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Citation for published version:

Lemmon, E, Woods, M & Van Gool, K 2018 'Palliative care in residential aged care: Identifying and funding palliative care needs in Australia'. <https://www.uts.edu.au/sites/default/files/2020-04/ELDAC_report_1.pdf>

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Publisher's PDF, also known as Version of record

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RESEARCH AND EVALUATION



PALLIATIVE CARE IN RESIDENTIAL 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.

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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 residential aged care in Australia. In particular, it addresses the identification of the need for, and funding of, palliative care for permanent residents of aged care facilities. A companion paper explores the interface between palliative care and community 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' programs (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 have direct access to these services in the same manner as other people – either through community-wide government supported programs (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 access to aged care programs to obtain the assistance 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 programs 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, 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 Program.

In 2016/17 the Australian Government spent around \$17.1 billion on aged care service subsidies and supplements (including accommodation supplements) (Australian Government DoH, 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 programs 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 programs 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 LLLLB 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. (Australian Government DoH, 2010)

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 program 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 program was assessed by the program consortium as meeting the three program 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, programs, 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 residential care setting. A partner paper considers issues of identifying palliative care needs and funding for those receiving aged care services in the community.

This paper addresses two questions:

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

OUTLINE OF THIS PAPER

The remainder of this paper is set out as follows. Section 3 discusses residential care in Australia. Sections 4 and 5 address the two palliative care 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 RESIDENTIAL 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).

Residential care is provided within an RACF to individuals who are assessed as no longer being able to live in their own homes. Residential care provides a range of services in an approved facility, including support for activities of daily living as well as 24-hour nursing support. It can be provided on a permanent or respite basis.

Residential care is provided by approved service providers in accordance with the Aged Care Act 1997. There were 902 approved residential aged care providers as of 30th June 2017, with 239,379 individuals receiving permanent residential care in Australia in the 2016/17 period. The average resident was 82 years old on entry (82 for males, 84.6 for females) and on average an

individual remains in residential care for approximately 34.6 months. (Australian Government DoH, 2017).

The funding of residential care comes from Australian Government subsidies and contributions by residents. In 2015/16 the Australian Government spent around \$16.2 billion on aged care services overall, approximately two thirds (\$11.3 billion) of which was accounted for by residential care subsidies and supplements, and accommodation supplements. Consumers contributed \$4.5 billion during the same period (including care contributions, accommodation payments, living expenses and extra service fees). Overall, the government provided about 66% of the total provider revenue of care and accommodation in residential facilities. (ACFA, July 2017).

FEDERAL FUNDING

Australian Government funding for residential care is made up of four key components:

1. Basic care subsidy

- Calculated for permanent residents (who have been assessed as eligible for permanent residential care by an Aged Care Assessment Team (ACAT)) via the Aged Care Funding Instrument (ACFI). The ACFI is administered by the aged care provider and is used to assess the core care needs of care recipients. This in turn will determine how much the Australian Government (and the resident – see below) will subsidise and supplement providers for caring for that resident (noting that the funding for all residents is pooled by each facility).
- The ACFI tool involves two diagnostic sections and twelve questions to assess the need of the recipient, covering three domains: activities of daily living, behaviour and complex health care.
- After completing the assessments, residents are given a rating for each domain, which RACFs will subsequently use to claim a subsidy for that resident. The complex health care domain involves a series of questions relating “to the assessed need for ongoing complex health care procedures and activities” (Australian Government DoH, Dec 2016, p. 38). Within these is a question (question 14) to identify whether the resident is on a “palliative care program involving end of life ... where ongoing care will involve very intensive clinical nursing and/or complex pain management in the residential care setting” (Australian Government DoH, Dec 2016, p. 42). In order satisfy the requirement for this question, a pain assessment must be carried out and a directive issued by a Clinical Nurse Consultant/Clinical Nurse Specialist in pain or palliative care or a medical practitioner.

2. Respite care payments

- Payments are made for individuals who have been assessed as requiring respite care according to an ACAT assessment.

- This payment is made at a set low or high rate depending on the outcome of the ACAT assessment.

3. Accommodation supplements

- Based on a set maximum accommodation payment that the Government will pay, less the share paid by residents according to their income and assets assessment.

4. Other supplements

- Other supplements are paid to RACFs in certain remote and rural locations, and to those with a high proportion of homeless residents.

INDIVIDUALS' FUNDING

Private individuals' payments also consist of four key components as described below:

1. Basic daily fee

- Flat rate fee which is charged to all residents regardless of their income and is intended to cover the costs of daily living expenses such as laundry and meals etc.

- The price paid is currently 85% of the basic government age pension.

2. Means tested care fee

- A contribution by some residents for their care costs.

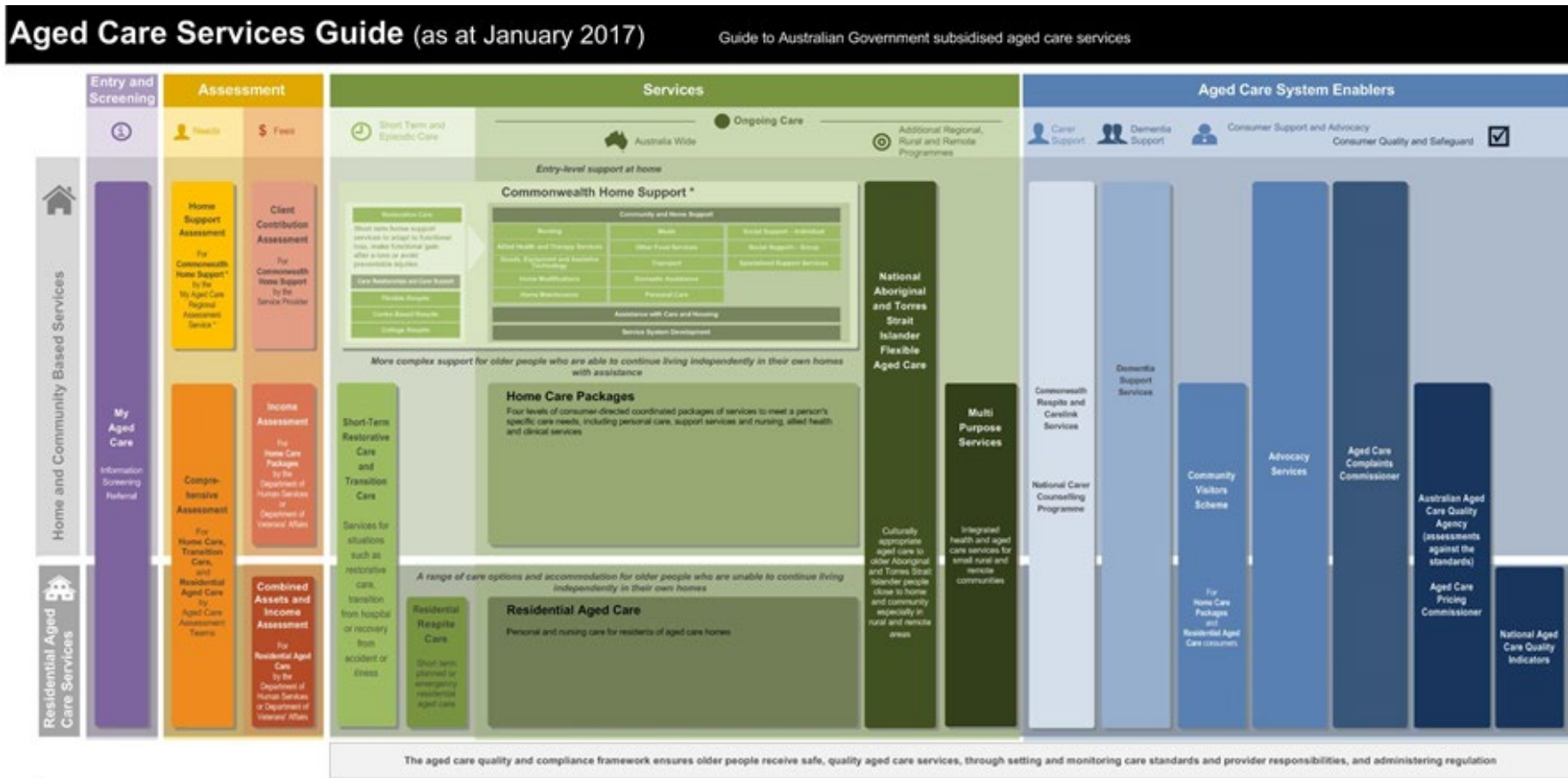
- This contribution is based on an income and assets assessment.

3. Accommodation payments

- Contribution towards accommodation costs.

- This contribution is based on an income and assets assessment.

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



4. Extra and additional service fees

- Extra fees are charged by some care providers to cover the costs for high standard accommodation, food and non-care services.
- Additional service fees may also be charged by providers who provide additional services other than those set out in the Schedule of specified care and services for residential care services (Schedule 1, Quality of Care Principles 2014)

The funding mechanisms for residential care are clearly defined and have evolved in line with the policy reforms.

4. IDENTIFYING PALLIATIVE CARE NEEDS IN RESIDENTIAL 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. The new standards recognise that identification of an individual's palliative care needs is one of the fundamental building blocks to providing high quality care. Accordingly, "Assessing Needs" is the first of the 9 standards. Furthermore, a mapping exercise carried out by PCA and set out 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).

Palliative care within residential aged care facilities is becoming increasingly important as the Australian population continues to age. In particular, 81% of permanent residents exit their residential facility due to death (AIWH, GEN, 2015-16a). This is an increase from 71% in 2008-09 (AIWH, GEN, 2015-16a).

In 2017 Palliative Care Australia, in collaboration with COTA Australia, Alzheimer's Australia, Aged & Community Services Australia, Leading Aged Services Australia and Catholic Health Australia, developed a set of principles for palliative and end of life care in residential aged care (PCA, 2017). The principles are guided by the National Consensus Statement: Essential Elements for Safe and High-Quality End-Of-Life Care, established by the Australian Commission on Safety and Quality in Health Care (Australian Commission on Safety and Quality in Health Care, 2015). The first principle states that "Consumers physical and mental needs at end-of-life are assessed and recognised" (PCA, 2017, p.3).

All residential aged care services have access to specialist palliative care support when required, within the limits of available resources. This is a particular challenge for rural and remote locations.

APRAC GUIDELINES FOR PALLIATIVE CARE IN THE RESIDENTIAL SETTING

In 2006 the Australian Palliative Residential Aged Care (APRAC) Project conducted a review into palliative care within the residential aged care setting. The review pointed out that as the population ages, RACFs face the unique challenge of providing palliative care to residents who are increasingly more likely to be living with dementia and other co-morbidities in the last stages of life. In 2015-16, 52% of permanent residents were identified as having dementia (AIWH, GEN, 2015-16b). As a result, their palliative care needs tend to differ from people diagnosed with cancers or other terminal illnesses and therefore they require a different approach to palliative care.

The outcome of that review was a set of guidelines, endorsed by the National Health and Medical Research Council (NHMRC), to support the delivery of palliative care within the residential setting (APRAC, 2006). The guidelines distinguish between three forms of palliative care for residents of RACFs, which reflect the changing needs of Australia's older population. Those are, a palliative approach, specialised palliative service provision and end of life care. The type of palliative care that is appropriate for an individual resident will depend on their needs. Proper and timely identification of those needs is vital for effective goal setting, planning and management of care.

APRAC considered that the palliative approach is one that requires the effective management of symptoms for people whose condition is incurable and aims to improve physical comfort and

function, as well as addressing their psychological, spiritual and social needs (APRAC, 2006). This approach is generally delivered by general practitioners, community nurses, allied health workers and other health workers, support staff and volunteers.

Specialised palliative services support the palliative approach with specific input from a specialised palliative care team or health practitioner. It aims to assess and treat the complex symptoms of the resident and provide information and advice on those issues to the aged care team.

Identifying when to implement a palliative approach or engage specialist provision requires ongoing assessments of the individuals' needs, rather than being based on their clinical stage or diagnosis. APRAC advised that the care team should have frequent and open discussions with the resident and their families. Discussions should generally involve Advanced Care Planning (ACP) to ensure that residents' wishes, including in terms of their treatment decisions, are known and respected and that there is a known substitute decision maker. The aged care team should ensure that residents' and families have full information about prognosis and condition trajectory, to promote understanding and encourage participation in the care decision making process.

End of life care can be relevant when a resident is in the final days or weeks of their lives. At this point, the care decisions for the resident will require frequent updating, and will often focus closely on the physical, emotional and spiritual comfort of the resident, as well as providing support for the family. The APRAC guidelines highlight that a resident's symptoms are merely indicators and should not replace individual assessments. The aged care team should prompt open discussions with families and residents about the terminal phase of the resident's life.

The APRAC guidelines do not constitute a specific toolkit or set of criteria to identify palliative care needs within residential aged care in Australia. At the same time there is no evidence to suggest how far the APRAC guidelines are adhered to within individual residential homes. Qualitative evidence cited in the APRAC project review in 2006 found that in many cases, where residents required a palliative approach, RACFs would choose to transfer residents to acute settings rather than attempt to implement the palliative approach themselves. This stresses the importance of having protocols, procedures and capabilities in place to recognise palliative care needs and to maximise the continuity of care for the residents in RACFs. In this respect 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.

The APRAC guidelines have more recently been incorporated and updated into an online evidence-based guidance and knowledge resource about palliative care in aged care for use by health professionals, the aged care workforce - PalliAGED. This resource also provides information for older Australians seeking advice on palliative care. The resource is the result of

close collaboration between key stakeholders from the aged care and palliative care sectors through a National Advisory Group as well as advice from clinical, evidence assessment and other content experts. The project also accessed expertise in evidence retrieval and translation from within the Australian Government funded CareSearch project to make sure that the evidence is ready for use.

THE ROLE OF THE GP IN RESIDENTIAL CARE

General Practitioners play an important role in identifying palliative care needs and planning the provision of palliative care to patients. In residential aged care this includes undertaking health assessments of residents and working with the RACF team, resident and family to implement palliative care.

In their 2006 Silver Book, The Royal Australian College of General Practitioners in Victoria set out guidelines aimed at assisting GPs to effectively provide medical care within RACFs specifically (RACGP, 2006). These guidelines discuss the role of the GP in palliative care for RACF residents and outline how GPs can help identify the palliative care that should be implemented.

More recently, PalliAGED, provides 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 residents in terms of their palliative care needs and it provides a variety of information and resources to help GPs plan for the delivery of that care. (PalliAGED, 2018)

INDIVIDUAL STATE TOOLS

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

Queensland

For example, Brisbane South Palliative Care Collaborative have developed a Residential Aged Care Palliative Approach Toolkit which is aligned with the 2006 APRAC guide for implementing palliative care within a residential setting. The toolkit “is a set of clinical, educational and management resources” which “assist residential aged care providers to deliver a comprehensive and evidence-based approach to palliative care for appropriate residents.” (Brisbane South Palliative Care Collaborative, 2013, website homepage).

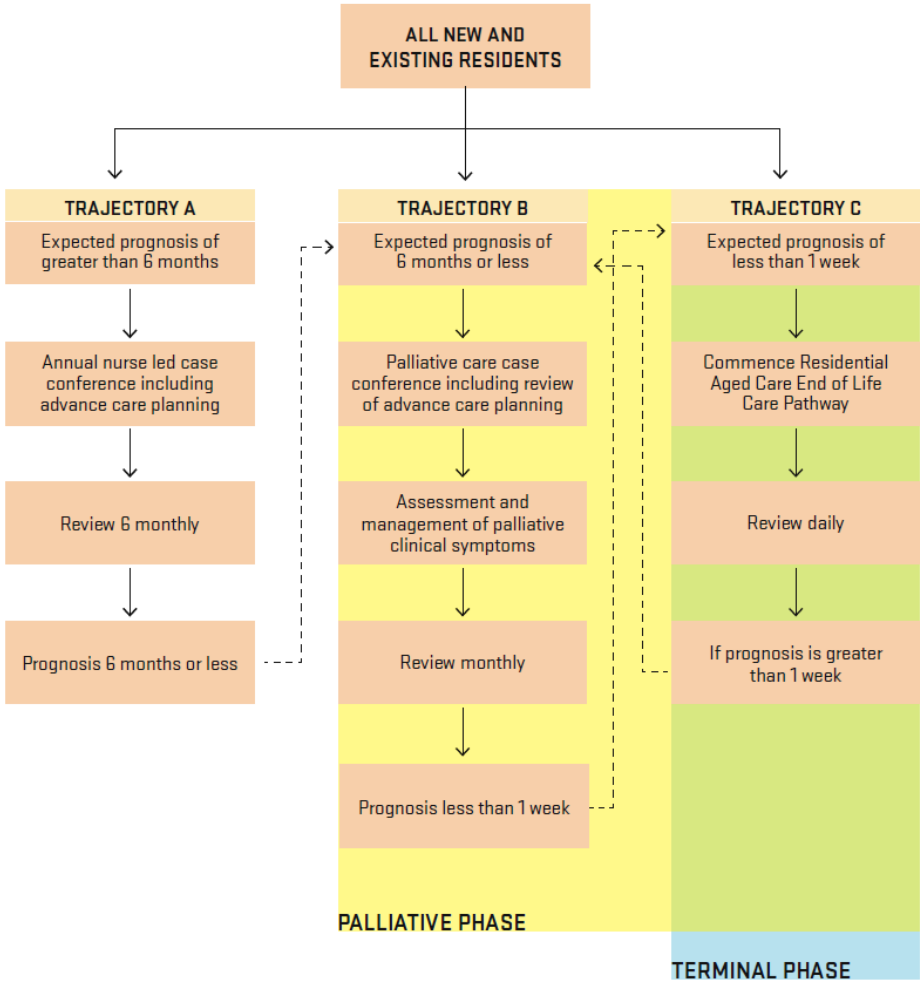
Within the toolkit is a Workplace Implementation Guide that is designed to support staff working in RACFs to implement appropriate palliative care (Brisbane South Palliative Care Collaborative, 2013). This guide sets out a Palliative Approach Trajectories Framework (p.5) as shown in Figure 2 below, which helps staff in identifying the palliative care needs of their residents. This framework echoes much of what is set out in the 2006 APRAC guidelines.

The framework shows that all new and existing residents should undergo assessments to determine which trajectory they are on. For those identified as being on Trajectory A, this should be reviewed every 6 months. For residents on a more critical Trajectory B, the framework suggests opening a palliative care case conference between a resident (and/or their family) and the aged care team to clearly identify the goals of palliative care and a review of their advance care plans. The resident's case should be reviewed on a monthly basis. Lastly, for residents on Trajectory C - the end of life pathway - care goals should be assessed and discussed with resident and family and reviewed daily.

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 residential care setting, there are no specific guidelines outlined in their documentation to identifying palliative care needs in RACFs (State of Victoria, 2016).

Figure 2: Palliative Approach Trajectories Framework- Brisbane South Palliative Care Collaborative



Western Australia

In Western Australia the Department of Health WA Cancer and Palliative Care Network (WACPCN) sets out a list of triggers for referral of patients in general practice or hospitals to palliative care services (WACPCN, 2014). Again, they do not set out specific guidelines for palliative care needs of RACF residents.

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. The focus of the toolkit is to start early conversations about palliative care but does not make explicit reference to the delivery of palliative care in residential aged care.

In summary, it is evident that the identification of palliative care needs is an essential component of providing high standard palliative care. Whilst there are a number of guidance documents both national and state specific for palliative care within the residential aged care setting, there are no national requirements or procedures for identifying palliative care needs in RACFs. Palliative Care Australia's position statement on Residential aged care and end of life calls for 'the development and implementation of nationally standardised referral criteria for patients with palliative care needs that promote needs-based service provision, support by a national rollout/education campaign' (PCA, 2018b). Furthermore, there is a considerable lack of data on how many residents receive palliative care assessments when appropriate, how well the needs of residents are assessed, by whom they are assessed and how well those assessments translate into best practice 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 is 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 2018)

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 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 tranquilize/depress the central nervous system)
- Stomatological preparations (drugs that treat diseases of the mouth)

FUNDING FOR PALLIATIVE CARE WITHIN RESIDENTIAL AGED CARE

Federal funding

As discussed in Section 3, the Australian Government provides the majority of funding for residential aged care, with the remainder being provided as resident contributions. Furthermore, the largest amount of that funding is in the form of the basic care subsidy, which allocates funding to aged care providers via the ACFI. The ACFI takes into account palliative care needs within item 12: Complex Health Care, as described in Section 3 above.

There has been a lot of discussion from key palliative care bodies surrounding the suitability of the ACFI for funding palliative care needs within residential care. The National Aged Care Alliance (NACA) also highlighted the problems inherent in the ACFI in their Aged Care Reform Series on palliative care. Specifically, they noted that it is difficult for RACFs to meet the ACFI palliative care funding criteria due to the need for a Directive from specialist staff and a pain assessment (NACA, 2012). In fact, in 2015-16, less than 3% of residents had an ACFI appraisal which indicated they required palliative care (AIHW, 2017). The NACA review recommends

changing the ACFI requirements for RACFs so that they can more readily access appropriate palliative care funding.

The findings from the 2012 Senate Community Affairs References Committee on Palliative Care echoed this view (2012). Moreover, a review of the ACFI carried out in 2017 by the Australian Health Services Research Institute (AHSRI) at the University of Wollongong concluded that the ACFI was “no longer fit for purpose” (AHSRI, 2017, vol. 1, p.7). The review found that some providers wouldn’t claim funding for the palliative care needs of the resident because it was easier to access funding via the pain domains of the instrument. Furthermore, they found that some providers and clinicians mentioned that the ACFI Palliative Care Guidelines, which support clinical care, are out of date and do not reflect the changed landscape of palliative care in the last decade (AHSRI, 2017).

In addition to this, the Tune Report (2017) chose to not consider the ACFI and its importance in evaluating the financial sustainability of residential care. In fact, the Report explicitly stated that the ACFI was out with the scope of the review, despite noting that “the effectiveness of ACFI has long been a source of concern for government and the sector, and has been subject to a number of changes intended to manage higher than expected increases in ACFI funding for residents” (Tune, 2017, p.19).

Federal health funding to the 31 PHNs can also be used to fund palliative care services within residential care. For example, in 2017 the Sydney North PHN commissioned HammondCare to provide palliative care training to nursing staff at some 20 to 30 local RACFs (Palliative Care Australia, August 2017). The Department for Health has also funded some palliative care projects within residential care. For example, Queensland’s Palliative Approach Toolkit for Residential Aged Care Facilities project, developed by Brisbane South Palliative Care Collaborative, is funded by the Australian Government Department of Health under the Encouraging Better Practice in Aged Care (EBPAC) Initiative (Brisbane South Palliative Care Collaborative, 2013).

State Funding

As set out earlier in this section, there is a range of state funding initiatives for palliative care services. However, given the progressive take-over of policy and funding responsibilities for aged care by the Australian Government, it is unlikely that State funding is allocated to palliative care services in residential aged care facilities.

Individuals’ payments for palliative care within residential aged care

As discussed above, any RACF resident who receives MBS or PBS palliative care items within their RACF will incur the out of pocket costs associated with those items. 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).

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 residential aged care sector where 81% of exits from RACFs are due to death (AIWH, GEN, 2015-16a). Alternatives such as unnecessary and unwanted transfers to hospitals is increasingly seen as inappropriate, adds stress to the resident 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, increasingly residents in RACFs are living with dementia and other chronic conditions and 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 residential aged care.

As discussed in Section 5, the ACFI requirements for palliative care funds are difficult to meet and claims for it are most likely a significant underestimate of the actual number of people who require palliative care services within residential care. Moreover, it is argued that the assessment is outdated and does not reflect the change in palliative care needs of older people living in RACFs. Following the review into ACFI by the University of Wollongong, the Department of Health has commissioned a residential care Resource Utilisation and Classification Study to inform potential reform options (ACFA, 2017).

With respect to identifying the palliative care needs of residents in RACFs, the 2006 APRAC guidance notes have been useful in reflecting the changing nature of palliative care specifically in the residential setting. The Queensland Residential Aged Care Palliative Approach Toolkit is similarly a significant resource (Brisbane South Palliative Care Collaborative, 2013). The PalliAGED and CareSearch online resources provide updated guidance for RACFs to identify the palliative care needs of residents. Palliative Care Australia have called for the development of a set of needs-based nationally standardised referral criteria that will outline the requirements for palliative care service provision within RACFs, supported by a national roll-out/education campaign (PCA, 2018b).

In addition, health care sector workers, especially GPs, nurse practitioners, pharmacists and some allied health professionals, can play a vital role in helping to identify and deliver the palliative care needed by residents in aged care facilities. It is imperative that they work closely with RACF staff, residents and their families in terms of advance care planning and the assessment and delivery of palliative care services.

There is a considerable lack of data on palliative care assessments and delivery within the residential 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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