Palliative Care Australia
Matters of life and death

The case for improved remuneration of palliative care in primary care

National Palliative Care Workforce Survey Report:
Palliative Care in Primary Care

FEBRUARY 2025

palliativecare.org.au

Palliative Care Australia

Palliative Care Australia is the national peak body for palliative care. PCA represents those who work towards high quality palliative care for all Australians who need it. Working closely with consumers, our Member Organisations and the palliative care workforce, we aim to improve access to, and promote palliative care.

What is Palliative Care?

PCA and the Australian Government (via the National Palliative Care Strategy 2018) subscribe to the World Health Organisation's definition of palliative care:

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

Acknowledgements

Palliative Care Australia thanks the survey respondents, who generously offered their time to consider and complete the National Palliative Care Workforce Survey. We are grateful for your considered input and the future impact this will have on improving the lives of people living with life-limiting illnesses.

The 2024 PCA National Palliative Care Workforce Survey and this report would not have been possible without the efforts of Les Winton from Winton Research & Insights. PCA is grateful to Les for his time, his advice and his dedication to promoting better palliative care.

Palliative Care Australia is located in Canberra. We acknowledge the traditional custodians of these lands and waters, the Ngunnawal and Ngambri Peoples and pay our respects to Elders past and present. We extend that same respect and acknowledge the continuing cultures and contribution of Aboriginal and Torres Strait Islander Peoples across Australia.

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Executive Summary

Overview

Primary care must play a major role if we are to meet the growing demand for palliative care as Australia's population ages. Palliative care is distinctly different to other kinds of care offered in primary care settings. It requires substantial time with patients and carers, preparedness for sensitive conversations including about prognosis and advance care planning, complex care coordination, and a multidisciplinary approach. Frequently, it involves intensive clinical care including at end-of-life, outside of standard hours and in people's own homes.

This report shares insights from Palliative Care Australia's 2024 National Palliative Care Workforce Survey, drawing on the responses of 129 respondents working in primary care settings. Survey results show that:

- Most primary care respondents (72%) reported that demand for palliative care had increased in the last year.
- Only 11% agreed that their practice is adequately funded to deliver palliative care.
- Just 35% reported that they had sufficient time to meet patients' palliative care needs.
- General practitioners provide palliative care "out of compassion" for minimal remuneration and often forego payment for palliative care provided at end-of-life because they feel uncomfortable about billing grieving family members.
- Many primary care professionals find palliative care rewarding and want to do more of it, but they are held back by remuneration structures that do not sufficiently recognise this work.

New approaches are needed to better remunerate palliative care in primary care. If this does not occur, the burden of care will continue to disproportionately fall on acute hospital-based services, which are more expensive than primary care, and poorly aligned with strong community preference to remain at home for as long as possible to receive palliative care (with appropriate supports).[1] International evidence shows that 1 in 3 patients near the end of life receive non-beneficial treatments in hospitals,[2] and in Australia it is conservatively estimated that 1 in every 9 people with a life-limiting illness undergo a potentially preventable hospitalisation in their last year of life.[3] These realities highlight the value of continuity of primary care for those with terminal illness.

PCA urges the Australian Government to consider the solutions proposed in this report, which have been developed with advice from primary care experts and key stakeholder groups.

Background and context

Australia's population is ageing, and the incidence of chronic and life-limiting illness is increasing. Half of all Australians over 65 have at least two chronic conditions,[4] many of which will become life-

limiting in time. Life-limiting conditions including heart disease, dementia and cancer are consistently the leading causes of death in Australia.[5] Yet there is a large and growing gap between community need for palliative care and our system's capacity to provide that care. Official data tells us that:

- Every day around 400 people die of a terminal illness in Australia. Each of these people could benefit from palliative care.[6]
- 62% of people with a life-limiting condition do not see a specialist palliative care service at any stage of their illness.[7]
- An estimated 92% of people who die in residential aged care would benefit from palliative care,[8] but, as of June 2023, just 0.1% of people living in residential aged care had entered to receive palliative care.[9]
- On average, people who receive specialist palliative care first do so just 15 days before death, despite palliative care being important from the time of diagnosis.[10]
- Australia has half the number of specialist palliative care physicians our population needs.[11]

Without action today, these pressures will intensify, as more people approach old age with life-limiting illnesses. Deaths per year will increase around 30% by 2040,[12] and almost double in the next 50 years.[13] Over that period the proportion of people aged 85 and over will triple.[14] Need for palliative care will continue to increase swiftly, and is projected to double by 2050.[15] Without action today, too many people will miss out on the palliative care they need, and to which they have a right under Australia's treaty obligations.[16]

To meet this need Australia requires a larger, well-trained, palliative care workforce. In addition to more specialist palliative care doctors and nurses working in hospitals, hospices and community settings, we need more primary care professionals with skills and training in palliative care. This includes general practitioners, primary care nurses (nurse practitioners, practice nurses and community health nurses), and allied health professionals (among them Aboriginal and Torres Strait Islander health workers and practitioners, occupational therapists, physiotherapists, paramedics, community pharmacists, speech pathologists, dieticians, and psychologists). All have a role to play in the care of people with life-limiting illness.

The primary care workforce is crucial to improving access to palliative care, now and in the future. But this change will only happen if we support and remunerate the primary care professionals who provide this care.

Key survey findings

PCA's survey findings confirm that the majority of **primary care professionals want to provide palliative care, but are held back by inadequate remuneration and funding arrangements**. A new approach to remuneration is urgently needed to meet current, and future, demand.

Survey findings confirm general practitioners, primary care nurses and other primary care professionals **see palliative care as an important aspect of their role.** The great majority of survey respondents agreed that:

- It is the responsibility of GPs to discuss palliative care with their patients (81% of respondents)
- All people should be able to access palliative care from the time of diagnosis of a life-limiting condition (93% of respondents)
- For people with life-limiting conditions, early discussion of palliative care is critical (96% of respondents).

Yet **primary care professionals cannot provide the palliative care they want to**. This is because remuneration for this work is inadequate. Existing MBS arrangements are not fit-for-purpose for the *"distinctly different"* approach demanded by palliative care – requiring extended time and sensitive communication with patients, assistance for carers and families (including those who are bereaved), complex care planning, asynchronous care, and intensive clinical care in the final weeks and days of life.

- 72% of primary care survey respondents said that demand for palliative care increased in the last year.
- Only 11% agreed that their practice is adequately funded to deliver palliative care.
- Only 35% reported that they had sufficient time to meet patients' palliative care needs.

GPs reported they provide palliative care *"out of compassion"* for minimal remuneration, providing services not covered by Medicare pro-bono, and often foregoing payment for palliative care provided at end-of-life because they feel uncomfortable about billing grieving family members.

Respondents told us:

> "Most GPs who provide palliative care accept that they are doing it out of compassion and wish to assist the patients, whilst taking a very low renumeration for this."

> "Medicare billing does not reward long complex consults with palliative care patients."

> "Medicare needs to start recognising the importance of primary care in palliative care by funding it properly."

This is an unsustainable basis for primary care involvement in palliative care. Concerningly, survey findings indicate that recent primary care funding reforms (voluntary patient enrolment via MyMedicare, the General Practice in Aged Care Incentive, and the introduction of long MBS

consultations of 60+ minutes) are to date not sufficiently incentivising additional palliative care activity in primary care.

Primary care professionals said:

> "The funding model change is not sufficient incentive to change practice."

> "The changes effectively decrease funding for palliative care in RACF settings."

Priorities for reform

A succession of reviews and inquiries over many years has called for changes to how primary care is funded, to recognise its evolving role and the changing patient profile. These include the 2022 *Strengthening Medicare Taskforce Report*, and the 2024 *Review of General Practice Incentives* and *Unleashing the Potential of our Health Workforce: Scope of Practice Review*.

PCA now adds our voice to calls for further reform to primary care funding. Cost should never be a barrier to receiving timely palliative care. Patients with a life expectancy of a year or less should be bulk-billed for their Medicare consultations, and GPs should not be forced to choose between billing a dying patient or receiving inadequate remuneration from Medicare.

New approaches to funding must be introduced to ensure all primary care professionals are fairly remunerated for providing care to people with terminal illnesses. A better remuneration model will:

- Recognise the unique demands of palliative care in primary care.
- Fund palliative care activities that are currently provided at a financial loss in general practice.
- Support consistent provision of quality palliative care as a core aspect of viable and sustainable general practice.
- Incentivise multidisciplinary primary care, and better enable all primary care clinicians (GPs, primary care nurses, nurse practitioners and allied health professionals) to work collaboratively to their full scope of practice when providing palliative care.
- Expand access to primary care to more Australians with life-limiting illnesses, and their families and carers.

PCA proposes five reforms to primary care funding, to increase access to palliative care:

1. A **new practice-level payment** to remunerate palliative care (for example, advance care planning, developing goals of care, and referral to family and social supports) – covering

activities undertaken by primary care multidisciplinary teams that are not currently billable to Medicare.

2. **Further guidance for general practice about the use of existing longer consultation items** (Level C, D and E) to be more explicit about their relevance to palliative care.
3. **Additional funding** for home visits, after-hours care (in-person and via telehealth), and shared care arrangements with specialist palliative care teams.
4. **Creation of an expert working group** to advise the Australian Government on how to best increase palliative care activity in primary care.
5. Development of a **Palliative Care in Primary Care Monitoring and Evaluation Framework**, to fill the gap in knowledge about palliative care provision and quality in primary care.

Properly resourcing these reforms will ensure all people who need palliative care in primary care can access it, now and into the future.

The following national organisations broadly support the 5 recommendations:

Australia New Zealand Society of Palliative Medicine
Australian College of Nurse Practitioners
Australian College of Rural and Remote Medicine
Australian Healthcare and Hospitals Alliance
Carers Australia
National Aboriginal and Torres Strait Islander Ageing and Aged Care Council
National Rural Health Alliance
Palliative Care Nurses Australia
Palliative Care Social Work Australia

PCA's member organisations are:

Palliative Care NSW
Palliative Care NT
Palliative Care Queensland
Palliative Care SA
Palliative Care Tasmania
Palliative Care Victoria
Palliative Care WA
Australia New Zealand Society of Palliative Medicine
Palliative Care Nurses Australia
Palliative Care Social Work Australia

1. This report

This report shares findings from PCA's 2024 National Palliative Care Workforce Survey. The survey heard from 1,400 health professionals and volunteers about their views on priority issues for Australian palliative care.

This report focuses on responses from 130 survey participants who provide palliative care in primary care. It builds on these survey findings by presenting proposals for reform to primary care remuneration to encourage more delivery of palliative care in primary care.

This is the second in a series of reports that share insights from the National Palliative Care Workforce Survey. A previous report explored workforce wellbeing. All reports in the series are available online: HERE

2. Method

1.1 The National Palliative Care Workforce Survey

The 2024 National Palliative Care Workforce Survey aimed to capture the views of the Australian palliative care workforce on priority issues including demand for care, organisational capacity, workforce sustainability, wellbeing and post-COVID recovery, and the introduction of Voluntary Assisted Dying (VAD) in most jurisdictions.

The survey was launched in National Palliative Care Week (19-25 May 2024) and was open until 11 August 2024. Anyone who worked for a service providing palliative care was welcome to complete it. The survey was promoted via social media, digital platforms, traditional media and direct invitations. PCA member organisations also promoted the survey to their networks.

As the survey sought information about workforce experiences, the findings presented in this report reflect the views and perceptions of health professionals, rather than the official positions of the services for whom they work, or objective data about service provision.

1.2 Primary care respondents

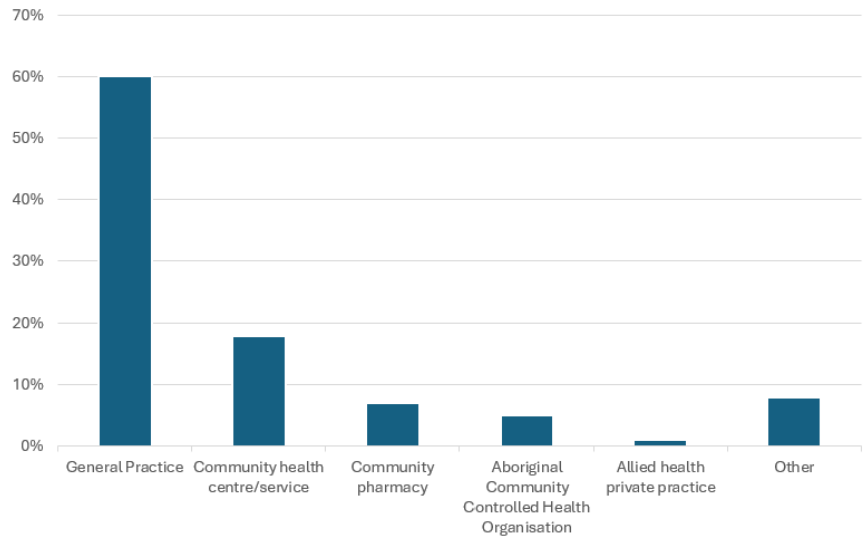
The survey sample includes 129 respondents who provide palliative care in primary care. These respondents were asked about issues including:

- Their attitudes toward palliative care, and their knowledge and confidence to provide palliative care.
- Their experience of referral to, and cooperation with, specialist palliative care services.

- Their perceptions of demand for palliative care in primary care, and a range of workforce challenges (e.g. recruitment, retention).
- The impact of recent primary care reforms, including the introduction of voluntary patient enrolment (through MyMedicare).
- Perceived impacts of VAD, in jurisdictions where VAD legislation has been introduced.

A majority of respondents to the National Palliative Care Workforce Survey work in General Practice (60%), followed by community health services. Smaller numbers work in community pharmacy, Aboriginal Community Controlled Health Organisations, and in allied health private practice.

Figure 1: Services where respondents work (n = 129)

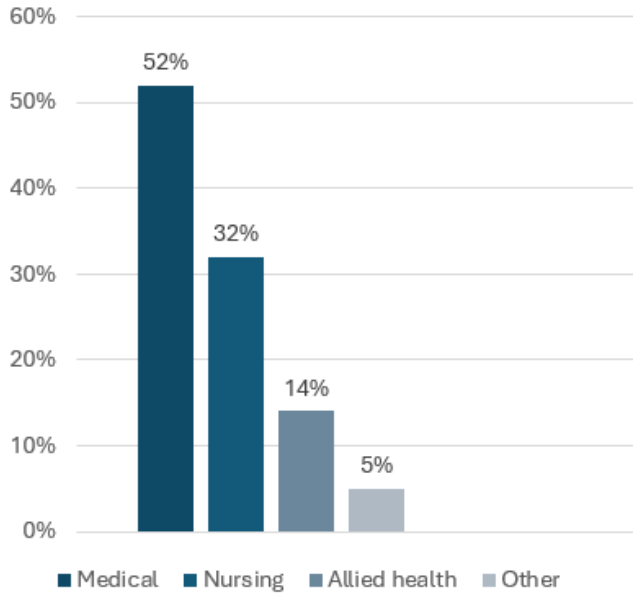


A majority of respondents to the survey (52%) were medical practitioners. Of these, 40% were general practitioners (GPs), followed by rural generalists (11%), and 1% of respondents were other medical specialists working in primary care.

A further 32% of respondents were primary care nurses. Of these, a majority were registered nurses (25%). The survey also heard from nurse practitioners (2%), enrolled nurses (3%) and other nursing professionals (2%).

Allied health respondents (14% total) included pharmacists (6%), social workers (2%), occupational therapists (1%), physiotherapists (1%) as well as “other” allied health professions (4%).

Figure 2: Professions of respondents (n = 129)



3. Findings

3.1. Primary care clinicians see palliative care as part of their role

Survey respondents working in primary care were clear that primary care services and clinicians have a central role in primary care. This is consistent with previous research which indicated that a majority of Australian GPs see palliative care as part of their work.[17]

Most survey respondents (81%) agreed that it is the responsibility of GPs to discuss palliative care with their patients. 78% of respondents agreed that care coordination, in their clinic or service, includes providing palliative care to patients with life-limiting illness or frailty.

The overwhelming majority (93% of respondents) were of the view that people should be able to access palliative care from the time of diagnosis with a life-limiting condition. 96% agreed that early discussion of palliative care is critical, and most (69% of respondents) were comfortable to proactively start this discussion with patients and carers rather than tending to wait until a patient or carer raises the issue. Overall, respondents saw themselves as knowledgeable about palliative care, and confident and comfortable providing it. This reinforces earlier research which showed that one in four Australian GPs (25%) find palliative care to be among the most rewarding aspect of their role.[18]

3.2. Palliative care is a unique aspect of primary care

Respondents to the survey indicate that palliative care is *"distinctly different"* to other kinds of primary care. In their responses to open-ended survey questions, primary care professionals drew attention to the unique requirements of a palliative approach, including:

- **Time for unhurried conversations with patients and carers,** about complex medical matters as well as the personal and psychosocial aspects of care. Discussions about prognosis, care options and preferences, advance care planning, emotional wellbeing, family meetings and bereavement support are all examples of issues that require longer and/or multiple consultations.
- **Significant asynchronous non-patient facing care** (much of which is not billable to Medicare in General Practice contexts), including liaison and complex care coordination with other services and professionals – both with other primary care professions, with specialist palliative care services, and with other clinical specialities treating a person with a life-limiting illness.
- **Complex clinical care**, including symptom management and responding to rapid or unexpected changes in symptoms.
- **A requirement to be available to provide care at short notice and outside standard hours**, particularly in the last weeks and days of life – including for clinical assessment and advice, and carer support (whether via telehealth or home visits, which may be extended and/or frequent at end-of-life).

- **Preparedness for the emotional and personal demands of palliative and end-of-life care**, which are inherently greater than other aspects of general practice care (such as routine or preventative care).
- **Confidence to communicate with patients, carers and families about sensitive matters** including death and dying; with sensitivity to patients' diverse preferences for how and when these conversations happen.

For example, survey respondents said:

> "Palliative care is time-intensive, and delivered in different settings (surgery, home, telehealth and residential aged care). It is distinctly different from usual consultations."

> "Cultural differences and patient perceptions exist around 'death avoidance' and challenge the ability to open the questioning about 'advanced care'."

Reflecting these realities, just over half of the respondents (55%) said it is commonly challenging to care for palliative patients.

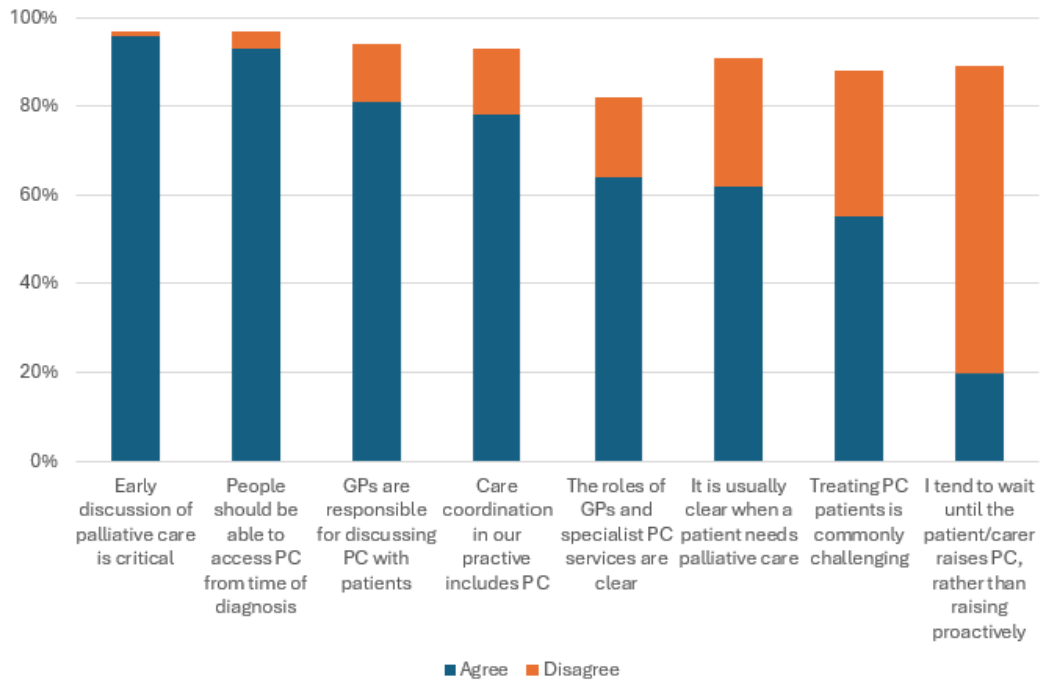
3.3. Primary care clinicians lack time and funding to meet growing need

A majority (72%) of primary care respondents to the National Palliative Care Workforce Survey said that in the past year the service or practice where they work has experienced increased demand for palliative care. This reflects a challenge for the whole palliative care sector - a majority of palliative care workers and volunteers across all sectors reported a significant increase in need for care.

Survey findings indicate that the increase in need for palliative care has not been matched by the necessary investment in additional services and professionals. Only 11% of primary care respondents to the National Workforce Survey said their practice or service is adequately funded to deliver palliative care. Over half (53%) of primary care professionals were of the view that there is insufficient time to meet the needs of patients.

Figure 3: Primary care professionals' views on their role in palliative care

(n = 129)



3.4. Coordination with specialist palliative care services requires support

Survey findings indicate that coordination of care between primary care and specialist palliative care clinicians and services can be challenging. Only 18% of respondents consider the boundaries between the role of primary care and specialist palliative care services to be clear. While there are likely a number of factors contributing to this situation, survey findings indicate inadequate remuneration for general practitioners and primary care teams to undertake liaison and care coordination is a significant challenge. For example, one respondent said that:

> "We... aren't paid for consultation with the local palliative care team, discussing and arranging care for home, or calling for advice if the patient is not present."

However, despite these uncertain boundaries most respondents (90%) feel comfortable making a referral to specialist palliative care services.

3.5. MBS remuneration is inadequate, and not the right fit for palliative care

Survey findings reflect concerns that that primary care professionals are not adequately remunerated for provision of palliative care under current MBS arrangements. Medicare Benefits Schedule (MBS)

billing arrangements are ill-suited to the longer consultations, asynchronous care and complex symptom management often required in palliative care. Current funding models do not encourage primary health professionals to provide palliative care in a collaborative and flexible way that can incorporate critical activities such as:

- non patient facing support
- longer consultations which might include family and carers
- care at home
- grief and bereavement support for families following a death.

There are no specific MBS items for important activities in palliative care (such as Advance Care Planning), making it difficult to bill for this work particularly when activities are not patient-facing. MBS billing arrangements require the treating general practitioner, or nurse practitioner, to provide direct care to the patient, allowing minimal flexibility to remunerate care delivered by other nursing or allied health team members. This undermines multidisciplinary team care, and limits the contribution of primary care nurses and allied health professionals to the care of those with life-limiting illness.

> "Medicare billing does not reward long complex consults with palliative care patients."

> "Medicare rebates go nowhere near the remuneration for time required to spend with palliative care patients."

> "The system is very poorly remunerated."

> "There are no dedicated MBS item numbers for Advance Care Planning or palliative care services."

Current MBS arrangements are a particularly poor fit for end-of-life care. Existing arrangements do *"...not adequately reimburse the time and commitment required by GPs in the terminal phases of care,"* during which a GP may provide frequent clinical advice to patients and carers, including outside usual practice business hours or via multiple home visits. Moreover, essential care provided following a person's death is not billable. There are no MBS item numbers that cover bereavement support for family members and carers.

"Most GPs who provide palliative care accept that they are doing it out of compassion and wish to assist the patients, whilst taking a very low renumeration for this."

"...When I do get involved in palliative care it actually costs me considerable income to do so. Whilst I'm happy to do that for a small number of patients, I cannot do it for many."

Survey evidence also indicates that introduction of Voluntary Assisted Dying (VAD) legislation in most jurisdictions is adding to the financial burdens for primary care professionals: 46% of survey respondents were of the view that their service is not appropriately recompensed for VAD services. All of these challenges are exacerbated by the reluctance of GPs to bill patients who are close to death. They perceive this could be considered *"wolfish"* and inappropriate at a challenging time for patients and families.

Because there are no palliative care-specific MBS items, it is not possible to identify the prevalence of palliative care activity in primary care settings from MBS administrative data. PCA is advocating for better monitoring and evaluation of palliative care provided in primary care. This evidence is essential, to expanding access and improving the quality of palliative care provided in the primary care sector.

3.6. MyMedicare has not incentivised more palliative care in primary care

MyMedicare – an overview

Recent changes to Medicare aim to support continuity of patient care, particularly for people with chronic and complex health concerns. The most significant of these recent reforms is the introduction of MyMedicare, a voluntary patient registration scheme.

MyMedicare aims to formalise the relationship between patients, their general practice, general practitioner and primary care teams.[19] The scheme intends to support patients to access longer funded telehealth consultations and offers a triple bulk billing incentive for longer Medicare benefits Scheme (MBS) telehealth consultations (Levels C, D and the 60-minute Level E consultation introduced in 2023) for children under 16, pensioners, and concession care holders. Participating practices can also access to the new General Practice in Aged Care Incentive.[20]

MyMedicare begins to shift funding for General Practices away from reliance on fee-for-service, and toward a blended payment model. This is a significant change which aligns with the recommendations of many reviews and inquiries into primary care funding, including the Strengthening Medicare Taskforce.

Survey responses indicate that the introduction of MyMedicare has not, at this stage, positively impacted primary care capacity to offer palliative care. 44% of primary care respondents said MyMedicare had not made any positive difference to palliative care provision or access for patients. Instead, it had introduced a range of new practical and administrative requirements (for patients and providers), which respondents said added workload without (as yet) providing readily-identifiable benefits for patients or professionals. Respondents described MyMedicare as a *"complete administrative nightmare"*, offering *"no benefit to patient or doctor"* in the palliative care context, and requiring *"time-consuming"* explanation to patients. Alarmingly,15% of primary care respondents were of the view that recent changes will make it harder to provide palliative care in primary care.

Respondents noted that patient enrolment can in fact create a barrier to palliative care, if a person is not registered with the right practice:

> "It involves the patient having to register to a certain medical practice to attract funding. If the patient lives in another town they may not be registered to our clinic, or if they do change may not consider it a priority to update this."

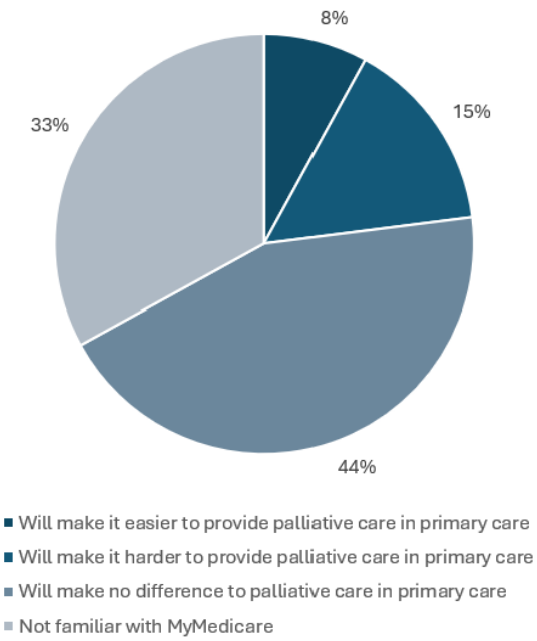
Nor did respondents think that the introduction of MyMedicare has prompted improved access to multidisciplinary palliative care, including nursing care:

> "Medicare changes do not provide nursing services from GP clinics to visit our patients at home for more thorough assistance/assessment."

Respondents were clear that, to date, this new approach to primary care funding has not resolved the issue of inadequate remuneration for palliative care activity. GPs and other primary care clinicians working in general practice continue to *"feel overwhelmed due to time and cost constraints"*.

> "The provision of... [palliative care] support will continue with those who were already providing it; the funding model change is not sufficient incentive to change practice."

Figure 4: Respondents' view on impact of recent changes to Medicare, including introduction of MyMedicare (n = 129)



3.7. The General Practice in Aged Care Incentive is not achieving its aim

Primary care workers raised additional challenges with remuneration models via MyMedicare. The recently-introduced General Practice in Aged Care Incentive (GPIACI) aims to make it easier for older people living in residential aged care to receive regular visits and care planning services from their GP and practice. The incentive is linked to MyMedicare: it provides GPs and practices with an incentive payment for providing care to each of their MyMedicare-registered patients living in a residential aged care facility.[21]

Unfortunately, early evidence from the National Palliative Care Workforce Survey indicates the initiative may not be achieving its goals of incentivising more primary care professionals to visit residential aged care. This is because this MBS item's eligibility requirements and quarterly assessment periods exclude many patients with short life expectancy. This appears counter to the policy intent behind the GPIACI.

The following quote exemplifies the problem:

> *"I am a GP managing nearly 100 patients in a local aged care facility, often covering for regular GPs and handling urgent care. I also look after palliative care patients as a regular GP.*

I am particularly concerned about the impact of the new incentive scheme on newly admitted palliative care patients (non-respite), who typically pass away within 2-4 weeks.

These patients, transferred from a hospital to nursing homes after an acute terminal diagnosis for end-of-life care, require intensive management including end-of-life support, family meetings, palliative care medications including syringe drivers, collaboration with local palliative care teams, and formulating death certificates upon their passing—often done pro bono as there is no Medicare rebate for this.

The new scheme's quarterly assessment periods exclude these patients from the incentive criteria since they usually do not live long enough to meet the minimum servicing requirements of two eligible services in separate months within a quarter.

This exclusion means GPs like myself do not qualify for incentive payments despite providing substantial care. How will the Department address this gap to ensure that newly admitted palliative care patients receive the necessary support, and that their GPs are fairly compensated?"

Other survey respondents shared that:

"Patients in RACFs do not meet the requirements for incentive payments due to short life expectancy."

"MyMedicare is seriously affecting the capacity for feasible business models of operating in aged care."

"The changes effectively decrease funding for palliative care in RACF settings."

3.8. Telehealth access remains challenging for patients

Despite recent changes to improve access to telehealth for MyMedicare-enrolled patients, primary care workers survey told us that *"access to longer consults will make it easier, but the rebate is still*

inadequate" and *"...there's still a gap."* Practices still need to weigh up the business impact of delivering services via telehealth, since it can cost them *"...considerable income to do so."*

One respondent observed that *"Telehealth billing requires a prior in-person visit within 12 months, limiting its use."* In the palliative care context, it is expected that services provide flexible, person-centred care, with ease of access and choice for the person.[22] Unfortunately, the requirement for an annual in-person visit to a GP practice (to be eligible for additional telehealth consultations) can impose an impractical burden on a person with a life-limiting illness as well as creating a cost and time burden. This requirement may also necessitate a home visit by a primary care clinician, if the person cannot attend the clinic in-person to receive necessary palliative care – with further cost impacts.

> "Even with longer phone calls permitted in MyMedicare the bulk billing rate is so low compared to costs that the economics of remote accessing pal care just don't add up."

3.9. Home visits are not recompensed

The Australian Government has introduced targeted measures to enable more delivery of palliative care at home,[23] reflecting the preference of around 90% of Australians to receive palliative and end-of-life care at home with appropriate supports.[24] However, survey findings indicate that primary care workers find the *"... ability to treat and visit in a patient's own home is still very prohibitive due to time, geographic, and cost reasons*." Given *"...it is expensive to visit someone at home and provide quality assessment and care*", recent changes through MyMedicare still "...*do not pay for the travel time of home visits*."

Many primary care workers who responded to the survey cited inadequate remuneration for home visits, with one person saying: *"I may have to reconsider home visits if they aren't adequately remunerated."* There is no remuneration for travel time, which places additional and significant burdens on primary care workers in regional Australia.

> "Bulk billing home visits is essentially uneconomic."

> "I try to visit my patient[s] out of hours to limit the impact on my other patients, but it is not sustainable."

> "The rebates for home visiting and long consultations remain pitiful."

3.10. Better funding for out-of-hours care is a priority

Limited capacity to provide 24/7 palliative care was another area of concern for survey respondents. Many specialist palliative care services are unable to meet the demand for out-of-hours care due to staffing shortages and funding limitations. If primary care needs to fill this gap, current incentives and funding arrangements for after-hours primary care are highly inadequate.

> The changes (to MyMedicare) do not pay for the travel time of home visits... and does not cover family meetings and the time these take. And they do take time – because they are important. Often, these conversations... occur out of hours due to family availability."

> "There are no incentives for home visits or proper funding for... after-hours services."

3.11. People in remote and regional areas have urgent unmet needs

Remote and regional areas pose particular challenges for palliative care service provision. Access to palliative care specialists is limited and inconsistent,[25] with the burden for palliative care generally falling on the local GP and/or primary care service, if there is one. While most GPs encounter the need to provide palliative care services, those in country towns and rural and remote areas see a higher number of people for palliative care than their counterparts in capital cities.[26] Primary health care nurses, including advance practice Registered Nurse roles and Nurse Practitioners, also play a critical role in providing palliative care in rural and remote areas.[27] This emphasises the need for increased primary care services in remote and regional areas. Survey respondents indicated that "*[t]here are no other access points or services available in rural settings*" and that *"palliative care services for remote communities are phone only."*

This indicates an urgent need for primary care funding and remuneration reform, to ensure equitable access to palliative and end-of-life care for people in regional communities. PCA notes the relevance of the Primary care Rural Integrated Multidisciplinary Health Services (PRIM-HS) approach, as a successful model of locally led and owned, multidisciplinary care enabled by block funding in thin regional markets.[28]

"MyMedicare does not suit a remote service model."

"Home visits remain costly, especially in rural areas."

3.12. Longer MBS consultations are promising, but barriers remain

Longer MBS consultation items (Level C, D and particularly the one-hour "Level E" consultations introduced to the MBS in November 2023) can support the unhurried conversations and complex clinical care often required in palliative care. However, primary care respondents said that while the new 60-minute consultations are positive, longer consultation items alone are insufficient to increase palliative care activity in primary care. In the time required for one Level E consultation a GP could complete 3 to 4 Level B consultations and be better remunerated for simpler and likely less demanding work. In the "see and treat" model increasingly predominant in primary care, 10-15 minute consultations with high volumes of patients is the norm. Generally, long appointments must be pre-booked days or even weeks in advance due to high demand for general practice care. This means patients with palliative care needs may be unable to access longer consultations at the time they need them. For many practices, this may require additional focus on practice improvement, support to develop capacity in this area and – with the right remunerational models, better use of the full multidisciplinary team.

"There needs to be cultural change to regularly include 40–50-minute consultations to allow palliative care conversations... Trying to then find a 30–40-minute slot when most GP are booked out 3-5 weeks in advance is a barrier for most."

4. Solutions

Results from PCA's survey of primary care workers demonstrates that our current funding models do not sufficiently remunerate palliative care activity in primary care. Neither existing MBS arrangements, nor recent reforms to Medicare, provide sufficient incentive to deliver this essential care at scale.

PCA therefore calls on the Australian Government to take more decisive action to support the necessary expansion of palliative care in primary care, to meet current and future needs.

"Medicare needs to start recognizing the importance of primary care in palliative care by funding it properly."

The approach proposed below is consistent with the recommendations of recent reviews commissioned by the Australian Government, including the *Strengthening Medicare Taskforce*, the *Review of General Practice Incentives* and *Unleashing the Potential of our Health Workforce: Scope of Practice Review*.

The proposals have been tested with primary care experts with a strong interest in palliative care, as well as key primary care stakeholder organisations. PCA looks forward to further consultation to ensure the reform directions outlined are realistic and workable.

Fee-for-service, practice-level payment or blended model?

A key policy question is whether the appropriate model for additional funding to incentivise palliative care in primary care should be a fee-for-service model, utilise practice-level payments, or take a blended approach.

There is a good argument that additional palliative-care related MBS items, such as items for palliative care needs assessment and for Advance Care Planning, could be introduced. There is also a counter-argument that the current primary care funding model is too complicated and needs to be simplified, with fewer MBS items rather than more. PCA's proposed approach seeks to achieve a balance, using a blended approach, via the introduction of a practice-level payment, along with efforts to make better use of existing MBS items explicitly for palliative care.

Integration with MyMedicare?

National Palliative Care Workforce Survey results indicate that many of a practice's palliative patients might be registered with another practice (if that practice does not specialise in palliative care, or wishes to refer to a practice with more expertise), and that some patients will have been recently referred following deterioration and perhaps a hospital stay. Evidence also suggests that take-up of the new General Practice in Aged Care Incentive, which is linked to a patient's enrolled practice, is lower than it otherwise might be. With under 10% of the Australian population yet enrolled with a primary care practice, PCA urges government to proceed with the proposals outlined below without linking eligibility to MyMedicare participation in the first instance. Such an approach could be revisited once MyMedicare has further matured, taking into account further expert advice.

Specific proposals to improve access to palliative care in primary care

PCA recommends that that Australian Government:

1. **Establish a new quarterly palliative care payment for primary care practices,** for each patient of the practice diagnosed with a life limiting illness and with a life expectancy of 12 months or less, where that patient has at minimum had a care plan completed or reviewed in the past 6 months.

   This payment would cover palliative care activities that cannot be billed to Medicare, including:

   - Asynchronous care, for example care coordination, coordination with specialist palliative care teams, and communicating with members of the family and other team members, that may not involve direct patient consultation.
   - Work carried out by nursing and allied health professionals , including but not limited to:
     - Providing psychosocial support
     - Referrals to allied health, including bereavement services
     - Advice on use of medicines prescribed for symptom management
     - Discussion of end-of-life preferences and development of advance care.

   Government could trial the new practice-based payment in rural and regional areas initially, given the high level of reliance on primary-case-based palliative care compared with metropolitan areas.

2. **Promote greater use of existing MBS items by GPs, Nurse Practitioners and multidisciplinary primary care teams to ensure that complex care planning and co-ordination is delivered at end of life.**

   This could be achieved by providing additional guidance on:

   - The recently introduced Level E 60 minute consultation, and the existing Level D and Level C consultations, to be more explicit about their use for palliative care. PCA supports the RACGP's call for an uplift in the Level D and Level C rebates to encourage GPs to spend more time with patients who may otherwise miss out on the care they need.
   - Existing care plan items that can be prepared by another team sharing care with GPs, and the existing case conference items
   - How a primary care practice can draw on the full range of MBS items applicable when delivering palliative care to recognise activity carried out by all relevant practitioners.

3. **Provide additional financial support for home visits, after-hours care (in person or telehealth), and shared care with specialist palliative care services.**

This could be provided via supplement payments (or new MBS items, or new guidance on existing MBS items) to recognise the costs involved in undertaking the following for palliative patients:

- Home visits where someone is unable to travel without patient transport, including potentially multiple home visits in the terminal phase of care, with allowance made for travel time.
- Services delivered after hours, and on-call availability after hours.
- Medical certification of death.
- Participation in shared care with health professionals from specialist palliative care services (for example palliative care nurses conducting home visits), within an explicit shared care model that includes appropriate clinical governance arrangements.

4. **Establish an expert working group to provide further advice to the Australian Government on promoting palliative care in primary care**, by:

    - Considering additional or amended payment structures which might increase access to quality palliative care in primary care.
    - Identifying funding approaches most appropriate to incentivising primary palliative care in regional Australia, noting the relevance of the PRIM-HS approach in this context.[29]
    - Recognising and incentivising professional development in palliative care among MDT members, for example via payments to reflect training undertaken.
    - Reviewing the comparative remuneration for delivering palliative care available to GPs, palliative medicine specialists and other medical specialists through the MBS, including for shared care.
    - Considering quality safeguards for primary care practices that claim additional remuneration for palliative care, for example with reference to the National Palliative Care Standards for All Health Professionals and Aged Care Services.
    - Considering additional pathways for GPs, and for primary care nurses and allied health professionals, to pursue formal qualifications for extended skills in palliative care.
    - Exploring incentive structures to promote the recognition of skills and experience in palliative care across disciplines working in primary care.
    - Consider how payment structures can achieve an appropriate balance between the needs of patients in different circumstances, including with respect to:
        - Patients enrolled in MyMedicare with a given practice versus patients enrolled with other practices or not enrolled
        - Palliative patients versus other patients with high or complex needs
        - Patients recently discharged from hospital, or patients with a recent deterioration, who are not necessarily enrolled with the relevant primary care practice

        - Patients in residential aged care versus patients living at home, taking into account experiences with the General Practice in Aged Care Incentive.
    - Identifying and scaling up promising locally-developed models of care, informed by the evaluation of the Greater Choice for At Home Palliative Care Program.
5. Develop a Palliative Care in Primary Care Monitoring and Evaluation Framework, and ensure that palliative care is explicitly covered in other government-led initiatives to generate primary care data to inform policy and practice.

At present there is no consistent national data gathered about palliative care provision, quality, or patient outcomes in primary care. This is a significant gap in knowledge and data about an essential component of primary care delivery. Palliative care in primary care matters, therefore we should measure it.

Appendix 1: The role of primary care in palliative care

1. What is primary care?

Primary care services are generally defined as the *first, non-emergency* services people go to for help with a health problem. They include:

- General Practices
- Aboriginal Community Controlled Health Services
- Community health centres
- Walk-in clinics
- Community pharmacies
- Community nursing services
- Community mental health services
- Allied health professionals in community and private practice, such as psychologists, physiotherapists, occupational therapists, and chiropractors.[30]

Primary care provides diagnosis and treatment of health conditions, long-term care of ongoing conditions, and health promotion and prevention.[31] The Department of Health and Aged Care's *Future focused primary health care: Australia's Primary Health Care 10 Year Plan 2022-2032*[32] *(Primary Health Care Plan)* identifies both the significant role of the primary care system in improving health outcomes, and the need for primary care funding reform.[33]

2. What is palliative care?

Consistent with the World Health Organization's definition of **palliative care**,[34] in the contemporary Australian context Palliative Care Australia considers palliative care to be:

> *"person and family-centred care... for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life".*[35]

Palliative care:

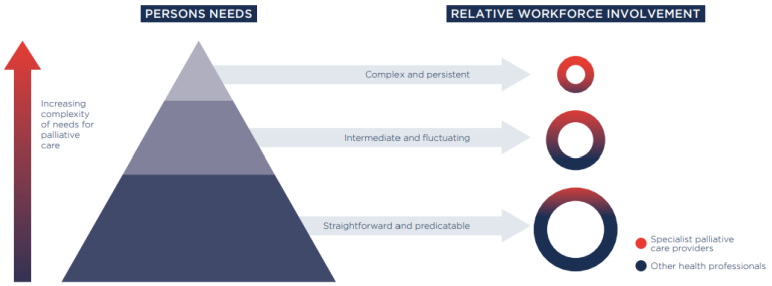
- Is appropriate from early in the course of illness, including alongside treatments intended to prolong life
- Is a multidisciplinary team approach to care
- Is based on effective communication, shared decision-making and personal autonomy
- Affirms life and recognises that dying is part of life – it is provided while a person lives with life-limiting illness, and is not directed at bringing forward or delaying death.
- Should be available to all people with advanced progressive illness, regardless of diagnosis.[36]

3. Primary care professionals in palliative care

All health professionals who care for people with a life-limiting illness should have basic palliative care competency, including to manage physical symptoms, support medication management, provide or refer to psychosocial and spiritual support services, and discuss prognosis and goals of care.[37]

According to the PCA Service Development Guidelines, primary care professionals and teams are well-placed to provide palliative care, particularly when people's needs are relatively straightforward or non-complex. As care needs become more complex, people with terminal illness may also need care from specialist palliative care teams that offer specialized multidisciplinary care and have advanced training and experience.[38]

Figure 1: Alignment of need for palliative care against workforce capability



PCA National Palliative Care Service Development Guidelines, 2018

Palliative care is a multi-disciplinary team approach. In primary care, many professions contribute to the optimal care of people with life-limiting conditions, and their families and carers.

General practitioners and other medical practitioners working in primary care settings (for example general physicians and rural generalists) play a central role in palliative care, as they are responsible for the medical management of people with terminal conditions.[39] Often, they are the first and most consistent point of contact for patients diagnosed with a life-limiting illness.

Nurses providing palliative care in primary care including nurse practitioners, registered nurses, and enrolled nurses who work in community settings, including people's own homes or residential care.

Allied health professionals include occupational therapists, physiotherapists, speech pathologists, dieticians, psychologists, spiritual care workers, and music and art therapists with knowledge or experience of working with people receiving palliative care.

Community pharmacists provide a range of eservice to optimise the quality of medicines.

Paramedics provide transport and emergency care of people receiving palliative care.

Other primary care professionals who play crucial roles in palliative care include Aboriginal and Torres Strait Islander health workers, medical imaging professionals, radiation therapists (in the context of palliative radiation treatments), personal care workers, grief counsellors and language service providers.[40]

The role of the GP, and primary care team, can take on particular importance in rural and remote areas, where access to specialist medical care for life-limiting illness is generally more limited than in metropolitan areas.[41]

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