



Palliative Care Australia
Matters of life and death

Aged Care Act - *Rules*

Service Lists

Consultation Draft

Submission to the Department of Health and Aged Care
October 2024

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 and the palliative care workforce, PCA aims to improve access to and promote palliative care.

Summary and recommendations

PCA welcomes the publication of the *Consultation Draft - Aged Care Rules 2024, Service Lists*.

In this submission PCA identifies opportunities to ensure the services lists support integration of palliative care within aged care, as envisaged by the Royal Commission into Aged Care Quality and Safety.

PCA's advice and recommendations are:

- The inclusion of “advance care planning, palliative care and end-of-life care” in the residential aged care nursing services list is critical and should be retained.
- However, responsibility for advance care planning, palliative care and end-of-life care is not confined to clinical nursing services – consideration should therefore be given to including these as stand-alone items.
- The home support service list should also include “advance care planning, palliative care and end of life care”, consistent with the requirements of the draft Strengthened Aged Care Standards (Standard 5.7, *Palliative care and end-of-life care*; and Standard 3.1.6 for advance care planning), which apply to both home support and residential aged care services.
- PCA recommends clarifying what is meant by “specialist care linkages” in the home support nursing care list. This term is vague and could be understood to mean simple referral, when in fact clinical governance arrangements, care coordination and ongoing liaison will often be required when providing care and services to a person with a palliative condition.
- The home support service list includes aged care services (clinical care, personal care and equipment) that are essential for people with palliative diagnoses, including in the last months and weeks of life when support and care needs can reasonably be expected to increase.
- However, the home support list does not specifically include complex clinical care services (e.g. medication management, complex nursing care provided in collaboration with specialist palliative care providers) or psychosocial support (including spiritual care) that may be required by people with advanced palliative diagnoses. These should be considered for inclusion on the home care service list;

and a regular process of review established to identify any additional services should be added to the service lists.

- Specific after-death care and services should be considered for inclusion on the service lists, or otherwise reflected in aged care pricing.

Additionally, PCA:

- Supports retention of psychology services in the home support service list, noting the importance of psychological care for those with palliative and other serious diagnoses.
- Welcomes inclusion of respite care, and transition care, in the service lists. These are essential to provision of high-quality care for people with palliative diagnoses.
- Welcomes confirmation that the Support at Home program will include a short-term End-of-Life Care Pathway; and recommends independent evaluation of the Pathway one year after commencement to ensure it is achieving expected uptake, and positive impact, for older people and their families.

In relation to the services offered in the Support at Home End-of-Life Care Pathway, PCA notes:

- People accessing the End-of-Life Care Pathway will benefit from ready access to the allied health services included in the home support list, including allied health services offered under the short-term restorative care pathway. Their eligibility should be confirmed.
- Program operational guidelines must clearly define the roles of aged care and health care services in providing coordinated care for older people with life-limiting conditions. This is essential to avoid situations where each system holds the other responsible for providing essential services (clinical care, equipment, or intensive clinical care and/or functional support at home in the last weeks of life).
- In reality, the policy and program intent of the palliative care pathway will only be achieved if palliative care providers (General Practitioners, and specialist palliative care services) and aged care services have capacity to jointly meet the needs of older people, in a timely way.

General comments

PCA welcomes the publication of the Service Lists for residential aged care and home support. PCA supports passage of the Aged Care Bill 2024 into law as soon as practicable following Parliamentary scrutiny. PCA encourages swift publication of the draft Rules in their entirety, allowing time for public comment and advice.

The Royal Commission into Aged Care Quality and Safety made clear that palliative care must become “core business” in aged care. The new Aged Care Act is expected to include a right to equitable access to palliative care and end-of-life care for all people using and seeking funded aged care. Following introduction of the Act, all funded aged care services offering clinical care will be assessed the quality of the palliative care they offer, under Strengthened Quality Standard 7.3, *Palliative Care and End of Life Care*. All services providing care planning will be required to provide Advance Care Planning. These expectations apply in home care as well as residential aged care.

The service lists play a role in supporting this transition, and ensuring older Australians can realise their right to palliative care and end-of-life care.

Inconsistencies between the residential and home support lists

PCA welcomes inclusion of “Advance Care Planning, palliative care and end-of-life care” in the draft service list for residential aged care. In PCA’s view, this should also apply to home support providers. Yet there is no such requirement in the draft service lists. This appears inconsistent with the draft Strengthened Aged Care Standards, which set out that:

- All services providing clinical care must demonstrate provision of care consistent with Clinical Standard 5.7, Palliative and End of Life Care (regardless of home or residential care setting)
- All services providing care planning should offer Advance Care Planning (Standard 3.6.1)

These aspects of care should be included in the home support service list.

Similarly, PCA recommends that preparation of dementia-specific support and care plans be included in the home support service list. This is currently included in the draft residential aged care service list, however provision of this care in home settings will meet a growing area of need.

PCA notes that “Advance Care Planning, palliative care and end-of-life care” are (appropriately) included in the (non-exhaustive) examples of clinical nursing services to be provided in residential aged care. However, responsibility for these activities is not confined to nurses. PCA suggests consideration be given to listing these services separately, to

recognise that they are whole-of-service responsibilities involving a range of professions working in aged care.

The home support service list and palliative care

Aside from the issues above, the proposed home support services list captures the essential aged care services that people with palliative diagnoses are most likely to routinely require. This includes clinical care (nursing and allied health), personal care and assistive technology / equipment that is likely to be required in the final months and weeks of life when more intensive supports may be required.

However, the home support clinical services listed do not explicitly reflect the *complexity or intensity* of clinical aged care services that can commonly be required by those with palliative care needs. These includes more complex medication management, and more complex nursing care (e.g. PEG feeding, syringe driver management) which would generally be provided under advice and in partnership with specialist palliative care services. Neither are more complex care coordination or clinical governance arrangements reflected in the service lists. PCA also notes the service list also does not specifically reflect psychosocial support for those with palliative care requirements, including grief and bereavement support and spiritual care, which can appropriately be offered by aged care providers.

It will be important to monitor over time whether there are any additional specific services that should be included in the service list, to meet the needs of people with palliative care needs. A transparent process will be required to review and update the services included in the list.

PCA welcomes inclusion of “specialist care linkages” among the nursing care activities in the home support clinical care service list. However, this wording is vague and open to interpretation. “Linkages” might be understood to mean simple referral to specialist services, when in reality nurses are likely to spend significant time in liaison, communication and care coordination for older people who require palliative care. Clinical governance arrangements will also be required. PCA suggests clarification of what is meant by “specialist care linkages” in the service list, supported by clear advice in program guidelines.

PCA welcomes the inclusion of psychology in the home support service list, noting the relevance of psychological care for those with life-limiting illnesses. PCA also welcomes the inclusion of “service coordination” as an aspect of “home support care management” service. As with clinical services, PCA emphasises that the complexity of service coordination for those with palliative care needs should be fully resourced. PCA also welcomes the inclusion of transition care on the draft service list for home support, given its demonstrated impact in preventing avoidable hospital admissions and re-admissions.

PCA welcomes inclusion of respite care in the home care service list. This is an essential service for older people with advanced palliative diagnoses, and their carers.

We support retention of all these components of the draft service lists.

After-death care

Care and services do not stop as soon as a person dies. For example, aged care services may provide liaison and psychosocial support to families, liaise with a medical professional to arrange medical certification of death, offer grief and bereavement support to other residents (in residential settings), and provide after-death care of the person's body. These services should be considered for inclusion on the service list, or otherwise reflected in aged care pricing and/or operational guidelines.

Flexible, timely and responsive care

The service lists must support flexibility for services to respond to all reasonably foreseeable palliative care needs. This includes the ability to identify and respond swiftly to people's changing needs for care, including through assessment and reassessment of need and rapid commencement of additional services as required. PCA notes that nursing care services listed under the home support service list can only commence for a "medical diagnosed condition". However, occasions will arise when nurses should commence care without waiting for a medical diagnosis. As an example, nurses might commence continence or wound care without waiting for medical confirmation of a diagnosis causing these issues. Aged care nurses caring for a person with life-limiting illness might also commence treatment for a presenting issue based on advice sought from a specialist palliative care nurse. It is not clear from the wording of the list whether this situation would be acceptable. PCA recommends this wording be reviewed for clarity.

Services provided in the Support at Home end-of-life pathway

PCA welcomes the inclusion of a short-term end-of-life pathway in the Support at Home Program. This will provide more intensive support for people who would like to remain at home during the anticipated final three months of their life. PCA strongly supports this initiative. However, we note three implementation considerations related to the service lists.

- *Access to allied health care.* Palliative care is multidisciplinary team-based care. Allied health professionals make an essential contribution to quality of life for people receiving palliative care, including in the final months and weeks of life. Clarification is required about whether people accessing the short-term palliative care pathway will also have access to allied health care. Many people receiving palliative care at home would benefit the same allied health services provided under the short-term restorative care pathway. Equally, access to allied health care is essential for people with palliative care needs in residential aged care. PCA supports retention of all the allied health services currently covered by the draft service lists.

- *Connection with palliative care and health services.* Operational guidelines must clearly define the roles of aged care and health care services for the coordinated care of older people. This is essential to avoid situations where each system holds the other responsible for providing services (for example some clinical care, equipment and home modifications, or functional support).
- *Capacity of palliative care services.* The policy and program intent of the new palliative care pathway can only be achieved if there are strong partnerships between aged care services, and General Practitioners and specialist palliative care services. Palliative care services, and aged care services, must also have capacity to meet the need for home care, and in a timely way.

PCA recommends the End-of-Life Pathway be evaluated one year after commencement to ensure it is achieving expected uptake, and positive impact, for older people and their families.

Concluding remarks

Again, PCA appreciates the opportunity to provide advice on the draft Service Lists. PCA looks forward to swift publication of the full draft Rules ahead of the anticipated passage of the Aged Care Bill 2024 into law.

We would be glad to provide further detail about any aspect of our submission.