Palliative Care Australia
Matters of life and death

Draft Aged Care Funding Rules

Submission to the Department of Health and Aged Care

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1. About Palliative Care Australia

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

2. Summary and recommendations

PCA appreciates the opportunity to provide advice to the Department of Health and Aged Care on the draft Aged Care Rules related to funding (Chapter 4 of the draft Rules).

Timely access to palliative care is fundamental to quality aged care. Conservatively estimated, 92% of people living in residential aged care settings would benefit from palliative care.[1] Among those receiving aged care at home, complex care needs are increasing,[2] in part reflecting the increasing prevalence of chronic and life-limiting conditions.[3] Around 90% of people in Australia would prefer to receive palliative care at home for as long as possible, with appropriate supports.[4]

The new Aged Care Act is clear that all people using or seeking Commonwealth-funded aged care have a right to palliative care and end-of-life care, when required. In this brief submission, PCA's advice aims to ensure the draft funding Rules support all older people with life-limiting diagnoses to access this essential care and that palliative care is embedded systemically in the aged care service system.

This submission re-states some points made previously in submission to consultation (Stage 2a) on the Support at Home Funding Rules. These are repeated here because in PCA's view, advice on the Chapter will be most meaningful if the document is considered as a whole.

Our advice covers:

- Three issues specific to home care: individual contributions to non-clinical care costs, roll-over of a proportion of unspent quarterly budgets, and the implementation of the Support at Home End-of-Life Pathway.
- Three issues relevant across both home care and residential aged care: funding of language services, refund of money owed after a person dies, and timely assessment and reassessment of palliative care needs.

PCA recommends that the Rules be amended to:

- Include an *exemption process,* to enable people who outlive the 4-month maximum timeframe for Support at Home End-of-Life Pathway funding to continue to access this additional support.

- Specify a process requiring that individual financial contributions to non-clinical home care services be suspended when a person is hospitalised for a period of time, or receiving residential respite care.
- Provide flexibility for people with life-limiting conditions to retain more than 10% (or $1000, whichever is greater) of their unspent quarterly home care budget, to better manage fluctuating needs and anticipated increases in support requirements.
- The Department of Health and Aged Care:
    - Closely monitor the extent to which the introduction of individual contributions to non-clinical home care costs disincentivises use of these services, and
    - Share relevant implementation data to support timely identification of any changes required to the Rules to remove any identified barriers to uptake of non-clinical services.
- The Department of Health and Aged Care commit to timely dissemination of initial implementation data about the Support at Home End-of-Life Pathway, to identify any gaps, unintended consequences or barriers to program participation. This includes considering whether funding arrangements are appropriate to the Government's stated policy aim to increase access to palliative care at home.

Additionally, PCA recommends:

- The Rules for both home care and residential care specify wait times for funding classification re-assessment, specifically the wait time for "high priority" support plan reviews for people with changing needs arising from a life-limiting condition, and for people participating in or seeking to enter the Support at Home End-of-Life Pathway.
- The Rules provide additional guidance about what constitutes grounds for "reasonable satisfaction" that a person is an "appropriate person" to receive funds owed after someone dies while receiving aged care services.
- The Rules clarify funding arrangements that ensure access to translating and interpreting services, in residential aged care and home care.

1. Home care funding arrangements

1.1. Subsidies and contributions for non-clinical care

Palliative care is a holistic approach to the needs of people facing the challenges of life-limiting illness. It includes clinical care, psychosocial and spiritual support, and non-clinical functional supports (such as personal care). In a palliative approach, all these services contribute to the best possible health and quality of life for individuals, and their families and carers.

The draft aged care funding Rules (and the November 2024 Support at Home Service List), set out arrangements under which aged care providers may charge means-tested individual contributions for non-clinical care provided at home. "Independence services" (including personal care) will attract a contribution of between 5% and 50% of the cost of services, while "everyday living" services (including domestic cleaning and food preparation) attract a contribution of between 17.5% and 80% of the cost of services. Clinical services, including nursing and allied health care, are fully subsidised.

Inadvertently, the lower subsidy for non-clinical care may undermine health outcomes for many aged care users, including those who are palliative. This is because people are likely to make decisions on financial grounds, to defer, or not take up, non-clinical services that are essential to their wellbeing. This includes personal care services (for example, assistance with showering, hygiene, oral care, dressing, eating, communicating and moving), and other day-to-day supports (such as housecleaning). Adverse health outcomes are likely to follow, leading to greater reliance on fully subsidised clinical services. For example, personal care workers providing bathing and other hygiene supports are well-placed to identify problems such as pressure sores early, before these worsen requiring a more intensive clinical response. For those with life-limiting illnesses (i.e. the majority of aged care recipients) the outcomes of lower use of functional supports include avoidable hospitalisation and earlier admission to residential aged care.

These potential outcomes remain of concern despite the hardship provisions outlined in the draft Rules, as financial priorities will continue to inform older people's decisions about their use of aged care services. Any administrative barriers will inevitably lower take-up of measures to lower costs for those facing financial hardship.

Many aged care stakeholders – providers, consumer groups and professional groups - share these concerns, which would apply to more or less the entire cohort of users of at-home aged care. PCA urges government to re-assess whether it has achieved the right balance between individual and government contributions right for the different categories of care, especially for independence services. Many thousands of older Australians are likely to receive a sizeable bill for their at-home aged care – making them re-consider the financial trade-offs between basics such as medicine, housing costs, food and now their aged care entitlements. Encouraging providers to bill users for their non-clinical aged care (and providing lower subsidies for non-clinical care) may not be worth the risk of poorer health outcomes and the downstream costs to government of greater use of the health system. It may also further exacerbate disparities in outcomes for those in lower social-economic groups.

As the Support at Home Program is implemented, PCA recommends the Department of Health and Aged Care release data shedding light on equity of use of clinical, independence and everyday living home supports among people paying varying levels of financial contribution (for example full pensioner-holders, part-pension holders and self-funded retirees).

The extent to which the introduction of individual contributions to the cost of non-clinical home care disincentives use of these services, will require close monitoring during the early implementation period.

PCA recommends that the Department of Health and Aged Care share relevant implementation data about use of these services early following commencement of the Support at Home program, to support identification of any changes required to the Rules. This could include changes to subsidy and/or service list arrangements to remove any barriers to uptake of non-clinical services.

Many people with life-limiting illness who access home care services will require hospital-based care for periods of time, before returning home. The Rules should specify arrangements for the suspension of individual contributions when a person is hospitalised for a period of time.

People with life-limiting conditions receiving home care services require ready access to residential respite care. This is essential both to the care and wellbeing of the person, and to supporting family carers to continue in their caregiving role. PCA welcomes the provisions for funding of respite care in the draft Rules, but notes the Rules should also specify arrangements for timely suspension of individual contributions when a person is receiving residential respite care.

The Rules should specify arrangements for the suspension of individual contributions to non-clinical home care, when a person is admitted to hospital for a period of time, or receiving residential respite care.

1.2. Arrangements for unspent budgets

The draft Rules set out arrangements for home care recipients to carry over up to 10% or $1000 (whichever is higher) in unspent funds between quarters. This approach is poorly suited to the situation of many people with life-limiting illnesses, who value the flexibility to save funds to manage fluctuating support needs, and to plan for anticipated future increases in support needs. For example, people may save a proportion of their budget to expend it on 24/7 personal care or additional nursing services later, when their support needs intensify.

PCA recommends the Rules include a specific provision to allow flexibility for those with life-limiting illness to carry over additional funds between quarters. This should apply to all people with life-limiting illness who use Support at Home services, not only to those participate in the End-of-Life Pathway

This could take the form of an exemptions process to allow individuals with advanced life-limiting illness or fluctuating needs to retain a greater proportion of any unspent budgets.

Under the "no worse off" provisions in the draft Rules, people receiving home support packages at 12 September 2024 retain greater flexibility to accrue unspent funds than new entrants to the system. This creates additional complexity in funding arrangements. Any differences these arrangements make to older people's experience of care, and their ability to access necessary supports, should be monitored.

1.3. Support at Home End-of-Life Pathway

PCA welcomes the inclusion of the short-term End-of-Life Pathway in the Support at Home program. PCA strongly recommends the Rules include an exemptions process, to allow individuals who outlive the 16-week maximum time period to expend Pathway funds, to continue to access additional necessary end-of-life supports beyond this timeframe. This will remove potential for interruption or reduction in services following their return to an ongoing Support at Home classification level. Extending this support until the time of the person's death would be consistent with the approach in residential aged care, where people eligible for A-ACC Class 1 (Entry for Palliative Care) must have a life expectancy of three months or less but are not required to be reassessed to lower funding classification level if they outlive this timeframe.

PCA recommends that the Department of Health and Aged Care share End-of-Life Pathway implementation data early (as it becomes available), to identify areas for improvement and change; including to allow consideration of whether funding arrangements for Pathway participants and providers are appropriate.

PCA advocates for independent evaluation of the Pathway one year after commencement, to ensure it is achieving its stated intent.

2. Palliative and end-of-life care: needs assessment, funding and billing

While trajectories of terminal illness vary, they frequently involve unpredictable change in care and support needs. Support and care needs frequently intensify as people approach end of life, and timely assessment of these changing needs is essential to high quality palliative care.

Confidence that assessment and re-assessment will happen in a timely way will be particularly important for people seeking to access the new Support at Home End-of-Life Pathway, and for people returning to an ongoing Support at Home classification if they outlive the maximum 16-week timeframe to expend End-of-Life Pathway funds. However, all people with palliative care needs will potentially receive care at any classification level (in home and residential settings) and they equally require swift assessment of changing needs with confidence that funding for their full service entitlement will follow. Future review of the Rules should consider a process for posthumous confirmation of reclassification to a higher level for people receiving palliative care who die before independent assessment can take place (for example via medical and service records).

Unfortunately, wait times for re-assessment of classification level (both in residential and home care settings) can mean that people receiving end-of-life care die before their needs are formally re-classified – meaning more intensive care provided during this period is unfunded. The draft Funding Rules for home care set out that 60% of the person's budget will be provided under “interim budget” arrangements, if wait times for funding to become available require. This creates the potential for long wait times to access the full budget entitlement, creating a significant barrier to accessing necessary care. This is a particular concern in a palliative care context, as the care needs of people with life-limiting conditions can change rapidly (or they may die), prior to confirmation of budget and classification level.

Whether in this Chapter or elsewhere, the Rules should specify indicative or target timeframes for assessment and re-assessment of funding classification level (both in residential and home care), following identified clinical deterioration indicating the need for re-classification. This should include timeframes for high priority classification re-assessment for people with a life-limiting illness or receiving end-of-life care, including for those whose function has not yet deteriorated to the point that they qualify for the End of Life Pathway.

PCA recommends the Rules should specify indicative timeframes for assessment and re-assessment of classification level (for home care and residential care), including for “high priority” assessment and re-assessment.

This will provide confidence that funding will be made available in a timely way, to ensure care meets changing needs including for those who require palliative care.

3. Refunds owed when a person dies

Appropriately, the draft Funding Rules set out requirements on aged care providers to return funds owed to people who have died, in line with their wishes. The draft Rules set out that funds must be returned in accordance with directions contained in either the probate of the will, or letters of administration of the estate of the individual (within 14 days of sighting the document/s). If these documents are not provided, money owed must be returned to “a person that the provider is reasonably satisfied that it is appropriate to pay the refund to within 28 days [of becoming]… aware of the [person’s] death”.

PCA recommends that the Rules provide additional guidance about what constitutes grounds for “reasonable satisfaction” that a person is “appropriate” in this situation. For example, would this be a person named as a supporter for the purposes of aged care information and decision-making? An immediate family member? What evidence is required that a person is “appropriate” to receive these funds? How are disputes to be resolved?

PCA recommends that the Rules provide additional guidance about what constitutes grounds for “reasonable satisfaction” that a person is “appropriate” to receive a refund of funds owed after a person dies.

4. Translating and interpreting services

Translation and interpreting services are essential to high quality palliative care in aged care. These services ensure people of non-English speaking backgrounds, and their families and carers, can make informed choices about care and access the aged care and palliative care services they need. Translation and interpreting can become more important as life-limiting illnesses progress, as people may experience diminished English language ability due to cognitive change or other factors.

PCA notes that neither the Act nor Rules are clear about the funding mechanism by which access to translating and interpreting services will be ensured. In relation to home care, the November 2024 service list appears to indicate that an individual contribution may be required for “assistance to access translation and interpreting services”. This approach is not consistent with that used in other service systems, including both NDIS and public health services – where translating and interpreting services are not funded through direct consumer contribution.

PCA recommends the Rules clarify arrangements for accessing translating and interpreting services.

5. Concluding remarks

PCA looks forward to finalisation of the Rules, to enable implementation of the new Aged Care Act from 1 July 2025.

We are glad to provide further advice on any aspect of this submission.

6. References

[1] Humphrey G, Inacio M, Lang C, Churches F, Sluggett K, Williaman H, Morgan D et al June 2024, Estimating potential palliative care needs for residential aged care: A population-based retrospective cohort study, Australasian Journal on Ageing *at:* https://doi.org/10.1111/ajag.13345

[2] AIHW Gen Aged Care Data, 8 July 2024,*Admissions into aged care* at: Admissions into aged care - AIHW Gen (gen-agedcaredata.gov.au)

[3] ABS, Health conditions prevalence, key findings on long-term health conditions and chronic conditions, and prevalence in Australia, 2022. Released 12/2023 at: Health conditions prevalence, 2022 | Australian Bureau of Statistics (abs.gov.au); *ABS, Causes of Deaths, Australia, 2022* at: Deaths, Australia, 2022 | Australian Bureau of Statistics (abs.gov.au)

[4] Agar M, Currow D, Shelby-James T, Plummer J, Sanderson C and Abernethy A (2008) Preference for place of care and place of death in palliative care: are these different questions? Palliative Medicine 2(7): 787-795; also

Pinto, S, S Lopes, A de Sousa, M Delalibera and B Gomes, 2024, Patient and Family Preferences about place of end-of-life care and death: an umbrella review, Journal of pain and symptom management 67(5), May 2024,