs References Committee conducted an inquiry into palliative care in Australia and made 38 recommendations. Several of those recommendations dealt with funding concerns (recommendations 2 and 3), barriers to access, data limitations (recommendation 4), a lack of training and awareness, as well as a poorly defined palliative care pathway (recommendation 12).

### **Evaluation of the 2010 National Palliative Care Strategy**

An evaluation conducted by Urbis in 2016 accepts that the Strategy, which was endorsed by all jurisdictions, is helpful in aligning palliative care priorities, but also identifies weaknesses and concludes that the Strategy has had limited impact on the provision of palliative care since 2010. Many of those weaknesses echo the recommendations from the 2012 senate inquiry. Specifically, the evaluation found that there is little evidence of jurisdictions referencing the Strategy in their own strategies and plans. Moreover, there is a lack of quantifiable outputs as a basis for measuring outcomes from the provision of palliative care. This stems from a lack of data and mechanisms for collecting data to measure how successful the Strategy has been. In addition, the evaluation highlights the ongoing lack of understanding around palliative care, and significant barriers to access. The report pointed out ways to improve the influence that the Strategy could



have in the future, proposing that the Strategy needs to be better aligned with other reforms and strategic frameworks such as the aged care reforms.

### **Australian Government National Palliative Care Projects**

The Australian Government is currently funding several National Palliative Care Projects centred on education, training, quality improvement and advance care planning. These include the Palliative Care Education and Training Collaborative, Palliative Care Online Training Portal, Palliative Care Outcomes Collaboration, Palliative Care Australia, Advance Care Planning etc.

Moreover, as part of the LLLB reforms, the Australian Government committed to funding the Specialist Palliative Care and Advance Care Planning Advisory Services Program (Decision Assist Program) from 2013 to 2017. This programme was established to “enhance national provision of palliative care and advance care planning advisory services to recipients of aged care services” (Decision Assist Program, 2016, website homepage). The programme was assessed by the program consortium as meeting the three programme outcomes of:

- “the empowerment of GPs and aged care providers with knowledge of advance care planning and palliative care”
- “the creation of links between aged care and palliative care
- “the provision of advice about palliative care, advance care planning and advance care directive resources, processes, legislation and accountabilities in the state or territory in which the aged care provider or GP is located” (Decision Assist, 2016, p.17)

Despite the inextricable link between aged care and palliative care, and despite the assessed success of Decision Assist, the two agendas have been somewhat unaligned. The aged care agenda has taken the policy spot light in a more coherent and future-looking manner, whilst the palliative care agenda has been a series of projects, programmes, strategies and guidelines. Nonetheless, palliative care services and funding have been growing and developing in recent years. Further, palliative care services are being progressively delivered within the aged care sector, and the extension of palliative care provision from the health care setting to the aged care setting is growing.

## 2. AIMS OF THIS PAPER

With this background in mind, the remainder of this paper will take a closer look at palliative care in Australia, specifically with respect to identification of need and funding within the community care setting. A partner paper considers issues of identifying palliative care needs and funding for those receiving aged care services in the residential setting.

This paper addresses two questions:

- 1) How are palliative care needs identified within the community aged care setting?
- 2) How are palliative care needs funded within the community aged care setting?

### OUTLINE OF THIS PAPER

The remainder of this paper is set out as follows. Section 3 discusses community care in Australia. Sections 4 and 5 address the two questions set out above. Section 6 provides a discussion of the adequacy and implications of the current arrangements with respect to identifying and funding palliative care needs and draws conclusions.

## 3. FUNDING COMMUNITY CARE

As outlined in Section 1, there are a number of aged care services provided in Australia. These include residential care, community care (CHSP and HCPP), respite care and flexible care (See Figure 1).

Community care is available in two forms: the Commonwealth Home Support Programme (CHSP) and the Home Care Packages Programme (HCPP). The programs aim to support older Australians to continue to live independently and safely in their own homes for as long as possible and for as long as they wish. The Australian Government announced that funding for the CHSP will continue until 2020 and in future it will be integrated with HCPP into one home care and support programme (ACFA, July 2017; Australian Government DoH, Feb 2018a).

The CHSP provides basic entry-level support at home for people aged 65 and over (aged 50 and over for Aboriginal and Torres Strait Islander people). Services provided under CHSP include meals, transport, personal care, social support etc. CHSP also includes flexible respite care to support care relationships and support carers. The programme has a strong focus on re-ablement and wellness and aims to help people become more independent in their own homes and within

the community, reducing the likelihood of early admission into a residential home (Australian Government DoH, 2017a). In 2016-17 there were 1,621 home support providers (1,523 CHSP providers and 98 HACC providers in WA) who provided care services to 797,313 individuals (Australian Government DoH, 2017a).

The HCPP provides care for those with greater and more complex care needs. Specifically, it has four levels of home care services: basic care needs (level 1), low level care needs (level 2), intermediate care needs (level 3) and high care needs (level 4). The services include personal care, meals, telehealth, transport, nursing, allied health etc. The HCPP is a consumer directed programme in which consumers can choose the services they wish to receive which are specific to their individual care needs.

In 2016-17 there were 702 home care providers who provided care to 71,423 individuals (Australian Government Department of Health, 2017). During the same period, the average age of a consumer on entry into the HCPP was 80.2 years (Australian Government DoH, 2017a).

As illustrated in Figure 1, the funding for community care, for both CHSP and HCPP, comes from subsidies from the Australian Government and contributions from the individuals who receive the services. Spending on aged care services overall by the Australian Government was \$17.1 billion in 2016-17. Of this, \$4.2 billion, or approximately 24.6%, was accounted for by community care (\$2.6 billion for CHSP and \$1.6 for HCPP) (Australian Government DoH, 2017a).

## **CHSP**

Access to CHSP services is subject to a needs assessment by a Regional Assessment Service (RAS) assessor. The assessment establishes what care services an individual requires.

### **Federal funding**

The Australian Government provides grant funding for the CHSP and funds the providers. They also provide funds to other services which support CHSP such as to the RASs.

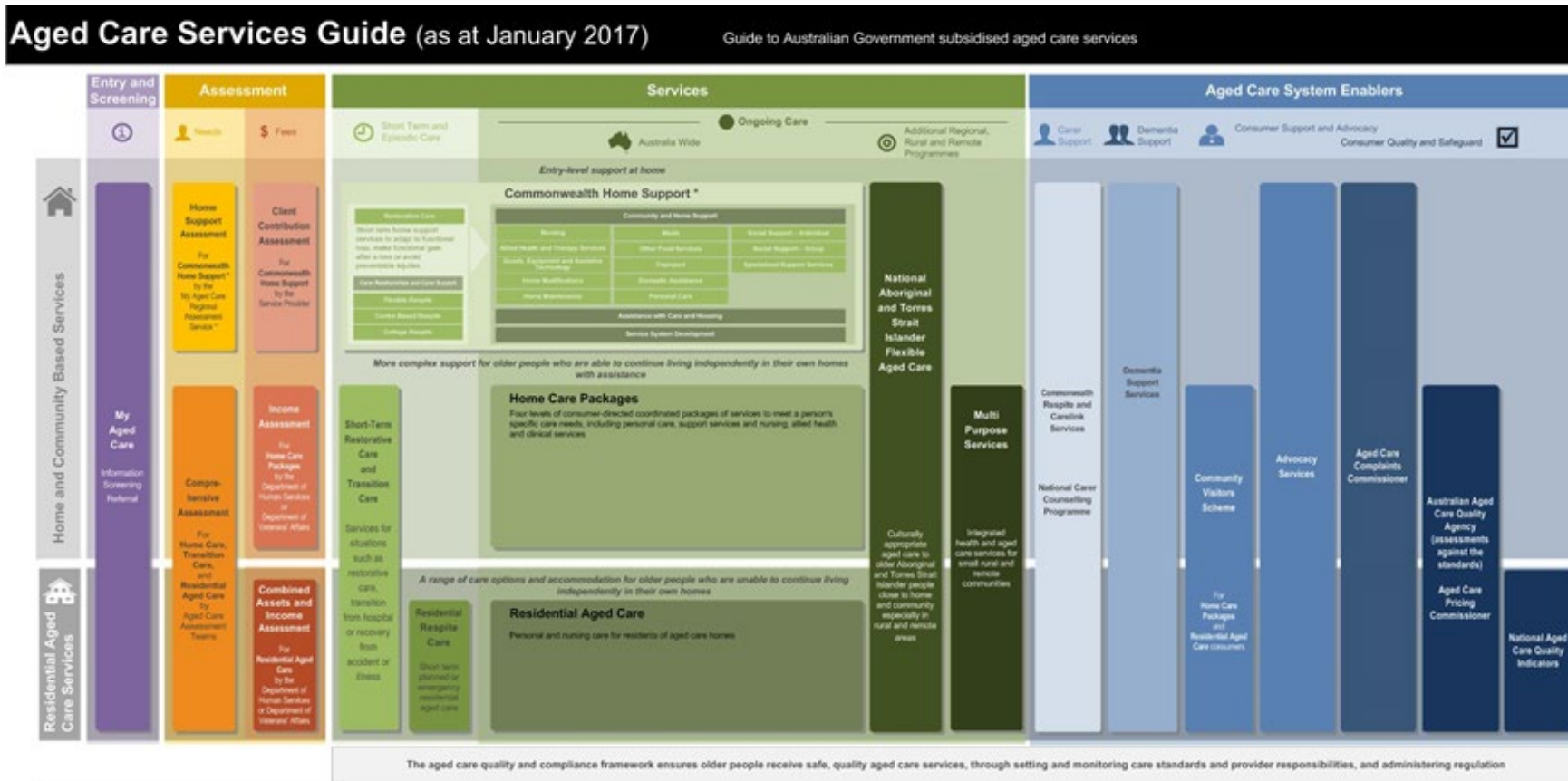
### **Individuals' funding**

Individuals are asked to contribute towards the cost of their home support if they can afford to. Individuals are not required to undergo an income assessment to access services, but their ability to pay is taken into account by service providers based on the RAS assessment. In setting the fees payable, service providers must adhere to the principles set out in the CHSP Client Contribution Framework to ensure fairness and consistency (Australian Government Department for Social Services, 2015). Individuals have choice over which CHSP provider they wish to receive services from, provided the provider has available funding.

# HCPP

In order to receive HCPP services, an individual is assessed by an Aged Care Assessment Team (ACAT) and their level of need is established.

Figure 1: Aged Care Provision. Source: ACFA, Fifth report on the Funding and Financing of the Aged Care Sector, July 2017



## Federal Funding

As outline above, there are 4 levels of HCPP. Australian Government funding for the HCPP is dependent on the package level that is identified in the ACAT assessment. The maximum annual subsidy payments by the government for the four levels of care package in 2015/16 were (ACFA, July 2017):

- Level 1: \$8,045
- Level 2: \$14,633
- Level 3: \$32,171
- Level 4: \$48,906

This amount is reduced by the amount consumers contribute towards the cost of their care by means of an income tested fee as described below.

The Australian Government also pays some supplements in special cases where care recipients require additional care and/or services. Supplements can be paid for those with dementia or cognitive impairment, for Veterans with a mental health condition, for individuals who require the ongoing administration of oxygen, and for those with a medical need for enteral feeding. Viability supplements might also be paid for those in remote and rural locations. Furthermore, hardship supplements are available to individuals who cannot pay their aged care fees due to reasons out of their control. (ACFA, July 2017).

## Individuals' Funding

Individuals are also asked to contribute towards their HCPP fees when they can afford to. All fees must be discussed between the provider and care recipient prior to the care package commencing. There are three fees that individuals may be asked to pay:

### 1. Basic daily fee

- Charged at 17.5% of the single person rate of the basic age pension. Current rates are \$10.32 per day or \$144.48 per fortnight (2018).
- This fee is the same regardless of the package level.
- All consumers can be asked to pay the basic daily fee, although supplements for Veterans and hardship supplements are available in special cases.

## 2. Income tested fee

- Individuals will undergo a formal means assessment by the Department of Human Services (DHS) or the Department of Veterans Affairs (DVA) to establish how much they should be contributing towards the cost of their care.
- This fee is paid in addition to the basic fee.
- Annual and lifetime caps apply to this fee. After these limits have been reached, the Australian Government pays the income tested care fee to the provider on behalf of the consumer.

## 3. Fees for additional services

- Individual HCPP providers might also charge fees for additional services that are not covered in the basic package levels. Any fees must be agreed between the consumer and provider before the services are delivered.

Since February 2017 the Government's subsidy funding is provided to the consumer who then chooses the provider and agrees on the services to be provided within their package. Consumers can change providers and change care services. This community directed care gives consumers choice and control over their care.

## 4. IDENTIFYING PALLIATIVE CARE NEEDS IN COMMUNITY CARE

The accurate and timely identification of palliative care needs is recognised as an essential component of effective palliative care delivery. Whilst there are national policies for palliative care, such as the National Palliative Care Strategy and national projects as mentioned above, palliative care models differ across Australia and each state has their own specific approach to providing palliative care services (AIHW, 2017).

Between 2015 and 2017, Palliative Care Australia consulted with key stakeholders and the palliative care community in order to update the 2005 4th edition of the 'Standards for Providing Quality Palliative Care for all Australians'. As a result, the 5th edition 'National Palliative Care Standards' was produced and published in 2018. The updated standards reflect the changing nature of palliative care over the past decade. "Assessing Needs" is the first of the 9 standards and is one of the fundamental building blocks to providing high quality care. Furthermore, a

mapping exercise carried out by PCA in the report shows that other agencies also recognise the assessment of needs as a core element of quality palliative care (PCA, 2018a, p.23).

CareSearch, an Australian Department for Health funded website that brings together information for patients, families and researchers on palliative care in Australia, outlines some of the tools and approaches which might be used to identify palliative care needs in general (CareSearch, 2018). These include a question on the perceived likelihood of needing palliative care within the next six months (the 'surprise' question), advance care planning, open discussions, use of the RADboud indicators for Palliative Care Needs (REDPAC), PEPSI COLA (a mnemonic encompassing all domains of holistic assessment: Physical, Emotional, Personal, Social support, Information and communication, Control and autonomy, Out of Hours, Living with your illness, Aftercare) and a distress thermometer. PalliAGED, a sub-website of CareSearch, also provides some guidance for various tools which can be used to identify palliative care needs in general (PalliAGED, 2018).

If given the choice, most Australians say that they would choose to die at home or in a home like setting (Swerissen, H and Duckett, S, 2014). Thus, it is important that there are national processes and protocols in place for palliative care to be provided within a person's own home.

## **GUIDELINES FOR A PALLIATIVE APPROACH IN THE COMMUNITY SETTING**

In 2011, the Australian Government Department of Health and Ageing published their Guidelines for a Palliative Approach for Aged Care in the Community Setting: Best Practice Guidelines for the Australian Context. These guidelines were proposed to act as a complement to the existing guidelines for palliative care in the residential aged care setting (APRAC, 2006) and were endorsed by the National Health and Medical Research Council. The guidelines define community aged care as "health related care and support provided in an older person's home, including retirement village setting, or similar, but excluding residential aged care facilities" (Australian Government DoHA, 2011, p.1). They are explicitly designed to aid health care professionals to provide palliative care in the community, but they also note that palliative care in the community will often be delivered by both health care and aged care teams working together.

The guidelines recognise that palliative care is often appropriate for individuals who are experiencing increasing frailty as a result of ageing. As with the 2006 guidelines for palliative care within residential care, the 2011 community care guidelines distinguish between three types of palliative care. Those are, a palliative approach, specialised palliative service provision and end of life care. Often in the community setting, older adults who are frail require a palliative approach to care. This palliative approach recognises that death is drawing near, although this could still be months or even years away. Furthermore, it is a holistic approach to care meaning that individual preferences are considered, families are involved and a multidisciplinary team of care providers is available as required. The importance of the relationship between health and aged care workers was also highlighted by the Australian Government funded Decision Assist project and enhancing links between the two was one of the key objectives of the project (Decision Assist, 2016).

The 2011 community care guidelines emphasise the importance of an individual's needs as the basis for implementing a palliative approach to their care. The guidelines' first 'good practice points' for health care professionals who are involved in providing a palliative approach to care discusses how the introduction of a palliative approach should occur on a case-by-case basis and should be updated continually as new needs emerge. The guidelines then discuss several conditions and symptoms that older people who require palliative care might experience and suggest tools to be used to assess and manage those symptoms. Moreover, the needs of family members as well as friends, volunteers and care workers, should also be considered and a number of tools are suggested to assess the needs of those carers. For example, the Caregiver Quality of Life Index, the Family Strain Questionnaire and the Caregiving at Life's End Questionnaire.

The guidelines also stress the importance of having open and honest communication with individuals and their carers throughout the palliative care process, to ensure the effective delivery of palliative care in accordance with a person's wishes. Advance care planning can help ensure that their wishes, including in terms of their treatment decisions, are known and respected and that there is a known substitute decision maker.

The palliAGED web-site (refer below) cites research that advance care planning appears to increase compliance with patients' end-of-life wishes and the chance of dying at home or in residential aged care. People with dementia with an Advance Care Directive (a more formal subset of a plan) in place are less likely to die in hospital or in ICU or undergo burdensome interventions such as ED transfer and hospitalisation in the last 3 months of life.

Although the need for aged care and health care teams to work together to deliver palliative care is well recognised, the interface between the two services still suffers from disjoint funding and service delivery. The experience of those receiving palliative care and their carers is not seamless.

The HCPP and CHSP service provision manuals explicitly rule palliative care out of scope of the services offered by these community aged care programmes. Specifically, the CHSP manual states that "CHSP nursing services are not intended to replace or fund support services more appropriately provided under another system, such as the health system or palliative care services" and "palliative care and nursing services that would otherwise be undertaken by the health system are not funded under the CHSP" (Australian Government DoH, 2017, p.46). The HCPP operational manual states palliative care under the list of services which care recipients might be able to receive but which they cannot access as part of their home care package (Australian Government DoH, 2015).

At the same time, there are no formal national arrangements for community aged care staff to work with health care professionals and specialist palliative care teams.



## THE ROLE OF THE GP IN COMMUNITY AGED CARE

General Practitioners play an important role in identifying palliative care needs and planning the provision of palliative care to patients. In the community setting, GPs often have an ongoing relationship with their patients and as a result might be best placed to initiate conversations about palliative care.

PalliAGED, an online guidance resource for aged care providers across settings developed by a team of researchers from the government funded CareSearch project team, sets out guidance for GPs to help them identify patients palliative care needs and provide palliative care within the health and aged care settings. PalliAGED suggests tools that GPs can use to recognise change in their patients. These include the Supportive and Palliative Care Indicators Tool (SPICT) to identify patients who are at risk of dying or deteriorating health, the 'surprise' question about the patients future life expectancy as well as health assessments of those aged 75+. The guidance also provides information about an app specifically developed for GPs – PalliAGEDgp - to support them in providing palliative care to older people in the residential or community setting. The app assists GPs to assess patients in terms of their palliative care needs and it provides a variety of information and resources to help GPs plan for the palliative care of the patient. (PalliAGED, 2018). PalliAGED also provides guidance and resources for GPs with respect to communication with patients, families and carers, advance care planning, providing palliative care and planning for home deaths.

### INDIVIDUAL STATE TOOLS

Individual states and territories, or particular agencies within those jurisdictions, may also implement their own tools for identifying the palliative care needs of recipients of community aged care services.

#### Victoria

The Victorian Government has set up its own palliative care and end of life framework. its focus is to guide providers across sectors to deliver high standard palliative care. Whilst their framework recognises the importance of palliative care within the community aged care setting, there are no specific guidelines outlined in their documentation to identifying palliative care needs in that setting (State of Victoria, 2016).

#### Western Australia

In Western Australia the Department of Health WA Cancer and Palliative Care Network (WACPCN) sets out a list of triggers for the referral of patients in general practice or hospitals to palliative care services (WACPCN, 2014). Again, they do not specifically state how the palliative care needs of older people receiving aged care in the community are identified.

## New South Wales

In New South Wales, HammondCare, together with a number of other collaborators, have developed a toolkit called Advance to help general practice nurses working with GPs to initiate advanced care planning for their patients (Advance, 2018). The toolkit includes screening and assessment tools to plan palliative care for patients.

In summary, it is evident that the identification of palliative care needs is an essential component of providing high standard palliative care in the community. The Australian Government, as well as leading palliative care research platforms such as PalliAGED and CareSearch, has set out guidance for the key elements of the provision of palliative care and different ways in which needs could be identified within the community aged care setting. However, there is no standardised set of national guidelines or a toolkit as to how palliative care needs of community aged care recipients should be identified. In their response to the Senate Inquiry into palliative care, Palliative Care Victoria recommended the development of evidence-based guidelines and the national roll-out of such guidelines (Palliative Care Victoria, 2012).

At the same time, there is considerable ambiguity around funding and the role that community aged care workers have in the delivery of palliative care, including in the identification of the palliative care needs of the people they are caring for. Palliative care is explicitly excluded from the list of services to be provided under both CHSP and HCPP, yet guidance from the Australian Government and from leading palliative care research platforms frequently discuss the idea of a multidisciplinary team of health and aged care professionals working together to deliver palliative care within the community. There is no national framework determining how this multidisciplinary team should operate.

The My Aged Care website also discusses palliative care at home and mentions that a number of aged care services, such as personal care, nursing care, domestic assistance, counselling, transport services, meals services and health support, are available to help a person who requires palliative care to stay in their own homes. The website also notes that as well as palliative care specialist teams, doctors, nurses and care workers can also deliver palliative care. This information seems to contrast with what is outlined in the official manuals of care provision under CHSP and HCPP and further highlights the vagueness associated with how community aged care is integrated with palliative care.

## 5. FUNDING PALLIATIVE CARE

One of the key concerns surrounding palliative care in Australia, which has been highlighted in the key documents mentioned in Section 2, is how it is funded. This concern further complicated

when it comes to palliative care within the aged care setting, due to the overlaps of the provision of care and the funding of that care.

## **FUNDING FOR PALLIATIVE CARE WITHIN HEALTH CARE**

### **Federal Funding**

Within the health care setting, the federal government provides funding for some palliative care Services.

Some palliative medicine specialist services are subsidised through the Medical Benefits Schedule (MBS). These services include, palliative medicine attendances in hospital or at home, and palliative medicine case conferences. In 2015-16, 74,300 MBS subsidised palliative care services were provided by palliative medicine specialists. These were provided to around 14,300 patients. Total benefits paid by the Australian Government in 2015-16 amounted to \$5.6 million. On average, between 2011-12 and 2015-16, spending on these items increased by 11.9% per year. (AIHW, 2017).

In relation to the Pharmaceutical Benefits Schedule (PBS), in 2015-16, 83,067 palliative care related prescriptions were provided to 52,470 patients, with 78.6% of the prescriptions being subsidised via the PBS. In total, the Australian Government paid around \$4.4 million in benefits for these medications. The benefits paid have increased by 9.4% on average per year between 2011-12 and 2015-16. (AIHW, 2017)

Federal funding is also allocated to palliative care via the sub-acute care component of hospitals' Activity Based Funding (ABF). ABF funds hospitals according to the volume and mix of patients they treat. The sub-acute care component of ABF includes palliative care, rehabilitation care, geriatric evaluation and management care (GEM), and psychogeriatric care.

Furthermore, health care funding is allocated to the 31 Primary Health Networks (PHNs) in Australia, many of whom choose to implement palliative care projects. The Department for Health announced funding via the 'Greater Choice for At Home Palliative Care' initiative of \$8.3 million in their 2017-18 budget. This funding was allocated to 10 PHNs. (Australian Government DoH, Feb 2018b)

In addition to this, as mentioned in Section 1, federal funding for health care also funds various palliative care projects, some of which are focused around education, training, advance care planning and quality improvement.

### **State Funding**

Individual states receive sub-acute care funds from the Australian Government and decide how to spend it as part of their overall responsibility for public hospitals and associated services. The 2012 Community Affairs References Committee on Palliative Care noted that there is "no

consistent reporting or data collection available that accurately sets out how the states and territories allocate the subacute funds they received from the federal government” (Senate Community Affairs References Committee, 2012, p.48).

States also provide their own funding for palliative care in public hospitals, hospices and community settings. Some palliative care initiatives are mentioned in individual state and territory 2017-18 budgets:

- **New South Wales:** In their 2017-18 Budget, the New South Wales Government set out plans to spend an additional \$100 million on palliative care services. This funding is to be spent both within the health and aged care sector. (New South Wales, 2017-18)
- **Victoria:** The Victorian Budget 2017-18 announced \$1.3 billion to be spent over four years within acute hospital and ambulance services, some of which will go to palliative care services. (Victoria, 2017)
- **Tasmania:** The 2017-18 budget set aside \$329.4 million to fund the continuing operation of the Mersey Community Hospital. This will include delivering “increased access to subacute services at the Mersey, including rehabilitation, pain management services, palliative and geriatric care” (Tasmanian Government, 2017, p68).

The 2017-18 budgets of the other States and Territories make no specific reference to palliative care funding. In this respect, Palliative Care Southern Australia highlighted the fact that the South Australian government failed to mention palliative care in its 2017-18 budget, despite the fact that there had been much discussion in Parliament of the need for appropriate funding for palliative care (Palliative Care Southern Australia, 2017).

### **Individuals’ payments for palliative care within healthcare**

Individuals pay out of pocket costs for any palliative care MBS items they receive from palliative medicine specialists. The AIHW categorise MBS subsidised palliative medicine specialist services as follows:

- Palliative Medicine Attendances
  - Attendances at hospital or surgery
  - Home visits
- Palliative Medicine Case Conferences
  - Community case conference- organisation and coordination
  - Community case conference- participation

- Discharge case conference- organisation and coordination
- Discharge case conference- participation

Individuals receiving palliative care in the form of PBS items will pay out of pocket costs to cover those medicines. A large part of palliative care is pain management which often involves the use of medications. Such medications can be prescribed by palliative medicine specialists, other medical specialists, GPs and nurse practitioners. In 2004, the Australian Government introduced the Pharmaceutical Benefits for Palliative Care Schedule. This is a sub-section within the PBS aimed at improving access to affordable and essential PBS medications for individuals who are receiving palliative care (AIHW, 2017). The AIHW summarised the items listed on the Palliative Care Schedule into the following groups (AIHW, 2017):

- Analgesics (drugs that relieve pain)
- Anti-epileptics (drugs that treat seizures)
- Anti-inflammatory and anti-rheumatic products (drugs that treat inflammation)
- Drugs for functional gastrointestinal disorders (drugs that treat impaired gastrointestinal function)
- Laxatives (drugs that treat constipation)
- Psycholeptics (drugs that tranquillize/depress the central nervous system)
- Stomatological preparations (drugs that treat diseases of the mouth)

## FUNDING FOR PALLIATIVE CARE WITHIN COMMUNITY AGED CARE

### Federal Funding

As discussed in Section 3, the Australian Government subsidises aged care services within the community via CHSP and HCPP. However, as noted in Section 4, the provision of palliative care services is explicitly excluded from the list of services subsidised under the two programmes because funding for these services occurs through the health system. As noted earlier, the Australian Government funds the MBS and PBS, which include palliative care services. Thus, there is currently no funding mechanism for the seamless delivery of palliative care within community aged care.

Having said that, Australian Government health funding to the 31 PHNs may provide an opportunity to fund palliative care services within the community aged care setting. In particular, the recent Department for Health funding via the 'Greater Choice for At Home Palliative Care' initiative of \$8.3 million will be used by 10 PHNs to deliver palliative care within the community

setting (Australian Government DoH, Feb 2018b). The initiative will aim to better coordinate and integrate end of life care across primary, secondary, tertiary and community health services. This will require PHNs to collaborate with State and Territory governments, local hospitals and aged care providers.

## **State Funding**

a Range of state funding initiatives fund palliative care services within the community setting. For example, Silver Chain in Western Australia, which is a not for profit organisation (funded by the Western Australia Department of Health, Department of Veterans' Affairs, donations and bequests), is a significant provider of health and aged care services to older people living in the community (NACA, 2012; Silver Chain website, 2018). They were also early adopters of a rehabilitation approach to aged care. They have extended services to South Australia, Queensland, New South Wales and Victoria. Silver Chain has a successful palliative care service that they offer to clients in their own homes. This care involves a multidisciplinary team including health professionals, aged care staff and volunteers. Their model of palliative care provision coordinates service provision across sectors and has demonstrated that people can be well supported to die at home. NACA advise that 60% of Silver Chain clients are supported to die at home compared to the national average of 25-30% (NACA, 2012).

The Victorian Government funds a number of community palliative care providers. In their 2017-18 budget, they announced growth funding of \$6.2 million for non-admitted palliative care in the community (Victoria, 2017). It is not aged care specific funding and it is not clear whether any of the funding will be allocated to care in the residential setting or to the home setting or either.

The New South Wales Government plans to spend an additional \$100 million on palliative care services within the health and aged care sector. Again, it is not clear how much of this funding will be allocated towards community aged care (New South Wales, 2017-18).

## **Individuals' payments for palliative care within community aged care**

Individuals on a CHSP or HCPP aged care package will pay the out of pocket cost for any MBS or PBS palliative care items they receive. Palliative Care Australia submitted a paper to the Senate Standing Committees on Community Affairs on an inquiry into the out of pocket costs in Australian Healthcare (PCA, May 2014). They drew attention to the fact that many medications prescribed outside of hospital are not listed on the PBS and are not affordable to patients, even though this might be the most appropriate medication for them (PCA, May 2014). The National Aged Care Alliance also identified limited access to non-PBS listed drugs in the community, which are available in hospital, as a significant barrier to the provision of palliative care in the community (NACA, 2012).

## 6. DISCUSSION AND CONCLUSIONS

Traditionally, palliative care has been seen as a health care issue and associated with end of life care. Further, half of all individuals who receive palliative care within the hospital setting are cancer patients- accounting for 50.6% of palliative care related hospitalisations in 2014-15 (AIWH, 2017). The funding mechanism for this type of care is clear and occurs via the Activity Based Funding (ABF) model.

Since the Productivity Commission Report in 2011, many reforms to aged care have been undertaken to create a system that is more focused on consumer choice and control, and quality of care. The Productivity Commission's report recognised the importance for policy to support older people dying well. However, there has been no policy change within aged care that is specific to palliative care. That is not to say that there has not been progress on the palliative care front - many government funded bodies and projects have emerged in the last ten years which have specifically focused on the role of palliative care within the aged care setting- – PalliAGED being a recent case in point.

Palliative care is extremely important within the community aged care sector where 70% of people say they would prefer to die if given a choice (New South Wales Health, 2017). Alternatives such as unnecessary and unwanted admissions to hospitals is increasingly seen as inappropriate, adds stress to the patient and their family and creates additional costs. As a result of population ageing as well as greater support for the elderly to remain in their own homes for longer, older people receiving aged care services in the community are increasingly frail and living with dementia and other chronic conditions which require a palliative approach to care. The overlap between the health care and aged care sectors is growing. However, there are problems to be addressed with respect to identifying and funding palliative care needs within community aged care.

With respect to identifying the palliative care needs of patients receiving community aged care, the 2011 Palliative Approach for Aged Care in the Community Setting guidance notes reflect the changing nature of palliative care specifically in the community setting. Key aged care palliative care research platforms such as PalliAGED and CareSearch have also compiled a series of resources and evidence for implementing a palliative approach within this setting. However, there are no nationally agreed and applied guidelines for identifying palliative care needs in the community.

In addition, it is unclear what role community aged care workers have in identifying the palliative care needs of their clients and in providing palliative care and how they are funded for any palliative care role they may play. The two community aged care programmes, CHSP and HCPP, explicitly exclude palliative care from the list of services provided. At the same time, it is widely recognised that a palliative approach to care should involve multidisciplinary teams working

together to deliver palliative care. There is no national framework on how health care sector workers, especially GPs, nurse practitioners, community nurses, pharmacists and some allied health professionals should work together with aged care staff to deliver palliative care in the community.

There are examples, such as Silver Chain, where palliative care services have been delivered within the community aged care setting. The 2016 Decision Assist project, funded by the Department of Health, sought to improve linkages between aged care staff and palliative care services. However, there is no national framework for community aged care providers and health care teams to follow in providing palliative care to older people living at home.

The final evaluation report of the Decision Assist project recommended that gaps in the training of aged care workers with respect to palliative care and advance care planning should be undertaken (Decision Assist 2016). Furthermore, Palliative Care Australia also call for “end of life care to be acknowledged as a basic competency for aged care workers (regardless of the setting in which they work) and included in the core curricula of aged care worker education and as an element of ongoing training” (PCA, 2018b).

Having said this, since palliative care services are excluded from the list of services to be provided via CHSP and HCPP, there is currently no clear funding mechanism for palliative care within community aged care. This further adds to the uncertainty surrounding the role that community aged care providers play in providing palliative care to their clients. The National Aged Care Alliance report recommended that the Australian Government should provide funding to establish linkages between aged care providers and specialist palliative care services within regional boundaries (NACA, 2012). These linkage projects should include community care as well as residential aged care.

Moreover, there is a considerable lack of data on palliative care within the community aged care setting and within aged care overall. In order to monitor the effectiveness of palliative care policy, the provision of palliative care and the quality of that care, good data are essential. The importance of data on palliative care has been recognised time and time again. Specifically, Recommendation 3.83 of the Senate Community Affairs References Committee’s review into palliative care in Australia (2012) suggested the need to introduce and develop a consistent nationally representative palliative care dataset.

The Urbis review of the National Palliative Care Strategy (2016) also called for a nationally consistent dataset to be developed. Furthermore, they recognised that there is no efficient mechanism for collecting data on palliative care within the aged care setting. Decision Assist (2016) also highlighted the significance of robust data in order to inform palliative care policy, planning and evaluation. They too noted the importance of having data to understand palliative care and advanced care planning within the aged care setting, which could be compared with data in the health care setting.



Overall, palliative care is a vital component of aged care. Whilst aged care has undergone considerable reform to improve consumer choice and control over their lives and their ability to die well, palliative care delivery within aged care and in the broader community setting has not had similar policy attention.

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