Flinders University | Research Centre for Palliative Care, Death & Dying

RePaDD Round Table

Understanding What Is Driving Change in Aged Care to Support Palliative Care Needs

Prepared by

Research Centre for Palliative Care, Death and Dying (RePaDD)
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Acknowledgement of Country

Flinders University was established on thelands of the Kaurna nation, with the first University campus, Bedford Park, located on the ancestral body of Ngannu near Warriparinga.

Warriparinga is a significant site in the complex and multi-layered Dreaming of the Kaurna ancestor, Tjilbruke. For the Kaurna nation, Tjilbruke was a keeper of the fire and a peace maker/law maker. Tjilbruke is part of the living culture and traditions of the Kaurna people. His spirit lives in the Land and Waters, in the Kaurna people and in the glossy ibis (known as Tjilbruke for the Kaurna). Through Tjilbruke, the Kaurna people continue their creative relationship with their Country, its spirituality, and its stories.

Flinders University acknowledges the Traditional Owners and Custodians, both past and present, of the various locations the University operates on, and recognises their continued relationship and responsibility to these Lands and waters.

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Setting the Scene: Aged Care, Palliative and End-of-Life

Australia is experiencing population ageing. As a population, we are living longer and dying older. This has implications for how we consider care in our health and social care systems. There is an increasing recognition that aged care is a priority for palliative care and palliative care is a priority for aged care. In a period of reform of the aged care system which is sitting alongside increasing demand for aged care services and anticipated increases in the number and proportion of people dying over 65 years of age, understanding how aged care, health care and older people intersect is critical.

The Research Centre for Palliative Care Death and Dying (RePaDD) has a specific focus on ageing, caring, dying and grieving and is active in this space through project and research grants in both health and aged care. Researchers have been involved in several national palliative care projects that address the interface between palliative and end-of-life care and aged care, in particular CareSearch, including palliAGED, and End-of-Life Directions for Aged Care (ELDAC). There have also been specific research studies examining bereavement in residential aged care, evaluation of aged care initiatives in South Australia, and reablement and restorative approaches in aged care.

The aged care reform to be implemented in 2025 represent some of the most significant structural changes for aged care that have been enacted and also feature palliative care and end-of-life as a part of aged care's responsibilities. There is a clear need to better understand the implications of these proposed changes to inform health and aged care practitioners. This understanding will help ensure that guidance supports successful implementation and a more integrated care journey for older people across ageing and end-of-life.

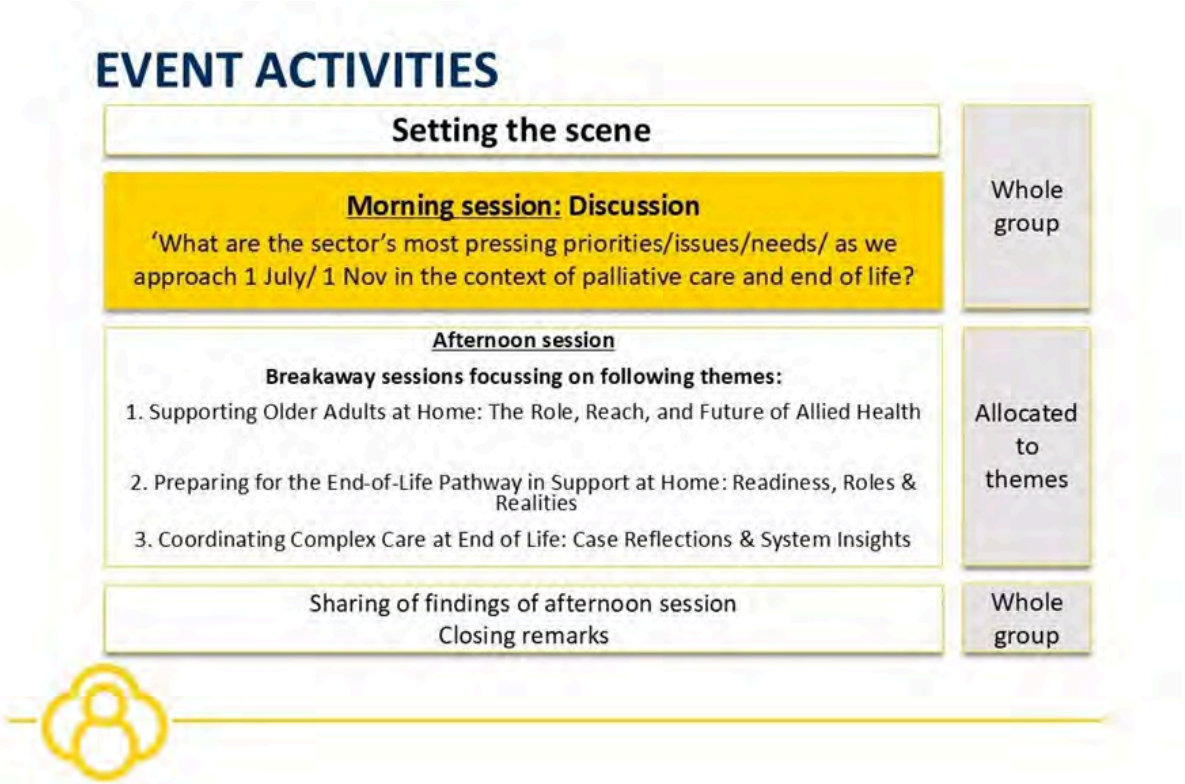
As this is a multi-perspective problem a national roundtable provided a unique opportunity to bring people together with different backgrounds, knowledge and views. It provided an opportunity to identify critical needs and to look at project and research responses. This is particularly important as palliative care forms a single issue in a crowded agenda for aged care. Participants were invited from aged care, health care, allied health, community organisations, and policy and advocacy groups. Prior to the roundtables invitees were sent a short briefing paper (Attachment 1). Ethics for this work was received through Flinders University (HREC 8532).

The aim of the roundtable was to identify critical issues within the aged care sector arising from pending changes relating to the aged care reform agenda. There was a specific focus on considerations and perceived impacts relating to the following issues:

- Support at Home Program model of care including the restorative care and end-of-life pathways
- Allied health workforce in aged care
- Care interfaces across health and aged care settings.

It is worth noting that this meeting was held in May and was foreshadowing the pending transition to the new Act and Standards on 1 July 2025. On the day prior to the meeting, the Australian Government announced that the transition day was being deferred until 1 November 2025. This provided an additional layer of context for these discussions.

The roundtable began with a brief presentation *Setting the Scene*. The presentation overview is found in Attachment 2. A collective session followed where all participants addressed critical concerns as the sector moves to the transition to the new Aged Care Act, Quality Standards and Support at Home Program. In the afternoon, attendees participated in a focused discussion looking at Support at Home Program and the End-of-Life Pathway; interface between health sector and residential aged care; or Allied Health and aged care.



Understanding the Sector's Most Pressing Needs

Facilitator: Professor Jennifer Tieman

Following the context setting in the Setting the Scene session, participants worked in groups to consider four key questions. These questions were:

- **Question 1:** What does delay of transition from 1 July to 1 November mean on the ground? What are the pain points?
- **Question 2:** How should primary care, aged care, unpaid carers, specialist palliative care and allied health interact in this brave new world?
- **Question 3:** What happens to older people who are at end-of-life but do not meet eligibility for the End-of-Life Pathway or for AN ACC Class 1?
- **Question 4:** What should RePaDD do to support aged care to deliver high quality care for older people with palliative care needs and older people at the end-of-life?

Following the group work session, the facilitator from each of the four groups provided a brief summary of the key points raised by the participants to each of the questions. These are summarised below.

Question 1: What does delay of transition from 1 July to 1 November mean on the ground? What are the pain points?

The groups all highlighted the complexity of understanding, preparing and then implementing the range of changes that have been announced. There was a general belief that pain points for the sector are still likely to exist on 1 November. It is unlikely that all issues can be resolved within a four-month extension. Providers were concerned that they would not be able to finalise processes, sort out education and training, rework systems when the Act and its regulations and specified work processes are not finalised.

A significant pain point was the lack of clarity around the funding for the End-of-Life pathway. There seemed to be uncertainty about what this dedicated funding would support particularly whether it could fund clinical care or only additional wrap around services? People have assumptions about how the funding can be used and not an understanding of the detail of the service list. There was also a concern that $25,000 will not be enough to meet the needs of a person in the last three months of life and wanting to die at home. How secondary service providers relate is unclear under the program and pathway in terms of clinical service. There was also concern about the AKPS of 40 and 3-month end-of-life period as frailty and dementia have fewer prognostic indicators of end-of-life decline but can have ongoing periods of significant care needs.

Issues relating to a sufficient, and a sufficiently skilled, workforce were noted by all groups. Their concerns around workforce included a lack of skilled nursing in the sector to support the scale of end-of-life anticipated and the role of allied health professionals in supporting care. The need for solid education for the sector on how to address and deliver care that meets Outcome 5.7 was also noted.

Participants highlighted pressures associated with providing comprehensive person-centred multidisciplinary care in a prescriptive funding system. There are also challenges in managing the requirements of claiming, documenting time spent on activity, and providing compassionate care. “Where is the funding that will support excellence in care?” was one comment made in reporting back.

There was broad discussion around how the role of the family, advocates and supporters in aged care will be managed particularly in the Support at Home Program. This was seen as a critical consideration if people are to have the option to remain at home in the last months of life.

There are digital implications in the change agenda and also in the role digital needs to play in integrating care pathways. This will become more complex in ensuring effective communication across sectors and services.

One table highlighted the need to be alert to unintended consequences. For example, people are trying to get on packages, but this is creating excess demand for Centrelink in determining their financial status causing delays. This will continue and has implications for rapid assessment requirements such as getting on to an End-of-Life pathway.

A common theme was that primary care, GPs and specialist palliative care services were not aware of many of the coming changes. This could also have consequences in terms of patient care and expectations for service provision. This highlighted an urgent need to ensure that primary care, PHNs, LHDs, GPs are aware of what is coming.

A range of issues relating to the capability to implement were also noted. The sector is suffering from change fatigue. Aged care services and staff also feel under pressure in their relationships with older people and families for things that they cannot control. They cannot answer their questions about how the changes will affect them.

One group also highlighted that there is very little that will enable the reality of providing person centred care across diverse population groups and settings.

Question 2: How should primary care, aged care, unpaid carers, specialist palliative care and allied health interact in this brave new world?

Highlighting issues raised as general concerns about awareness and mechanisms that enable effective interactions between the health and aged care sectors, a series of more specific issues were raised.

There is a need to break down silos and enable collaborations across sector. At the moment, it seems that solutions and problems are only being addressed by some of the parties in the systems. A lack of understanding of what comes before and what happens next means that problems are often seen as organisation or sector specific. Without considering the problem within a system lens, solutions may not be addressing the root cause of an issue. An example was given of state funding looking at mechanisms to support hospital avoidance mechanisms but not including aged care in the discussions. Learning how to work together was seen as critical.

A related concern was sharing knowledge and expertise. There are significant knowledge gaps across the sectors and professionals around palliative care and end-of-life care. Communication channels do not necessarily enable and foster best practice from expert groups into aged care. This is made more complex with specialist groups not understanding the context of aged care in terms of funding structures and staffing differences.

Practical gaps in the interface between provider groups were noted. One statement was that any aged care providers should start with the assumption that the GP does not know about the End-of-Life pathway and what is expected of them requiring sign off of the required form. There are still considerations around access to drugs, availability of clinical care, and 24/7 access to medical support. There is also a need to support aged care staff (with a restricted scope of practice) to be comfortable and confident interfacing with GPs, NPs and palliative care services. This may become particularly important in Support at Home interactions. Escalation pathways will be needed.

Digital issues are creating problems. Essential information is often not easily accessible at the point of care, and the flow of information between aged care and hospitals is not always straightforward. The electronic health record needs to be a single source of truth for the person requiring care regardless of setting. Some participants believed the government should just tell aged care providers what systems to use to enable more interoperability and prevent the necessity to have connection to multiple systems. Some providers are still not systems based.

It was noted that there seems to be limited use of AN ACC Class 1. Some aged care providers noted it is difficult to navigate and simpler to stay on AN ACC Classes 11-13. Some acute care providers appear not to be aware of AN ACC Class 1 as a direct entry route for palliative care admission to residential aged care.

How to effectively provide multidisciplinary care across sectors was also highlighted. Needs rounds and virtual care have provided some benefits in residential care. What mechanisms will work in the home care context for the individual older person is less known. There is uncertainty around how Support at Home Program providers can help to proactively identify deterioration and change in older people receiving support packages that may lead to consideration for the end-of-life pathway.

Unpaid carers are going to continue to shoulder the burden of dying at home. There will still be a need for an unpaid carer to be available. The reality is that $25,000 cannot provide 24/7 care in the home for three months. There needs to be more information available for family and friends on end-of-life in aged care and aged care needs to have more information on working with the family, supporters, carers. There are also specific concerns such as how to best support care when both the older person and the unpaid carer are on home care packages. It was noted that family carers may already be using their carer allowance to subsidise end-of-life care.

Question 3: What happens to older people who are at end-of-life but do not meet eligibility for the End-of-Life Pathway or for AN ACC Class 1?

There is uncertainty that the proposed end-of-life pathway for home care will cover all people who die receiving a Support at Home service. Eligibility criteria may make it difficult to receive the additional funding. The sector is also waiting for additional details relating to the Support at Home Program. The **Joint Statement** to clarify roles and responsibilities of health care for people receiving aged care services recognises that access to palliative care and end-of-life care is a shared responsibility of the aged care provider, primary care providers, and state health systems. It also notes that access to Voluntary Assisted Dying must be supported (where legislated) for eligible older people if this is their choice and preference.

Participants noted there were complexities in the Program framework and issues around the capability and capacity of the aged care workforce. They also provided examples of how organisations have set up mechanisms to streamline processes in advance of the reform changes. For example, in rural SA, discharge planning involves AN ACC Class 1 consideration and the person's GP. However, others noted that many hospitals are not aware of AN ACC Class1 and that not all care facilities wanted to take on AN ACC Class 1 residents.

The lack of detail around the Support at Home Program meant that preparation for care provision in the eight ongoing service categories and the restorative and end-of-life pathways is slowed. Participants were also concerned that GPs were not aware of the end-of-life pathway nor familiar with AKPS which could mean existing care recipients may not be able to receive reclassification. GPs may also not initiate support at home options and instead refer to specialist palliative care only.

Gatekeeping means that reassessment is not necessarily straightforward. Without rapid assessment, the older person is likely to bounce around in the systems. One suggestion was that assessment should be required while the person is in hospital, not going home to start the process. The need to initiate advance care planning when end-of-life is recognised was another complexity in terms of how it should be done and who should be responsible for this set of discussions. Clarifying what happens to funds that are unspent on a current package and the rate of expenditure over three months were also raised as pragmatic concerns as recipients may want to save funds for emergencies.

Concern that disparities will continue were also expressed. While more savvy consumers and providers will work out systems and processes to optimise care provision, others may find it more difficult and offer a more limited range of services or not have access to other supports to meet the needs of individuals. This could be exacerbated for groups who are already under-represented in their use of aged care service.

There was a general agreement that regardless of what pathway someone is on, there are workforce gaps. Understanding of and confidence in providing palliative care and working in a multidisciplinary team to provide comprehensive care are skills that are needed in the workforce. The role and contribution of new roles such as end-of-life doulas was seen by some as offering opportunities to provide new forms of support within the sector.

There was also a concern that with AN ACC Class 1 or on a Support at Home (End-of-Life Pathway) the burden of caring for someone approaching the end-of-life is likely to fall on family and unpaid carers. They will need to provide care or take up advocacy. Without appropriate inclusion and support, unpaid carers may not be able to continue to cope increasing pressures on the acute system.

Question 4: What should RePaDD do to support aged care to deliver high quality care for older people with palliative care needs and older people at the end-of-life?

A number of practical suggestions were put forward around how the Research Centre can contribute to address the concerns and issues raised. Possible areas that could be addressed include:

- Creating a model of care that demonstrates how to optimise packaged care would be useful.
- Unpacking multidisciplinary care in the home and how to organise.
- Journey pathways that highlight ways older people may access the End-of-Life pathway and care across the pathway with palliative care needs.
- Could there be an exemplar End-of-Life package of equipment for the Support at Home?
- We need to build more death literacy to counterbalance the healthy ageing paradigm which doesn't address end-of-life. Need to see quality end-of-life care and palliative care as a value asset in aged care.
- Given there is so much policy and many documents, assessments and processes, a how-to-do-it package, making sense of it for palliative care and for aged care would be helpful.
- RePaDD could take a role in building GP and PHN awareness of these issues.
- Consider reframing quality of life to well-being across the life course.
- Create resources that support the disenfranchised grief of careworkers particularly those working in home care who lose contact with the person when they go to RAC to die.

Breakaway Session 1: Supporting Older Adults at Home (Allied Health)

Facilitator: Dr Olivia Farrer

The Allied Health roundtable addressed the role, realities, and futures of different allied health professionals in the changing aged care context. Details of the introduction to the session are found in Attachment 3. The comments made in the general discussions were then thematically identified to highlight key issues for these professions in providing care to older people. Four major themes which were identified from the discussions:

Theme 1. Systematic misalignment between policy, practice and funding

Participants felt that the role and value of allied health contributions was poorly understood and that direct face-to-face consultation was lacking. This was shown in funding models that spoke only to direct care provision not planning, travel and documentation.

Unrealistic Funding Models

Allied health practitioners expressed frustration that new funding frameworks like Support at Home allow billing only for face-to-face time, excluding essential tasks like travel, documentation, client education, care coordination, and indirect interventions.

Pricing was set using flawed, provider-focused data, with minimal consultation from actual allied health professionals—resulting in unviable unit prices.

"*No allied health peaks were involved in the pricing discussion… they <only> asked <aged care> providers, 'What do you reckon that would cost?'*"

Policy Disconnect and Lack of Sector Understanding

Participants highlighted that the policymakers and assessors often do not understand the full scope or nature of allied health work.

Several professionals pointed out that governments treat allied health work as commodified, interchangeable, and transactional, with little regard for its preventive, restorative, and psychosocial value.

"We became interchangeable—'Are you the physio?' 'I don't even care what you are, just come in and do the same thing.'"

Theme 2. Allied Health Value is Undervalued and Underutilised

Current rules and priorities suggest that allied health is undervalued and will not be able to contribute to an optimal scope of practice to provide benefits to older people. Rather than valuing the unique expertise, skills were seen as interchangeable or able to be enacted by others.

Misunderstood Professional Roles

Many felt that allied health professionals are being reduced to tick-box technicians rather than being recognised for their clinical reasoning and holistic contribution to care. For example, dietitians are brought in for malnutrition management with little recognition of comorbid issues like gut health or psychosocial determinants.

Other allied health professional roles also suffered from funding frameworks that made care practices not viable. As one participant noted, "Community pharmacists are capped at 30 medication reviews per month...how is this viable if servicing rural areas, can't block book reviews during a window of travel without maxing out monthly services."

Loss of Preventive and Restorative Focus

Allied health professionals often only get involved when a person is in significant decline, missing opportunities for early intervention, wellness promotion, and supportive end-of-life care. The group expressed concern about a regression to a reactive care model focused solely on deficits.

Inadequate Training for Assessors and Support Workers

A lack of understanding of the unique contribution of allied health is compounded by a lack of training and substitution of allied health professional skills with support workers. Many service recommendations are either not followed through or poorly implemented due to lack of understanding or skill among support staff. Allied health professionals are being asked to hand over complex care plans to underqualified or cheaper personnel, increasing clinical risk.

"As soon as [funding] finished, most facilities cut their allied health team right back. Made a whole bunch of them redundant."

Theme 3. Data Gaps Undermine Advocacy and Accountability

Inadequate Outcome Tracking

Participants noted that there is no national or system-level data on the impact or scope of allied health in home and palliative care, especially in relation to service outcomes or consumer wellbeing. Quality indicators focus on high-level metrics like falls or malnutrition, without tracking who intervened or what was done.

"We're not collecting data to show [our impact]. We have no way of proving value in a palliative care setting."

Invisible Work and Uncaptured Value

Much of the indirect care and planning work, like writing behaviour support plans, developing communication tools, or mentoring staff, is either unfunded or invisible in reporting systems. The lack of structured outcome measurement (particularly person-centred outcomes) means that allied health's contribution is often overlooked or misattributed.

"Unmet need will increase. And that data? It won't show up anywhere."

Given that most aged care allied health work is typically mobile work providing support for the older person in their home, funding schemes do not acknowledge the reality of time and travel costs to deliver face to face services.

Fear of Misuse and Spin

Several speakers warned that poorly contextualised data, such as counts of care types from Medicare or CDM plans, risk being used to make misleading conclusions about what services are needed.

"ROSA used CDM data as if it were a reflection of all allied health use—'Oh, lots of podiatry? We should just fund that.'"

Theme 4. Opportunity for Collective Action and Sector Leadership

The Session participants explored ways that could highlight contribution of allied health professionals and the importance of having collaborative approaches to further changes. Storytelling was seen as an effective way to share knowledge.

Ground-Up Change through Collaboration

Participants called for the formation of cross-disciplinary communities of practice to share data, co-create models of care, and collectively advocate for policy and funding reform. The participants suggested that RePaDD could lead or support this coordination, particularly in amplifying lived experience, facilitating co-design, and translating research into practical resources.

"What we should mobilise is how to drive value—consumer lived experience is our outcomes."

Elevating the Role of Research and Storytelling

There was consensus that real-world case studies and lived experience narratives are critical to influencing policy, especially in the absence of formal outcome data. Participants called for RePaDD to help collate, analyse, and publish these stories as part of a broader advocacy strategy.

"We need to start collecting case studies of unmet need and unintended consequences, because that's all we'll have."

Strategic Leverage Points Identified

Participants made suggestions as to how change in the perception of allied health could occur. Ideas included lobbying for changes to national quality indicators, embedding allied health metrics in data reporting, and engaging with departments like the Inspector-General of Aged Care. A consistent message was that meaningful reform will only come through evidence-based pressure and showing what is lost when allied health is devalued or excluded.

Breakaway Session 2: Preparing for the End-of-Life Pathway

Facilitator: Dr Priyanka Vandersman

The Support at Home Program is replacing Commonwealth Home Support Program and Home Care Packages with a single integrated program focused on wellness and reablement. The End-of-Life Pathway is a dedicated support system for palliative and end-of-life care within the Support at Home program. The End-of-Life Pathway session examined the preparedness of the sector to implement the Support at Home Program and the End-of-Life Pathway. Details of the introduction to the session are found in Attachment 4. The following key themes emerged from the responses to specifically posed questions relating to this program.

Theme 1. Provider Category, Readiness, Clinical Governance, Policy and Funding

Provider Category and Readiness

The reform aims to better support people to die at home, but implementation is complex and evolving. There is confusion about classification under the new system, particularly around identifying someone as at end of life or palliative. Challenges exist in balancing classification accuracy with the practicalities of care delivery and reporting. Preview letters have been issued outlining provider categories, but final registration letters are still pending for some organisations. Providers were asked to self-assess and notify the department if they believed their categorisation was incorrect. Final registration categories are expected by June.

Registration Categories and Provider Implications:

To be a Support at Home care provider, registration in at least categories 4 and 5 (personal and clinical care) is required. Providers with limited services (e.g. only domestic assistance) must apply separately if they want to expand their service scope. Some providers have already received funding agreements based on their assigned categories. There is still uncertainty regarding the duration of registration; providers are awaiting clarity on expiry dates and renewal processes.

Impacts on CHSP and Service Groupings:

CHSP remains in place until 2027, with parts of the reform applying selectively. Some services previously offered under CHSP are now grouped into broader categories (e.g. Allied Health, Personal Care), which can be confusing for providers. There is variation in how services have been categorised, creating challenges in understanding eligibility and funding.

Lack of Clarity and Communication:
There is deep concern about the lack of clear guidance from the Commission, particularly regarding whether the new standards will apply from July 1. Accreditation principles remain separate from the Act, which adds complexity and uncertainty. Silence from the Commission is causing confusion, particularly around expectations for clinical responsibilities and funding pathways in end-of-life care.

Systemic Barriers to Equitable End-of-Life Care
There's an ongoing disconnect between reform intentions and real-world aged care practice, especially in regional and remote areas. Stories were shared of communities where people simply don't die at home due to a lack of palliative care infrastructure and on-call support. Home care providers face limitations in clinical scope, without proper governance, multidisciplinary support, or funding, safe and appropriate care is difficult to achieve.

Clinical Governance and Provider Capacity:
Larger providers with embedded clinical governance teams are starting to map processes, client journeys, and information flows. Smaller providers are likely to struggle without internal clinical expertise or dedicated staff to lead reforms. Governance isn't just about infrastructure, it also involves equipping frontline staff, like care workers, to understand and engage with new systems.

Misalignment Between Policy and Practice:
There appears to be a disconnect between what the government expects and what's feasible on the ground. The assumption that states and territories will deliver clinical end-of-life care in the home, while aged care providers offer adjunct support, raises questions about coordination and funding. Examples of how services might work (e.g., GPs accessing My Aged Care portals and processing palliative care packages rapidly) are seen as unrealistic and untested.

Disconnect Between Policy and Practice:
Promises of rapid funding and streamlined processes do not reflect reality, with GPs and providers expressing doubts about feasibility. There's a widespread perception that key sectors are expected to pick up complex care without adequate support or communication. No clear national or regional guidance on what roles different providers should play in delivering end-of-life care in home settings.

Barriers in Application and Referral Processes:

Limitations around who can submit applications (e.g. employees of certain providers not being allowed to complete forms) may create blockages. Absence of clear entry points into services can stall access and disrupt care planning. System complexity discourages participation and risks replicating issues seen in broader aged care reform.

Governance, Policy, and Medication Management Concerns

Large providers have governance systems in place but face challenges with overly prescriptive compliance expectations. Medication management in home settings presents significant risks, particularly around availability, access, and pharmacy coordination. Families often bear responsibility for sourcing medications without proper guidance or support.

Challenges with Palliative Care Funding

Some providers and specialists were unaware they could access additional palliative care funding; this highlights the need for better communication and education. There is concern about a lack of system readiness and clarity on how to implement the funding effectively. While the funding is welcomed, there's caution about overpromising, as the rollout may be messy and misunderstood initially, parallels drawn with the early days of the NDIS and Healthcare Homes.

Theme 2. Readiness – Role, Coordination, Implications, Types of Care, Triggering the EOL Pathway

Home Care and GP Involvement – System Gaps

There's significant uncertainty and fragmentation between aged care and primary care (GPs), especially regarding how new models and funding will work. GPs feel unprepared, under-informed, and at times alienated from these changes, likening the situation to the early days of the NDIS. Concerns raised around practical expectations, e.g., completing clinical assessments like Karnofsky scores without training or systems in place. Lack of clear, shared protocols or "playbooks" makes it difficult for providers and GPs to align care goals or responsibilities.

Need for Standardisation and Structure

Providers and clinicians are calling for: standardised tools and guidelines, clear communication and shared understanding across care sectors, and defined clinical governance models to ensure quality and safety. Communication between providers, GPs, and care workers needs to be proactive, structured, and timely. There's a strong desire to avoid automatic hospital transfers, with frameworks like the "seven-step pathway" shifting focus toward comfort and dignity in the home.

Challenges for GPs and Care Providers

Concerns raised about the unrealistic expectations placed on GPs within the current system, particularly around assessments and rapid responses under the new models. Lack of consultation with GPs, aged care providers, and acute care sectors has created a gap in understanding and readiness. Uncertainty about responsibilities, especially regarding end-of-life care and medication reassessment, is causing anxiety across the sector.

Communication and Coordination Gaps

Primary Health Networks (PHNs), aged care, and acute care sectors are not consistently connected, despite overlapping responsibilities. Coordination of palliative and aged care requires cross-sector partnerships and shared planning, which is currently lacking. This siloed approach leads to duplication, missed opportunities, and inefficiencies.

Jurisdictional Involvement and Gaps

Jurisdictions need to clarify the role of specialists and pharmacists in medication management and palliative care access. NSW is ahead in some areas, allowing aged care homes to hold essential medications and reviewing national lists for community pharmacies. Cost and PBS listing affect availability of critical medications; rural and remote areas may face greater barriers.

Theme 3. Dying at Home - Impact of EOL Experience – Making it Work

Care Models and Workforce Readiness

The idea that specialist palliative teams will take over clinical care, while home care providers offer non-clinical support, was challenged as unrealistic and unsustainable. Deterioration is unpredictable, and personal care alone may not meet people's needs in the final phase of life. Providers fear a default to hospitalisation if staff are not supported and trained to make holistic, values-based decisions.

Assessment and Access Delays

The current aged care assessment process is slow, with people dying before assessments are completed or funds are released. Even proposals for streamlining access (e.g. My Aged Care triggering faster approval) are viewed as disconnected from on-the-ground realities.

Training, Mindset, and Cultural Sensitivity

Care Partners (formerly case managers) will play a vital role in coordinating care, but need significant training to manage risk, uncertainty, and complex symptoms. There is a lack of clarity on what training is required for care workers, particularly in multicultural communities. Without proper mindset and preparedness, care workers may default to risk-averse decisions like unnecessary hospital transfers, undermining person-centred care.

Fragmentation Between Sectors

The divide between aged care, primary care, and acute care is a core issue that reform has not yet addressed. Collaboration across sectors is essential to support people to die well, particularly in under-resourced areas. There's a need for aged care to educate other sectors about its scope, limitations, and needs.

Concerns About Consultation and Policy Disconnect

While consultation processes exist, they often feel tokenistic, feedback is collected but rarely implemented in meaningful ways. Many experienced advisors and officials have left, leading to a sense of lost momentum and fragmented policy continuity. There's hope for deeper, more authentic consultation with people working on the ground.

Theme 4. Supporting Carers – Current Challenges & Recommendations

Supporting Carers

The reform assumes the presence of informal support at home, often without acknowledging its limits or sustainability. Not all carers are family; many are neighbours, friends, or others with no close emotional bond. Some carers are in these roles unwillingly or are experiencing abusive dynamics. Young carers, sometimes as young as 12, are providing complex care without adequate support or training.

Ongoing Carer Challenges:

Carers face long-term impacts: mental health challenges, higher suicide risk, reduced educational and employment opportunities. While paid care workers receive training and support, unpaid carers are often left without skills, recognition, or resources. Expectations around palliation place additional emotional and physical burdens on carers.

Post-Care and Recognition Gaps:

Carers often remain involved even after someone enters residential care, providing psychosocial support and advocacy. Their role is often unrecognised, leading to emotional distress and a lack of tailored support services. The Carer Gateway offers limited wellbeing support (e.g. counselling, short breaks) but lacks provisions for advocacy or skill-building. Many carers request supports not covered by the Gateway, highlighting the gap between need and available resources.

The Role and Challenges of Informal Carers:

Informal carers play a central role in navigating care, often without recognition or adequate support. Many carers do not identify as "carers"—they see themselves as partners, spouses, neighbours, or children, which can lead to being excluded from decision-making. There's a heavy reliance on their time, intention, and capacity, with limited structured support. Unpaid carers are estimated to save the government billions annually, underscoring their value. Carers often face significant emotional and logistical challenges, particularly during end-of-life care at home—feeling overwhelmed, unprepared, and unsupported during crises or after hours.

Emotional and Practical Burden at End-of-Life:

By the time palliative care is needed, many carers have already been providing support for years and are experiencing burnout. The fear of not understanding what dying looks like, or how to respond, is common and can be paralysing. Even with support services, carers are often alone at critical times (e.g., overnight), making the home setting overwhelming and frightening. There's a need to balance the dying person's wishes with the carer's capacity and willingness—this is often overlooked.

System Navigation and Information Gaps

There is a lack of centralised, clear information for people who may be eligible for aged care but are not yet connected to services. Many families and unpaid carers don't know what they don't know, accessing services often relies on word-of-mouth or incidental conversations. My Aged Care is not always known or intuitive to access; people may go to Centrelink, GPs, or hospitals without knowing the correct entry point. There's no clear checklist or pathway to follow, making access confusing and inconsistent. Carer organisations often do not have updated or adequate information to guide people, even when people actively ask. Participants expressed the need for a simple, unified script or tool, even a short ad campaign, to help families navigate the system. The strength of nurse-led models, continuity of care, and escalation processes are key assets to build upon.

Role of Care Workers in Detection and Escalation:

Care workers often identify signs of decline before anyone else and act as "the eyes and ears" on the ground. Good practice includes reporting deterioration, selecting escalation flags in apps (like Mabel), and calling providers directly. Some organisations respond well to care worker reports; others have inconsistent follow-up and communication gaps. Care workers sometimes feel they need to go beyond their role due to delays or inaction from providers calling repeatedly or making safety decisions themselves. The importance of timely, respectful, and structured feedback loops is clear, to ensure what is reported is acted on appropriately.

Fragmentation and Inconsistencies in Services:

Providers vary significantly in how they respond to deterioration, offer oversight, and coordinate care. Some do not have strong clinical governance or adequately qualified staff for escalation. There are inconsistent models of support depending on funding, organisation size, and available oversight. People are navigating complex family dynamics, which can block or delay timely care and decision-making.

The Need for Better Pathways and Integration:

Current care is often reactive rather than proactive, with people only entering the system during crisis. There is reinventing of the wheel across providers, each working in isolation with their own approach. A coordinated, person-centred model would include a clear care pathway, proactive planning, and regular review mechanisms. Aged care navigators and care coordinators are valued, but the scale and effectiveness are inconsistent. Future models need to better integrate digital tools, clinician oversight, and personal choice, especially with growing home deaths.

End-of-Life and Future Care Considerations

There are concerns about the impact of funding models, such as Support at Home and the End-of-Life pathway, on the quality and equity of care. Financial discrepancies could affect the experience and type of death for people dying at home. The group acknowledged that while choice is important, the system must provide enough clinical and emotional support for those without families or informal carers. Delivering quality end-of-life care at home remains resource-intensive despite increased funding. High complexity in clients' needs: medication management, cognitive impairment, wound care, catheters, and daily support. Staffing and availability are key bottlenecks; money alone won't solve the issue if workforce capacity is lacking.

The Role of Care Partners (Case Managers):

Success hinges on skilled care partners who can personalise care packages, coordinate across sectors, and support family expectations. Flexibility and creativity in designing individualised support plans are crucial.

What Can and Can't Be Funded:

Funding is tied to approved services, not lifestyle or "bucket list" items (e.g. turmeric lattes on the roof). Providers may only discover ineligible expenses after submitting claims, creating frustration and confusion. In principle, care should not differ, whether or not the person qualifies for extra funding. The additional "bucket" allows for enhanced care (e.g. equipment, overnight support, counselling) that keeps people at home longer.

Clinical Uncertainty and Diagnostic Challenges:

Predicting a three-month prognosis is difficult, especially in non-cancer conditions (e.g. heart failure, renal disease). Many clinicians are hesitant or ill-informed about their role and responsibilities in this new model.

Communication Gaps and Education Needs:

A significant disconnect exists between policy development and on-the-ground providers. There's been little to no communication or preparation for major reform among key players, including GPs and Carer organisations. Providers may need to take the lead on education and awareness.

Access and Transport:

Simple structural challenges, like how a frail client gets to appointments, remain unresolved. These barriers are critical for continuity of care and connection to GPs or specialists.

Telehealth as a Partial Solution:
Telehealth helps overcome distance and mobility issues, especially in rural settings. Uptake is promising, but inconsistent infrastructure (e.g. black spots) remains a barrier.

Financial Contributions and Access:
Financial co-contributions are causing distress and reluctance to accept care. Clients might refuse help due to costs, preferring to manage alone rather than contribute financially. Disparity between promised care (e.g. 16 hours/week) and what's delivered (e.g. 1 hour twice a week). Services may feel intrusive or burdensome rather than supportive.

Use of End-of-Life Pathway Funds:
The End-of-life pathway may offer $25,000 in extra care, but clarity around usage is lacking. Some clients may prefer clinical care over social care if out-of-pocket costs are involved. Clients may be hesitant to accept services if they're not meaningful or feel overly medicalised.

What Happens If Someone Lives Beyond the Three Months?
Anxiety about care ending abruptly after three months is common among families and clinicians. There is no clear guidance yet on transitions after the three-month funded period with a risk that people may feel abandoned or under-supported if care reverts to pre-existing lower levels. Automatic escalation to urgent care review may lead to a higher level of care. Concerns were raised about the seamlessness and clarity of this process. There are questions around eligibility, e.g. someone aged 66 with a chronic diagnosis but living longer than expected. Some people might avoid applying due to confusion or believing they are not at the "tipping point" yet. The risk of not accessing needed care remains because illness trajectories can be unpredictable.

Role of Family and Emotional Burden
There was a strong emphasis on the need to support and empower family caregivers. Home care providers must also consider how to support families, not just the client. Emotional triggers in families can lead to crisis responses or unnecessary hospital admissions. Adding more services without coordination can increase confusion and emotional distress. Real experiences show families dealing with under-delivery of promised services.

Training Gaps and Compassionate Support
Care workers are often deeply affected by their experiences with dying clients. The emotional impact of end-of-life work needs to be acknowledged and supported. Reflective practice can be beneficial but is currently limited. Gap in clinical readiness is significant, especially without adequately trained or qualified staff. Even with new pathways, systemic issues like staffing shortages and unreliable scheduling remain.

Culturally Diverse Communities and End-of-Life Care

Culturally and linguistically diverse communities often face additional challenges such as language barriers, lack of nearby family support, and migration-related trauma. Community trust and culturally sensitive care are crucial. Providing integrated services (e.g., carer support and palliative care from one provider) is seen as beneficial. Continuity of care is enhanced by having fewer providers involved. Holistic palliative care should include spiritual and emotional support, not just clinical needs. Earlier conversations about death and dying are vital, ideally before crisis points when carers are overwhelmed.

Digital and Data Transformation in Aged Care

The aged care sector is undergoing significant digital reform, spanning GP systems to audit tools and quality indicators. Digital systems are increasingly required under new care standards, particularly for governance and board-level reporting. Data should be meaningful and tailored to each organisation's needs (e.g., tracking complaints, incident trends). Monitoring the uptake of advance care planning can inform service focus and improvement. Systems like AlayaCare are being used to centralise data and generate useful reporting, such as diversity profiles. Individual-level data is crucial in emergencies (e.g., overnight home visits by paramedics). Key elements needed include Advance care directives; Care pathways (e.g., 7-step non-hospital transfer plans); Diagnoses and goals of care; Current medication lists; Diagnostic imaging and pathology; and Access to up to date, shared digital information can significantly improve acute care responses.

<u>Challenges with Current Data Collection of Client Health Care</u>:

Excessive and repetitive data collection was highlighted as a frustration (e.g., three versions of the same assessment in a week). This inefficiency can waste time and resources, cause client fatigue and frustration and lead to re-traumatisation. The original intent of models like the waiver assessment was to reduce duplication and streamline data sharing.

<u>Better Use of Data to Reduce Cognitive Load</u>:

There is a strong desire to reduce the exhaustion caused by communication barriers, such as hearing loss or translating for clients. Making better use of existing data can reduce repetitive information gathering and improve care experiences. Point-of-care systems on mobile devices enable visibility and ease for all team members, including clients and carers.

Data Collection Linked to Funding and Efficiency:
With new reform changes, particularly around care management and billable hours, providers must now show evidence to claim funding (e.g., from 35% down to 10% unless supported by documented hours). There's a need to document care actions efficiently and accurately, which can double workloads for staff already time-poor. Suggestions include exploring technology to capture data during care interactions, e.g., voice-to-text or automatic reporting tools.

Administrative Burden and Resource Allocation:
Time-and-motion style studies are being used to identify which staff actions are billable and what tasks might be more efficiently done by administrative support staff. Care staff may be stretched too thin to document in a way that meets new funding or quality requirements.

Person-Reported Outcomes and Experience Matter:
Data should reflect the person's lived experience, values, and goals, not just service delivery metrics. Current indicators often overlook whether services are meaningful or accessible from the client's perspective. There's a growing recognition that better person-reported outcomes lead to more targeted and cost-effective services.

Quality vs. Quantity in Data:
There's a disconnect between clinical outcomes and what people value most, especially relevant in end-of-life care. Families and carers can offer rich insights into what "a good death" looks like, which should inform future service design and funding. There was a humorous but insightful suggestion to use disposable placemats in hospitals as continuous feedback tools, emphasising the value of spontaneous, user-initiated input. Quantitative data often misses the real impact of care, for example, someone eating well after days of poor appetite due to meaningful engagement with a carer. That simple act was a mark of quality care, yet such outcomes are rarely captured in current systems. These moments reflect deeply personal, lived outcomes, like a reduction in depression or improved wellbeing, that matter just as much (if not more) than traditional indicators. Deeper understanding and meaningful relationships between care workers and clients can lead to more responsive and compassionate care. The development of trust and familiarity is a critical aspect of high-quality care, yet it is difficult to quantify or formally measure.

Collective Vision for Success in Reform

When prompted to reflect on the top five enablers of success in aged care reform within community settings, five key concepts emerged:

Sustained Support: Long-term, consistent support over years not just short bursts, is essential for embedding reform and maintaining quality care.

Collaboration and Connection: Feeling a shared sense of collaboration across sectors (health, aged care, disability) strengthens reform efforts. Participants expressed a sense of joy and hope from the collective energy of the group.

Digital Health Readiness: Efficient, integrated digital systems are needed to enable smooth coordination of care and reduce burdens on providers.

Training and Workforce Development: Ongoing, meaningful training is essential, not just compliance-based, but reflective of real-world needs. Some noted that training systems are lagging behind the pace of reform, and this needs urgent attention.

Recognition of Unpaid Carers: Parents, carers, and unpaid supporters must be seen and acknowledged within care models, not as invisible contributors but as central to outcomes.

Breakaway Session 3: Coordinating complex care (Health-Aged care)

Facilitator: Dr Raechel Damarell

A 4-step case study was used to stimulate discussion around the care interface of residential aged care and the health sector. The case study looked at managing complex chronic issues being experienced by an aged care resident as new symptoms emerge and she becomes more fatigued. Family issues and uncertainty in goals of care add to problems as her condition deteriorates.

The group work highlighted a range of actions that could have supported care in the facility and decision making and communication between care providers. The use of screening tools such as SPICT can trigger care planning and proactive decision making. Advance care planning was seen as necessary but is not often well resourced. The group noted that often processes for care are in place but nurses recognise signs too late. Careworkers and families can also play an important role in signalling change/decline.

The importance of taking a person-centred approach was seen core to good care. It is critical to understand the person's goals, wishes and preference. Ongoing symptom assessment and management supports an understanding of how things are changing, and referrals or transfers are needed. When many specialists are involved, agreeing a coordinator or liaison process is important too. Sometimes it's the RNs who liaise with the specialists, the GPs, the person, the families.

GPs were seen as being able to help with leading the discussions of goals of care with residents and their family. Communication is an important element of providing care in complexity, uncertainty and decline. However, participants recognised that discussions about deterioration, decline, end-of-life care, and palliative care are difficult.

Transitions between care setting were also seen as challenging. Discharge summaries are often not accurate, may arrive late, may not be received by GP/RAC; may be too wordy to be helpful; information is lost when only the last paragraph is read. Commonly residents do not return from ED/hospital with a discharge summary. Even when available, the information arrives at a facility that needs to be processed in the aged care system. The absence of a common communication platform was seen as a significant barrier.

There was active discussion regarding the best place for care. While the home or aged care facility is preferred where there is good and well-planned care, difficulties can arise with unanticipated acute episodes that cannot be managed, timing where it makes it difficult to get support or have sufficient staffing, medication availability and family concerns that care needs to be in the hospital. Lack of supports and experience can exacerbate staff capabilities with RAC nurses "losing skills" such as cannula insertions, transfusion, IV antibiotics. Participants also noted that acute care staff often do not see hospitals as a place for residents. "Shouldn't she be in aged care?" The group saw a clear need for nurses and other staff coming into aged care settings to be supported to maintain and develop their skills.

To prevent unnecessary transfers a good care plan, clear handovers and regular updates for all people involved in care are needed. This needs to be supported with workforce skills and confidence and GP availability and reassurance that appropriate care can be provided in the facility. The participants believed that aged care can manage the right care and the right medication if they have the right staff and are well resourced. There was a call for a minimum standard of palliative care to be available across all regions (metropolitan, regional, rural and remote), noting that it is not possible to provide the same levels of care across differently resourced and populated areas. There was also discussion of the mental health of older people in aged care services as these can fail to be identified and addressed (tends to be "forgotten" or ignored).

The importance of reflecting on care provision was noted. The ELDAC after-death audits can be a useful tool to evaluate actions and put in place new processes

Follow up Actions from the Round Table

In the last session of the round table, reports from each of the discrete working groups were made by the facilitators. The participants felt there was value in the roundtable engagement and an interest in continuing the engagement. Given the interest and commitment by participants, the Research Centre will continue to identify and promote critical actions through the Centre and through partner projects, particularly palliAGED, ELDAC and CarerHelp. Findings from this roundtable will be shared with the participants and with other key stakeholders.

An open invitation has been issued to participants and to others in the sector to connect and engage with RePaDD to progress and address these complex issues and sector needs.

About the Flinders Research Centre for Palliative Care, Death and Dying

The Research Centre for Palliative Care, Death and Dying (RePaDD) is hosted by the College of Nursing and Health Sciences at Flinders University.

The Centre's mission is to make a difference to palliative and end-of-life care by examining issues and challenges experienced by people living with a life-limiting illness, their families and carers, and health and care professionals supporting them.

RePaDD comprises of a multidisciplinary research team with a diverse set of skills and experience in working in a variety of settings. The group has an extensive track record in delivering successful national palliative care projects as well as high impact research and evaluation relating to palliative care, community experience of death and dying, innovative models of palliative care, and the contribution of palliative care to individuals at the end of life, health professionals and health and social care systems.

Attachment 1

Flinders University | Research Centre for Palliative Care, Death & Dying

Roundtable brief: Australian aged care reform: Implications for palliative and end-of-life care

Australia's aged care system is undergoing a significant transformation in response to the findings of the Royal Commission into Aged Care Quality and Safety. The Government's vision is to establish a system that is **person-centred, safe, inclusive, and sustainable**. Major reforms will take effect from **1 July 2025**. The new Aged Care Act introduces a Statement of Rights and legal obligations for providers. Strengthened Quality Standards emphasise clinical safety, inclusion, and measurable outcomes. A new regulatory model will enforce proactive, risk-based oversight. The Support at Home Program will streamline and personalise home care services. Workforce reforms focus on qualifications, fair pay, and mandated care minutes, while digital transformation will enhance data sharing and transparency, including new reporting requirements for allied health.

https://www.health.gov.au/our-work/aged-care-reforms/about

About the Roundtable Event

This roundtable is convened by the **Research Centre for Palliative Care, Death and Dying (RePaDD)** and affiliated projects (CareSearch, including palliAGED, and ELDAC) to explore the intersection of aged care reform and palliative and end-of-life care. These two projects offer a significant range of evidence, practice resources and tools to support aged care in caring for older Australians with palliative care needs and those coming to the end of their life. This includes the ELDAC toolkits e.g. allied health toolkit and palliAGED Tip Sheets for Careworkers and palliAGEDnurse app.

As Australia prepares for the most significant overhaul of its aged care system in decades, this event provides a timely opportunity for stakeholders across the sector to come together and discuss how these changes will impact the delivery of care for older Australians. With the introduction of new legislation, quality standards, and regulatory frameworks, the aged care workforce will be expected to play a more active role in delivering compassionate, person-centred palliative care. This roundtable will provide a platform to:

- Share insights and concerns from across the sector
- Identify practical strategies for implementation
- Explore opportunities for collaboration and innovation in multidisciplinary care

Together, we aim to shape a future where all older Australians receive the support they need to live and die with dignity.

Why focus on palliative and end-of-life care in aged care?

Palliative care and end-of-life care are core business for aged care. Many older Australians receiving aged care services live with chronic, complex, or life-limiting conditions. The reality is most people will die receiving aged care services, and the generalist aged care workforce must be equipped to deliver compassionate, person-centred end-of-life care.

The aged care and primary care workforce can support early conversations around advance care planning and can support the maintenance of independence and quality of life through to end-of-life.

Measuring quality in palliative and end-of-life care

The strengthened Aged Care Quality Standards now include a specific outcome: **Outcome 5.7 - Palliative Care and End-of-Life Care.** Providers must deliver care that:

- Is compassionate and person-centred
- Responds to changing needs and manages symptoms effectively
- Meets emotional, cultural, and spiritual needs
- Respects the person's preferences, dignity, and rights
- Involves families, carers, and health professionals in planning and delivery

By embedding a palliative approach earlier in the care journey, aged care providers can better support quality of life, manage symptoms proactively, and align care with the individual's values and goals.

ELDAC has prepared an **Aged Care Service Guide – Addressing Outcome 5.7: Palliative Care and End-of-Life Care.**

Reflection questions for participants

Please consider the following in preparation for the roundtable:

1. **What opportunities and challenges** do the reforms present for your role or organisation?
2. Are these **challenges or opportunities different** for residential aged care versus in-home aged care?
3. Delivering non-specialist/generalist palliative care will require **effective multidisciplinary team (MDT) collaboration**. What might this look like in practice, and what is needed to support it?

Have you heard of the ELDAC Digital Dashboard? Designed to track and visually represent key end-of-life (EOL) care processes and indicators relevant for reporting and clinical decision-making. There is a dashboard prototype demo if you want to give it a go!

Attachment 2

Flinders University | Research Centre for Palliative Care, Death & Dying

RePaDD Round Table: Understanding What Is Driving Change in Aged care to Support Palliative Care Needs

Welcome and Opening

This roundtable is hosted by the Research Centre in Palliative Care, Death and Dying which has a specific focus on ageing, caring, dying and grieving.
We welcome all participants and note that some of you may already have been involved in Flinders project and research activities through ELDAC, CareSearch and palliAGED.

We recognise that Flinders operates on Indigenous peoples' traditional lands and waters and acknowledge their continued responsibility to care for country at the University's various teaching locations, including the lands and waters of the following peoples: Kaurna, Arrernte, Boandik, Bungarla, Gunditjmara, Jawoyn, Larrakia, Nauo, Ngarrindjeri, Peramangk, Wuundjeri, Yolgnu.

HOUSEKEEPING

Venue Info

- Toilets Location
- Fire Exits
- Wi-Fi: Network

[Flinders Conference]

Password: [mushylead24]

Recording Notice

- This event is being recorded
- Please use a mic and speak clearly
- The workshop is covered under ethics (Flinders University 8532)

Phones & Tech

- Please silence phones

Timings & Sessions

- Whole of group: [9:45am– 2:25 pm]
- Breakout Rooms: [12:45pm-3:00pm]
- Wrap-Up & Close: [3:30pm]

Restricted access to Level 14

Get to know your table

EVENT ACTIVITIES

Settingthe scene	Whole group
Morning session: Discussion 'What are the sector's most pressing priorities/issues/needs/ as we approach 1 July/ 1 Nov in the context of palliative care and end of life?	
Afternoon session **Breakaway sessions focussing on following themes:** 1. Supporting Older Adults at Home: The Role, Reach, and Future of Allied Health 2. Preparing for the End-of-Life Pathway in Support at Home: Readiness, Roles & Realities 3. Coordinating Complex Care at End of Life: Case Reflections & System Insights	Allocated to themes
Sharing of findings of afternoon session Closing remarks	Whole group

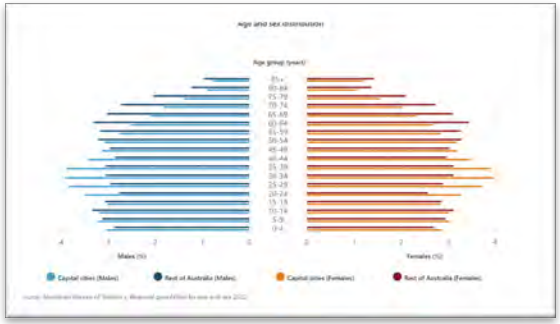
Flinders University | Research Centre for Palliative Care, Death & Dying

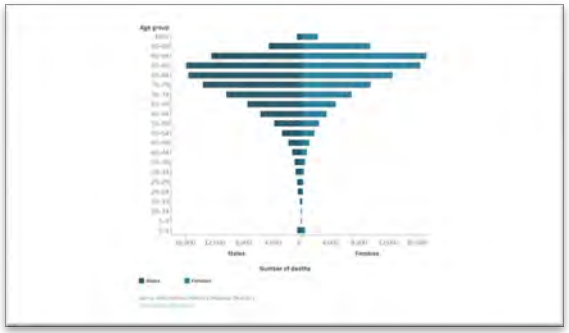
Setting the scene: Aged care, palliative care and end of life

Background

As with most countries, Australia is experiencing population ageing. As a population, we are living longer and dying older. This is recognised in the aged care reforms to be enacted on 1 Nov 2025.

EAPC: *Aged care is a priority for palliative care. Palliative care is a priority for aged care.*





Few older Australians (people aged 65 and over) die at home: Hospital is the most common place of death (50% of deaths), followed by residential aged care (36%).

This changes as age increases: Residential aged care is the most common place of death for people aged 85 and over (50%), followed by hospital (40%).

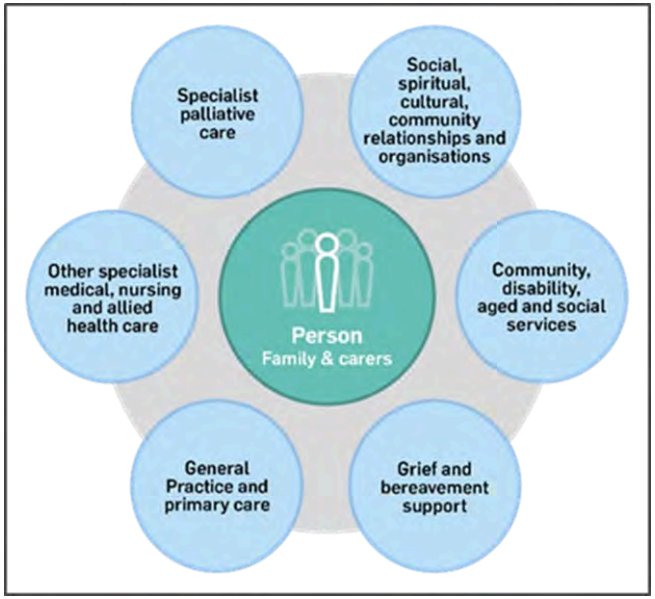
Of older people who had been living in residential aged care in the week before death, **4 in 5 (79%)** died in residential aged care. Of other older people, **7 in 10 (71%)** died in hospital.

Palliative Care in Australia

National Palliative Care Strategy (2018) and National Palliative Care Program (2023-2026)

Dying is a part of life. End of life is part of ageing and aged care. Palliative care supports people who are living with a life limiting illness. Needs based palliative care provision

Changing demography has implications for living well, ageing well and dying well. It requires whole of systems and whole of society thinking.



RePaDD

Flinders University Research Centre for Palliative Care, Death and Dying. Focus on outcomes and benefits for people, services and systems, communities and society

Acknowledges community need and existing research expertise while providing a base for expansion and responsive action to emerging issues

Strengthens the theoretical base to enhance applied research and translation

Connection point for clinical, community and policy partners

Integrates academic role with

research and project capabilities

Making a difference to care at the end of life

Palliative care across the health system
Death and dying across the community
Online evidence and practice translation

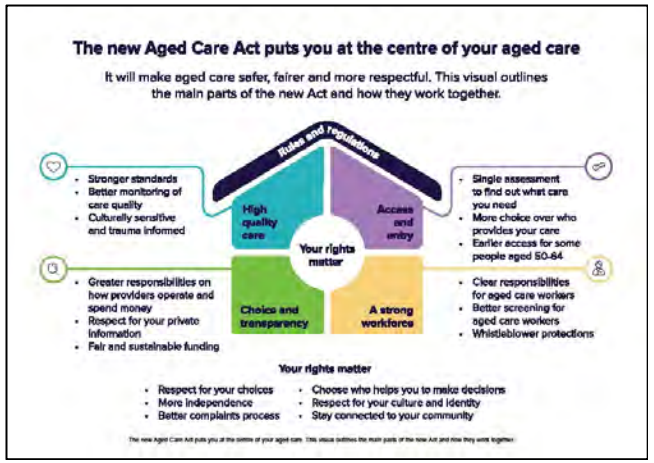
So why a roundtable?

- RePaDD projects already have a footprint in the health and aged care sector. So, we are looking at the implications of the changes.
- This is a multi-perspective problem so a roundtable can bring people with different backgrounds and views together.
- Indications that the magnitude of the changes are causing stress.
- Services and organisations are seeking information and guidance.
- Palliative care forms a single issue in an overcrowded agenda but there is growing demand and implications for both health and aged care. So how we can we ensure it is not overlooked?
- Opportunity to identify critical needs and to look at project and research responses.
- Opportunity to assess how (and if) the proposed solutions meet the needs in real time and what are markers of progress?

Transition Day: 1 Nov Reforms

NewAged Care Act 2024 includes

- A Statement of Rights, single assessment system and code of conduct
- New provider registration model and sector governance arrangement
- Support at Home Package replaces current home care packages and short term restorative package (includes an End of Life Pathway)
- RAC packages assigned to the resident not the facility. Changes to fees and charges
- Strengthened Standards are more measurable, detailed and reflect expected quality of aged care.



Statement of Rights

Replaces the current Charter of Aged Care Rights. Gives older people the right to:

- make your own decisions about your own life
- have your decisions not just accepted, but respected
- get information and support to help you make decisions
- communicate your wishes, needs and preferences
- feel safe and respected
- have your culture and identity respected
- stay connected with your community.

Under equitable access the Statement of Rights includes the right to palliative care and end-of-life care.

New Regulatory Model

The new model changes:

- How providers enter, remain and exit the sector
- Provider obligations and reporting
- Regulatory oversight of the sector
- How complaints and feedback are managed
- How information is available to older people.

Providers delivering government-funded aged care will need to:

- Be registered
- Apply to have this registration renewed regularly.

Governance of Aged Care System

These include:

1. The System Governor (Secretary DoHDA)
2. The Inspector-General of Aged Care
3. The Complaints Commissioner
4. The Aged Care Quality and Safety Commissioner
5. The Aged Care Quality and Safety Advisory Council who oversee the work of the Aged Care Quality and Safety Commission.

Strengthened Aged Care Standards

Seven Strengthened Standards each structured with:

- the intent
- the expectation
- the outcome (enforceable); and
- the actions to meet the outcome

Different service types can have different responsibilities

Categories 1 – 3: HACC, Assistive Tech and Home modifications, Advisory services (eg squalor or hoarding) do not have to meet the Standards but do have to comply with Code of Conduct and provider obligations.
Category 4: Personal and social care in including respite Must meet Standards 1 – 4 and Outcome 5.1 Clinical Governance(Applies to the service types of care management and restorative caremanagement only)
Category 5 – Nursing and transition care – Must meet Standards 1-5
Category 6 – Residential care – Must meet Standards 1-7

Standard 5 - Clinical Care

The Clinical Care Standard describes the responsibilities of providers to deliver safe and quality clinical care services to older people.

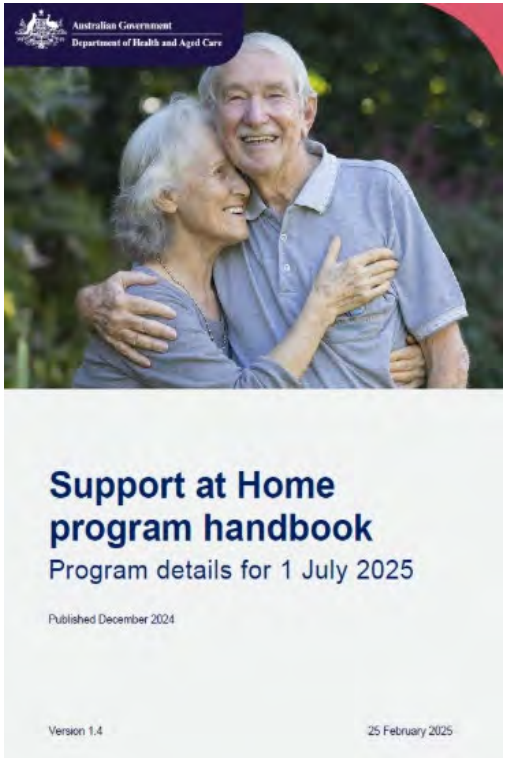
Outcome 5.1: Clinical governance
Outcome 5.2: Preventing and controlling infections in delivering clinical care services
Outcome 5.3: Safe and quality use of medicines
Outcome 5.4: Comprehensive care
Outcome 5.5: Safety of clinical care services
Outcome 5.6: Cognitive impairment
Outcome 5.7: Palliative care and end-of-life care

Support At Home Program

1 Nov 2025, Support at Home replaces Home Care Packages Program and the Short-Term Restorative Care Programme.

The Commonwealth Home Support Program (CHSP) will transition to Support at Home from no earlier than 1 July 2027.

Support at Home has 8 classifications for ongoing services and 3 short-term classifications: Restorative Care Pathway, **End-of-Life Pathway** and Assistive Technology and Home Modifications scheme.



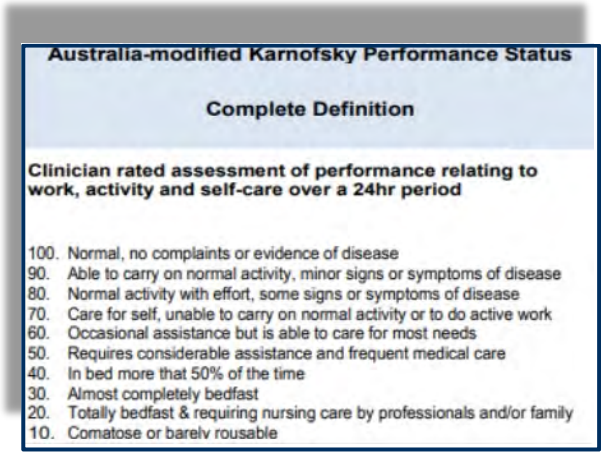
Support at Home Funded Services

Funded services are grouped into three categories:

- clinical supports – such as nursing care, allied health.
- independence – such as personal care, social support, respite care, community engagement and transport
- everyday living – such as domestic assistance, home maintenance and repairs, and meals.

Support at Home: End-of-Life Pathway

- Supports participants diagnosed with 3 months or less to live and wish to remain at home. Provides $ for increase in funded services.
- Only one episode of funding permitted. $25,000 over a 12-week period. Services from a service list
- Can be current SatH or a new SatH. There is paperwork, review and assessment processes
- Eligibility: 1) doctor or nurse practitioner advises estimated life expectancy of 3 months or less to live and 2) Australian-modified Karnofsky Performance Status (AKPS) score of 40 or less.



Australia-modified Karnofsky Performance Status

Complete Definition

Clinician rated assessment of performance relating to work, activity and self-care over a 24hr period

100. Normal, no complaints or evidence of disease
90. Able to carry on normal activity, minor signs or symptoms of disease
80. Normal activity with effort, some signs or symptoms of disease
70. Care for self, unable to carry on normal activity or to do active work
60. Occasional assistance but is able to care for most needs
50. Requires considerable assistance and frequent medical care
40. In bed more that 50% of the time
30. Almost completely bedfast
20. Totally bedfast & requiring nursing care by professionals and/or family
10. Comatose or barely rousable

End-of-Life Pathway: Providing service/care

A care plan should be developed for participants receiving services under the End-of Life Pathway, in the same way as for ongoing classifications.

Participants accessing the End-of-Life Pathway will likely need palliative care to support them to stay at home…. The Australian Government provides funding to state and territory governments for delivery of generalist and specialist palliative care services in their jurisdictions….The End-of-Life Pathway is designed to complement these services.

Table discussion

“Our most pressing issues”

Small group discussions
10 minutes per question (x4)

Reporting back from each table
20 minutes

4 key questions

Question 1	Question 2
What does delay of transition from 1 July to 1 November mean on the ground? What are the pain points?	How should primary care, aged care, unpaid carers, specialist palliative care and allied health interact in this brave new world?
Question 3	**Question 4**
What happens to older people who are at end of life but do not meet eligibility for the End-of-Life Pathway or for AN ACC Class 1?	What should RePaDD do to support aged care to deliver high quality care for older people with palliative care needs and older people at the end of life?

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Highlights from tabletop discussions:
*Key takeaways
*Shared insights
*Broader conversation

Attachment 3

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Session 1 –Supporting Older Adults at Home: The Role, Reach, and Future of Allied Health

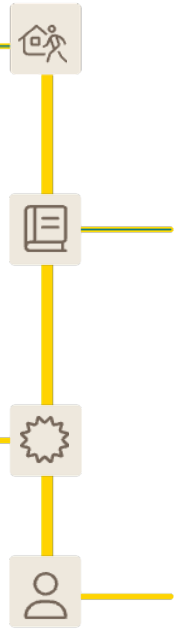
What we know about the Aged Care Reforms

Support at Home Program

Replacing Commonwealth Home Support Programme and Home Care Packages with a single integrated program focused on wellness and reablement

Updated Quality Standards

Eight new standards cominginto effect from July 1, 2025, focusing on person-centered care, dignity, and respect



New Aged Care Act

Replacingthe Aged Care Act 1997 with legislation that emphasizes rights-based care and greater transparency

End of Life Pathway

Dedicated supportsystem for palliative and end-of-life care within the Support at Home program

Allied Health - Preparing for Support at Home

- The Support at Home Program, launching in July 2025, represents a major shift in how allied health services are delivered and funded in the community.
- As the program replaces CHSP and Home Care Packages, allied health practitioners will need to navigate new service models, payment structures, and expectations for transparency and outcomes
- Allied health professionals are essential to enabling older Australians to maintain independence, function, and quality of life at home but what supports are needed to adapt to the evolving aged care landscape.

Key questions….

1

How do you see the Support at Home Program changing the way allied health services are delivered in the community?

What opportunities or challenges do you anticipate with the new service and funding models?

2

How can allied health be better integrated into multidisciplinary care planning under the new model?

What does effective collaboration look like in practice, and what barriers currently exist?

Key questions we will cover today…

3

What supports or system changes would help you adapt to the new expectations for transparency, reporting, and outcome measurement?

Are there specific tools, training, or infrastructure you feel are currently lacking?

4

Do you feel the current reform adequately recognises the role of allied health in maintaining function, independence, and quality of life?

5

What is your understanding of the End of Life (EOL) pathway, and do you see your allied health discipline/service playing a role in delivering care through it?

6

What are the practical, emotional, and ethical considerations for you and/or your staff as they engage in working with older adults in palliative and end-of-life care?

Key questions we will cover today…

7

How can we ensure that older people and their families understand the value of allied health services under the new system?

What role can practitioners play in improving health literacy and informed decision-making?

SUMMARY AND REFLECTION

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Attachment 4

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Theme 2 –Support at Home: End of Life Pathway

What we know about the Aged Care Reforms

Support at Home Program

Replacing Commonwealth Home Support Programme and Home Care Packages with a single integrated program focused on wellness and reablement

Updated Quality Standards

Eight new standards coming into effect from July 1, 2025, focusing on person-centered care, dignity, and respect

New Aged Care Act

Replacing the Aged Care Act 1997 with legislation that emphasises rights-based care and greater transparency

End of Life Pathway

Dedicated support system for palliative and end-of-life care within the Support at Home program

Preparing for the End-of-Life Pathway in Support at Home:

- With the upcoming changes in Australian aged care, like the Support at Home program, the new Aged Care Act, and refreshed Quality Standards, there's a real shift on the horizon.
- For providers of the proposed higher-level package (Level 5) in the new 'Support at Home' program, it's about more than just compliance; it's about being ready to thoughtfully adapt and align with what's coming into effect by July 2025.

Key questions….

1

How prepared is your organisation for the upcoming Support at Home program, particularly in terms of clinical governance and your provider category responsibilities?

2

What is your understanding of the End of Life (EOL) pathway, and do you see your service playing a role in delivering care through it?

3

How do you think the EOL pathway will impact the coordination of care, especially in identifying, planning, and leading support for someone nearing the end of life?

4

What are the practical, emotional, and ethical considerations for your staff, your organisation, and families when supporting someone through the EOL pathway?

Key questions we will cover today…

5

Do you believe the EOL pathway will enable more people to die well at home, and what supports or partnerships are needed to make that a reality?

Key questions we will cover today…

6

What kinds of data and digital systems do you currently use to support care delivery, reporting, and coordination, and how might these support or limit implementation of the SAH EOL pathway?

7

What features or capabilities would make it easier to collect, share, and act on data related to end-of-life care in a home care setting?