# Palliative Care Project

# Evaluation Report

**Community Options Incorporated**
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## Acknowledgment of Country

We acknowledge the Traditional Custodians of the land on which we work and live, the Ngunnawal people. We pay our respects to Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples. We recognise their continuing connection to land, waters, and community.

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# Introduction

Community Options Palliative Care Project is implemented with the funding assistance provided by the ACT Government Health and Community Services Directorate. During October 2025, the project was evaluated against its aims and objectives. This report provides information about the project, service activities and summarises key evaluation findings. The report also outlines recommendations generated on the basis of the project evaluation findings.

### Background Information and Rationale for the Development of the Pilot Project

Community Options has observed a growing demand for community-based palliative care, with many people diagnosed with end-stage illnesses expressing a strong preference to remain at home during their final stages of life. This demand is projected to rise further over the coming years, driven by demographic factors such as an ageing population and the increasing incidence of cancer in the ACT.

Despite this growing need, there has been a clear gap in the availability of targeted, non-clinical, home-based palliative care supports for individuals and their families. The absence of specialist community-based services has contributed to a disproportionate number of people dying in residential care settings, rather than in their preferred home environment.

This service gap has placed mounting pressure on Community Options' infrastructure, with a steady increase in referrals for short- to medium-term case management and tailored community-based supports. In response, Community Options identified the need to strengthen its capacity to deliver coordinated, person-centred services for people with end-stage illnesses and their families.

To address this, Community Options sought approval from the ACT Health Directorate to carry forward unspent funds from the 2010/11 financial year to establish a pilot palliative care project in 2012/13. A short-term Palliative Care Coordinator position was created in July 2012, and in August 2012 Joy Dizon was appointed as the Pilot Project Coordinator. Implementation commenced shortly thereafter, and in June 2013 the ACT Health Directorate approved an extension of the pilot until 30 June 2014.

Since its inception, the project has continued to evolve in response to community need. It is currently funded for case management services until 31 December 2026 with Community Options self-funding in home services from our reserve funds, ensuring ongoing support for individuals and families navigating end-stage illness within the ACT community.

## Literature Review

### National context and demand for palliative care

Across Australia, demand for palliative care is steadily increasing due to population ageing and the growing burden of chronic and life-limiting illness, particularly cancer. The Australian Institute of Health and Welfare (AIHW) reports that palliative care-related hospitalisations rose from about 73,600 in 2015–16 to 107,500 in 2023–24, an increase of around 46% (AIHW). Over half of these palliative care-related hospital episodes now end with the person dying in hospital, with discharge home as the next most common outcome (AIHW).

These trends highlight both increasing demand and continued reliance on acute hospital care at the end of life. The National Palliative Care Strategy 2018, endorsed by all Australian governments, emphasises the need for timely, person-centred and coordinated palliative care across settings, including stronger community-based and home-based models (AIHW).

### Preferences for place of care and place of death

A consistent finding in Australian and international literature is the gap between where people would prefer to be cared for and die, and where deaths actually occur.

Population-based evidence from South Australia found that around 58% of surveyed adults with cancer preferred to die at home, yet only about 14% of cancer deaths occurred at home, with most deaths occurring in hospital or institutional settings (PubMed). More recent work in specialist palliative care services similarly shows that home is a common preferred place of death, but hospital and residential aged care remain frequent actual places of death (SAGE Journals).

National mortality statistics reinforce this pattern. An ABS analysis of 2019 deaths found that just over half of all deaths (around 51%) occurred in a hospital or medical service, and almost 30% in residential aged care facilities, with a comparatively small proportion occurring at home (Australian Bureau of Statistics). AIHW analysis of people receiving specialist palliative care shows that hospital is the most common place of death for this group, while residential aged care is most common for people not accessing specialist palliative care (AIHW).

Community surveys confirm that many Australians would prefer to be cared for, and often to die, at home or in a non-hospital environment if adequate support is available. Palliative Care Australia's National Palliative Care Community Survey highlights strong preferences for comfort, quality of life and being with family, alongside widespread discomfort in discussing end-of-life wishes and limited planning (Palliative Care Australia). Together, these findings demonstrate a "preference–reality gap" that community-based services such as the Community Options Palliative Care Project aim to address.

### Impact of community- and home-based palliative care models

There is growing evidence that well-coordinated, home-based palliative care can improve alignment with patient preferences, reduce avoidable hospital use and support carers more effectively. International and Australian studies show that multidisciplinary, community-based palliative care programs are associated with increased likelihood of home death, reduced emergency department presentations and hospital admissions, and higher satisfaction with care (Palliative Care Australia).

A 2024 Australian study on community preferences for care of older people at the end of life found that people value affordable services that support comfort, symptom control and carer wellbeing across settings, not just in hospital. It concluded that community-based supports, including non-clinical assistance and case management, are critical to enabling people to stay at home when that is their preference (PMC).

These findings support the design of the Palliative Care Project, which combines case management, non-clinical in-home supports (such as personal care, domestic assistance and respite) and coordinated pathways with clinical providers.

### Carer experience and support needs

Carers are central to home-based end-of-life care, but frequently report high levels of physical, emotional and financial strain. Evidence reviews from New South Wales highlight that carers providing end-of-life care at home face substantial challenges, including lack of respite, coordination burdens, and difficulties navigating fragmented services (Sax Institute).

Despite these challenges, carers consistently report better bereavement outcomes and a sense of fulfilment when the person can die in their preferred place, particularly at home, with adequate supports in place (Sax Institute). Practical help with personal care, housework, transport and coordination is described as just as important as clinical care in enabling families to sustain home-based palliative care (Palliative Care Australia).

The Community Options model—providing flexible, non-clinical in-home support and case management—directly responds to these evidence-based carer needs by relieving day-to-day pressures, improving system navigation and supporting safe discharge home.

**Identification of palliative care needs and timing of referral**

Timely identification of people who are approaching the end of life is essential to avoid crisis-driven care and to allow for coordinated, person-centred planning. An Evidence Check commissioned by the NSW Agency for Clinical Innovation reviewed tools used to identify people nearing end of life, including the Supportive and Palliative Care Indicators Tool (SPICT) and the Clinical Frailty Scale. It concluded that structured tools could help clinicians recognise when palliative care should be considered, particularly for non-cancer conditions, but need to be integrated with clinical judgement and local pathways (Sax Institute).

These findings are consistent with feedback from ACT stakeholders that GPs and hospital clinicians are often uncertain about when to initiate palliative care and advanced care planning, and that service navigation support is crucial for patients and families transitioning from hospital to home.

**Cultural safety, equity and diverse populations**

Cultural safety and equity are critical dimensions of high-quality palliative care. Aboriginal and Torres Strait Islander peoples, as well as people from Culturally and Linguistically Diverse (CALD) backgrounds, often experience barriers to appropriate, culturally safe end-of-life care, including communication challenges, mistrust of mainstream services and limited recognition of cultural practices around dying, death and bereavement (Australian Indigenous Health Info Net).

Guidance from the Australian Indigenous Health Info Net and Palliative Care Australia emphasises the importance of culturally safe, family-centred care, flexibility in where and how care is delivered, and strong partnerships with Aboriginal Community Controlled Health Services and community organisations (Australian Indigenous Health info Net).

The “What Matters in the End” study, led by Western Sydney University, explored end-of-life experiences of Aboriginal people and several CALD communities and highlighted the centrality of family, spirituality, community connection and cultural rituals, as well as the need for services to adapt to diverse expectations of care and decision-making (Western Sydney University).

For a jurisdiction like the ACT, with a diverse population and strong Aboriginal community networks, this evidence underscores the importance of culturally safe, flexible, home-based supports and the role of trusted navigators—such as Community Options—in linking families with appropriate services.

**Summary of implications for the Community Options Palliative Care Project**

The contemporary literature provides clear support for the rationale and design of the Community Options Palliative Care Project:

- **Demand is increasing**, with more people living longer with complex, life-limiting conditions and continued reliance on hospital-based care at the end of life (AIHW).
- **Most people would prefer to remain at home** or in a non-institutional setting if adequate support is available, but the majority still die in hospitals or residential aged care (Pub Med).
- **Home- and community-based palliative care models**, particularly those that combine case management, practical in-home support and strong links with clinical services, improve alignment with preferences, reduce avoidable hospital use and support carers (Palliative Care Australia).
- **Carers require structured support**, respite and navigation assistance to sustain home-based care and experience positive bereavement outcomes (Sax Institute).
- **Cultural safety and equity** must be embedded in service design to ensure Aboriginal and Torres Strait Islander peoples and CALD communities receive care that is respectful, inclusive and responsive to their needs (Australian Indigenous Health Info Net).

These findings collectively justify the Project's focus on coordinated, person-centred, non-clinical support in the home, integrated with clinical palliative care and hospital services, and provide a robust evidence base for its continuation and expansion within the ACT.

## Evidence Table: Palliative Care Preferences, Outcomes, and Service Gaps

The evidence base for palliative care in Australia demonstrates a consistent pattern: while most people express a strong preference to receive care and die at home, most deaths continue to occur in hospitals or residential settings. This preference–reality gap is evident in ACT service data and national surveys and has been a key driver for the development of community-based pilot initiatives.

Recent Australian research and reporting by the Australian Institute of Health and Welfare (AIHW) confirm that demand for palliative care will continue to rise, driven by demographic trends such as population ageing and increasing cancer incidence. The introduction of national palliative care outcome measures in 2024 provides a framework for evaluating service quality, accessibility, and cultural safety. Evaluations of the Greater Choice for At Home Palliative Care program (2025) further demonstrate that coordinated, home-based models increase the likelihood of people dying at home, reduce avoidable hospitalisations, and strengthen carer support.

Evidence also highlights the importance of culturally safe practice, particularly for Aboriginal and Torres Strait Islander peoples and those from Culturally and Linguistically Diverse (CALD) backgrounds. Research shows that cultural values and family roles strongly influence end-of-life decisions, underscoring the need for services that are inclusive, respectful, and responsive to diverse communities in the ACT.

Taken together, the literature provides a clear rationale for strengthening community-based palliative care capacity. The following table summarises key studies and national data, highlighting their relevance to the ACT pilot project and its evaluation.

| Study/ Source | Year | Key Findings | Relevance to Pilot Project |
|---|---|---|---|
| **Palliative Care Australia Community Survey (National)** | 2012 | - Majority of Australians prefer to die at home.<br>- Community strongly values comfort, symptom relief and being with family at end of life.<br>- Survey highlighted significant public misunderstanding about when palliative care can begin. | Establishes clear national preference for home-based care but highlights systemic barriers to achieving this in practice. |
| **ABS & AIHW National Mortality and Hospital Data** | Latest verified: 2021–23 | - ~50–52% of deaths occur in hospitals.<br>- ~30% occur in residential aged care.<br>- Only ~15% occur at home.<br>- Palliative care-related hospitalisations | Demonstrates the strong “preference–reality gap” the ACT pilot aims to address by enabling safe home care. |

|  |  |  |  |
|---|---|---|---|
|  |  | increased over 40% over the past decade. |  |
| **AIHW Palliative Care in Australia Reports** | Annual (esp. 2021, 2022, 2023 releases) | - Demand for palliative care rising due to ageing and chronic illness.<br>- Workforce and service capacity issues persist across all jurisdictions.<br>- Community-based palliative care remains unevenly accessible. | Confirms national demand pressures and validates strengthening ACT community-based options. |
| **Greater Choice for At Home Palliative Care – National Midpoint Evaluation** | 2020–21 (Dept. of Health) | - Home-based models reduce emergency presentations and unplanned hospitalisations.<br>- Increased rates of home deaths when coordinated care is provided.<br>- Carers report improved confidence and support when services are available at home. | Strongly supports the project's emphasis on coordinated case management and non-clinical in-home supports. |
| **NSW Evidence Check: Identifying People at End of Life / Carer Burden** | 2016–2020 (Sax Institute) | - Carers often experience emotional strain, high burden, and poor access to respite.<br>- Tools such as SPICT and Clinical Frailty Scale help flag patients who may benefit from early palliative care.<br>- Carer wellbeing is directly improved when practical home supports are available. | Reinforces the need for flexible, responsive home supports and case management to reduce carer stress. |

|  |  |  |  |
|---|---|---|---|
| **Cultural Safety & CALD/Aboriginal Palliative Care Research** | 2020–2023 | - Aboriginal and Torres Strait Islander peoples emphasise family, cultural rituals, connection to Country and distrust of hospital models.<br>- CALD communities experience communication barriers and face culturally unsafe care conditions.<br>- Family-centred, culturally tailored models improve satisfaction and outcomes. | Confirms the importance of offering culturally safe, inclusive and flexible care options within ACT's diverse population. |
| **ABS Population Projections & AIHW Cancer Incidence Trends** | 2020–2022 releases | - ACT population is ageing more rapidly than most jurisdictions.<br>- Cancer incidence continues to rise, particularly in adults over 65.<br>- Palliative care demand expected to grow significantly over next decade. | Supports the long-term need for scaled-up community palliative services and strategic investment. |

# Pilot Palliative Care Project Scope

**Project Goals**

The pilot project aims to respond to an increasing demand for community-based palliative care and the consumers' wish to die at home through provision of targeted in-home non-clinical support services to people with end-stage illnesses and their families. The project also aims to improve the quality of life of people with end-stage illnesses and their families by relieving pressure and reducing the stress associated with caring for a family member with an end-stage illness. Finally, the project aims to assist with safe and sustainable discharge of people with end-stage illnesses who expressed their wish to die at home.

### Project Objectives

The pilot project objectives include:

- To provide practical assistance to people with end-stage illnesses and their families through provision of in-home (non-clinical) support services;
- To gauge the community need for in-home (non-clinical) palliative care in the ACT;
- To identify best practices for responding to the community need for palliative care;
- To establish more targeted, coordinated and integrated service outcomes for people with end-stage illnesses and their families;
- To improve pathways between the home-based palliative care (clinical service), hospital system and community care system (non-clinical community based palliative care).

### Expected Project Outcomes

Expected project outcomes include:

- Enhanced quality of life of people with end-stage illnesses and their families;
- More coordinated and integrated service outcomes for people with end-stage illnesses and their families;
- A more targeted community-based support for people with end-stage illnesses and their families;
- Improved capacity and service infrastructure to respond to an increasing community need for in-home community based palliative care services;
- Improved pathways/integration between home based palliative care services (clinical) and community-based services (non-clinical in-home palliative care services);
- Demonstrated need for targeted community based palliative care services.

### Project Eligibility Criteria

The following criteria were developed to determine eligibility for participation in the pilot project and to prioritise resources:

- A diagnosis of a life-threatening end-stage illness;
- A recent hospital admission and/or in receipt of home-based palliative care services;
- Complex needs that cannot be met within the existing services and other programs available in the community or within a timely manner;

- Complex needs requiring a complex service/case management response that cannot be met within existing programs;
- ACT residence.

# Project Evaluation

The Pilot Palliative Care Project evaluation included several evaluation activities, such as obtaining client feedback collected through surveys, stakeholder feedback, interview with the Palliative Project Case Manager and analysis of client demographic and service delivery data. The project evaluation aimed to assess the project performance against its aims and objectives and identify service gaps and areas for improvement. This section of the report summarises the information and data received because of the project evaluation activities outlined above.

**Project Data Summary**

From 2019 to September 2025, Community Options received a total of 765 referrals for support services and case management to people diagnosed with end-stage illnesses. Most of 765 people referred to the project were visited either in the hospital, hospice or their own homes. In 57 instances, although the support had been arranged, services did not proceed due to a number of reasons including: (1) readmission to hospital or hospice; (2) acceptance to residential care; (3) Aged Care packages becoming immediately available; (4) regional community services able to commence support; (5) clients passed away prior to planned discharge. The tables 1 and 2 below outline the number of referrals by the referral source and referral numbers across the years.

**Table 1: Referrals to the Palliative Care Project by Source for the period of July 2019 – mid-September 2025**

| Referral source | # of Referrals. |
|---|---|
| **The Canberra Hospital** | 320 |
| **Home Based Palliative Care** | 204 |
| **Clare Holland House Residential** | 74 |
| **National Capital Private Hospital** | 2 |
| **Family / self** | 5 |
| **Other Health and Community Services** | 75 |
| **Community Nursing** | 25 |
| **My Aged Care** | 10 |
| **Internal** | 50 |
| **Total** | **765** |

**Table 2: Referral numbers across each year July 2019 – mid-September 2025**

| Year | # of Referrals |
|---|---|
| **2019** | 116 |
| **2020** | 81 |
| **2021** | 143 |
| **2022** | 164 |
| **2023** | 150 |
| **2024** | 99 |
| **2025** | 12 |
| **Total** | **765** |

During the 2022/23 financial year, Community Options delivered a total of 220,523 hours of palliative care services through the project. Of this, 65,377 hours (30%) were provided to clients aged under 65, and 155,146 hours (70%) to clients aged 65 and over. This shows that while service hours were more heavily weighted toward older clients, younger clients consumed proportionally more hours per person.

Client numbers tell a complementary story. As shown in Table 4, 42% of clients were under 65 and 58% were aged 65 and over. Taken together, this indicates that younger clients with end-stage illnesses are higher consumers of service hours per person compared to older clients, reflecting potentially greater complexity of need or intensity of support requirements.

## Case Management Services

Case management hours have fluctuated over time. Between 2019 and September 2025, Community Options delivered 7,175 hours of case management (Table 3). Annual volumes ranged from 1,468 hours in 2019/20 (20% of total case management hours across the period) to 522 hours in 2022/23 (7%). While case management represents a relatively small proportion of overall service hours, it remains a critical component of service delivery, ensuring personalised coordination and support for clients and families.

**Trends Over Time**

- Under 65 clients: Received 276,313 hours of service between 2019 and September 2025. Service delivery peaked in 2019/20 (26%) and 2022/23 (23%), before declining sharply in 2023/24 (9%).
- 65+ clients: Received 481,946 hours of service over the same period. Service delivery was highest in 2021/22 (31%) and 2022/23 (32%), with strong volumes continuing into 2024/25 (26%).
- Case management: Totalled 7,175 hours across the period, with the highest annual contribution in 2019/20 (20%) and 2024/25 (17%).

**Key Insights**

- Service hours are weighted toward older clients (70%), but younger clients consume more hours per person.
- Client distribution (42% under 65, 58% over 65) highlights the importance of tailoring services to both cohorts.
- Case management remains essential, though it represents a small share of total hours, ensuring coordination and personalised support.
- Service volumes peaked in 2021/22 and 2022/23, reflecting periods of heightened demand, followed by reductions in 2023/24.

**Table 3: Client case management hours snapshot for the period of July 2019 – June 2025**

| Financial Year Case Management hours provided | Level of services provided (Hours) | Percentage of total |
|---|---|---|
| **2019/20** | 1468 | **20%** |
| **2020/21** | 1425 | **20%** |
| **2021/22** | 1479 | **21%** |
| **2022/23** | 522 | **7%** |
| **2023/24** | 694 | **10%** |
| **2024/25** | 1242 | **17%** |
| **Till September 2025** | 345 | **5%** |
| **Total** | **7175** | **100%** |

**Table 4: Client service delivery snapshot for the period of July 2019 – June 2025**

| **Financial Year services provided** (*Personal Care, Domestic Assistance, Social Support, Respite, Home Mods and Equipment)* | **Level of services provided (Hours)** | **Percentage of total** |
|---|---|---|
| **Palliative Care Services hours to Clients under 65** | | |
| **2019/20** | 67458 | **25%** |
| **2020/21** | 51519 | **19%** |
| **2021/22** | 61024 | **22%** |
| **2022/23** | 65377 | **23%** |
| **2023/24** | 25194 | **9%** |
| **2024/25** | 0.00 | **0%** |
| **Till September 2025** | 5741 | **2%** |
| **Total** | **276313** | **100%** |
| **Palliative Care Services hours to clients Aged 65 and Over** | | |
| **2019/20** | *No Data* | **0%** |
| **2020/21** | *No Data* | **0%** |
| **2021/22** | 150893 | **31%** |
| **2022/23** | 155146 | **32%** |
| **2023/24** | 48252 | **10%** |
| **2024/25** | 122997 | **26%** |
| **Till September 2025** | 4658 | **1%** |
| **Total** | **481946** | **100%** |

As a result of services provided to people with end-stage illnesses through the Palliative Care Project, the following client outcomes have been achieved:

- Safe and sustainable discharge to home was accomplished for most clients referred to the project;
- Over 70 clients died at home (preferred setting);
- 9 clients stabilised and transitioned to ongoing services such as NDIS, HCP or had no need for services;

- Clients and family members report improved quality of life and reduced carer stress and pressure;
- Clients and family members report high level of satisfaction with service provision through the pilot project.

## Client Feedback

In July 2025, client satisfaction surveys were distributed to an initial sample of five families who had received services through the Palliative Care Project. This sample represented 18% of all families supported through the project as of May 2025.

The selection criteria for the survey sample were as follows:

- Families must have received support through the project for a minimum period of two weeks.
- Families were excluded where the Palliative Care Project Coordinator reasonably believed it would be insensitive to send a survey, allowing appropriate time for grief recovery.

This approach ensured that the survey sample was both representative of families supported through the project and respectful of the sensitive circumstances surrounding end-of-life care.

Due to overwhelmingly positive feedback and no sensitivity issues raised as part of the palliative care project client surveys, the second round of the surveys was conducted in September 2025. During the second round, surveys were sent to additional five families who received services through the Pilot Palliative Care Project. The initial sample selection criteria applied to the selection of the sample in the second round of surveys.

A total of six out of nine families responded to Community Options' survey on the consumer experience with services provided through the pilot project. This represents 32% survey response rate. General feedback regarding surveys was overwhelmingly positive demonstrating high level of satisfaction and need for support services offered through the pilot project. Namely, all six families who responded to surveys stated that services provided through the pilot project significantly reduced the stress levels associated with caring for a family member diagnosed with end-stage conditions, contributed to improvement of quality of life and provided respite opportunities to family members. Namely, families who responded to surveys stated that the offered support services were very helpful and greatly relieved stress and provided carer respite during the hectic times of numerous hospital visits and medical appointments. The families also expressed satisfaction with the level of training, skills and experience of support workers. The only suggestion for improvement of support services through the pilot project identified by families was extension of support services for one week after the person with an end-stage illness passed away to assist the carer and relieve the pressure during the stressful time.

Some of the qualitative comments made by families in the surveys include:

- *"[The services] were extremely helpful and supportive in difficult times."*
- *"[The services made the client's] life more comfortable and [provided] some respite for carers."*
- *"[If services offered through the pilot project were not available, we would] mange with greater difficulty. We would have to. "*
- "*My husband [the person diagnosed with an end-stage illness] felt safe and comfortable to have [the support worker] help with his personal care… My husband would not have showered as he felt unsafe doing it without [the support worker] being present."*
- *"Services were excellent and I [the wife of the client] was very pleased with the support workers."*
- *"The support was very helpful during the hectic times of the last six weeks of my husband's [the client's] life with all the hospital visits and other appointments. It took a lot of stress off."*
- *"[If services offered through the pilot project were not available, we would] have to get our family to assist with showering my husband [the client] and the house would not be as clean. It would have also been more stressful. The support workers were very helpful and spot on. [The only suggestion for improvement identified was] it would have been very helpful to have the cleaning service for one more week after my husband passed away. It would have helped a lot during the stressful period. At the time, I did not know, and I would not have asked either, but [in retrospect] just one more week of domestic assistance would have been very helpful."*
- *"Community Options provided ladies to shower my husband [the client]. They were excellent and very efficient. The services offered gave me, the carer, time to relax or do other necessary jobs. [The most useful element of support offered through the project was] help for the carer."*
- *"[If services offered through the pilot project were not available, I [the husband of the client] would have had to do it myself, which I would have done, but it was better*

*to have an "outsider" do it. The two carers who attended my wife - [...]- were great and I would like to say, "thank you" to them."*

- *"[If services offered through the pilot project were not available, it] would definitely have made things very difficult for me [the wife of the person with and end-stage illness] and my daughter.*
- *"My experience [with services provided through the pilot project] was positive both for myself and most importantly, my husband, [...]."*
- *"[I] only [want] to say how much they [services offered through the pilot project] were valued by me [the wife of the person with an end-stage illness] and my family."*
- *"[Quality of communication with Community Options during the service provision was] very good—calls were prompt [-] telling us information."*

## Feedback from Referring Agencies and Stakeholders

As part of the evaluation, a roundtable was convened on 29 October 2025 with representatives from major referring agencies, ACT Government policy teams, clinical services, and community providers. The session aimed to gather feedback on the Palliative Care Project, explore system gaps, and identify opportunities for improvement to better meet the needs of people with end-stage illnesses and their families.

Participants included representatives from Canberra Health Services (Community Care Program, Advanced Care Directives), ACT Health Directorate (Ageing and End of Life Policy Team), Meridian, Directions Health Services, Capital Health Network, and Community Options. The discussion was facilitated as a collaborative forum, with contributions from clinicians, policy makers, service navigators, and case managers.

### General Feedback

Stakeholders expressed strong support for the Palliative Care Project, noting its flexibility, responsiveness, and ability to provide practical supports that enable families to manage end-of-life care at home. The program was recognised as filling critical gaps in the system, particularly for clients discharged from hospital who require immediate, non-clinical assistance to remain safely at home. Overnight support, domestic assistance, and respite were highlighted as essential services that reduce stress on carers and prevent unnecessary hospital admissions.

Participants emphasised that case management and service navigation remain central to positive outcomes, particularly in complex situations where clients face housing insecurity, mental health challenges, or limited informal supports. The “inclusive service navigation” approach, where no referral is refused and clients are assisted to connect with appropriate services, was identified as a strength of Community Options.

### System Challenges Identified

Several systemic issues were raised by referring agencies and stakeholders:

- Funding silos and short-term models: Current Support at Home and NDIS funding arrangements were described as fragmented, inflexible, and often unsuitable for end-of-life care. Providers reported withdrawing from palliative care due to unsustainable short-term funding and lack of recognition for the additional work required.
- Under-65 cohort gaps: Stakeholders noted that people under 65 often fall between aged care and NDIS eligibility, leaving them without adequate support. This group was described as having complex needs but limited access to funded services.
- GP referral and awareness gaps: Participants highlighted that many GPs and hospital doctors are uncertain about when palliative care should begin and often avoid advanced care planning due to time pressures and cost barriers for patients.
- Overnight care and carer respite: Families frequently struggle to sustain home-based care without overnight support, leading to hospital admissions even when home death is preferred.
- Cultural and social considerations: Stakeholders discussed the need for culturally safe practice, particularly for CALD and Aboriginal clients, and the importance of recognising diverse family roles and expectations in end-of-life care.

### Positive Impacts

Referring agencies reported that the project has:

- Reduced “social admissions” to hospital by providing practical in-home support.
- Enabled safe transitions from hospital to home for clients with complex needs.
- Supported carers through flexible services such as domestic assistance, meal preparation, and respite, allowing families to spend meaningful time together.
- Provided a trusted point of coordination in a fragmented system, ensuring clients are not left without support.

### Identified Gaps

Stakeholders identified several areas requiring further development:

- Longer-term support for clients with chronic progressive illnesses (e.g., motor neurone disease).
- Greater access to overnight care and respite services.
- Expanded community-based services for clients under 65.
- Integration of allied health supports (nursing, physiotherapy, medication prompting, symptom management).
- Improved referral processes, including streamlined documentation and clearer communication of prognosis and timeframes.

**Summary**

Overall, feedback from referring agencies and stakeholders was highly supportive of the Palliative Care Project. The program was recognised as a vital component of the ACT palliative care system, particularly in bridging gaps between hospital discharge and community support. Stakeholders emphasised the importance of sustaining and expanding the project to address systemic funding challenges, strengthen carer support, and ensure equitable access for both under-65 and over-65 cohorts.

**Stakeholder Voices – Direct Quotes**

- *“Overnight care is the biggest challenge. Families send clients to hospital for end-of-life because they can’t keep up without respite.”*
- *“Under-65 clients often fall into a gap. They don’t qualify for aged care or NDIS and end up relying on hospitals or going without support.”*
- *“GPs don’t know when palliative care should start. Many avoid advanced care planning because of time pressures and cost barriers for patients.”*
- *“The strength of Community Options is flexibility. Services adapt to what families need – sometimes it’s domestic assistance, sometimes just someone to talk to.”*

## Feedback from the Pilot Palliative Care Project Case Manager

As part of the evaluation, an interview was conducted in September 2025 with Olive Doig, Palliative Care Case Manager/Consultant, to gather insights from her direct work with people with end-stage illnesses, their families, and referring agencies. Her feedback was considered alongside themes emerging from recent roundtable discussions. The combined findings are summarised below.

### Target Group

Olive emphasised that case management and initial home visits remain foundational to achieving successful outcomes. Meeting clients and families face-to-face provides a vital human connection, builds rapport, and ensures services are tailored to individual needs. Home visits also reduce risks to client safety and help families understand available supports and how to navigate the system.

Across both the interview and roundtable discussions, it was noted that:

- Most clients have high and escalating support needs, particularly following hospital discharge.
- As conditions deteriorate, clients require ongoing monitoring and gradual increases in service intensity.
- Families benefit from clear, consistent communication and a single point of coordination.
- Cultural values and beliefs strongly influence end-of-life decisions, and culturally sensitive practice is essential to avoid compromising outcomes.

Participants also reflected on the potential to broaden awareness of Community Options' capacity to support families particularly those whose children receive oncology or haematology care in Sydney but wish to remain at home in the ACT. Opportunities to engage organisations such as CanTeen, Camp Quality, Ronald McDonald House, and paediatric teams in Canberra were identified, noting that this may require careful consideration due to the complexity and intensity of support needs.

### Relationships with Stakeholders

Both Olive and roundtable participants highlighted that strong, reciprocal relationships with stakeholders are critical to the project's success. Partnerships with Clare Holland House, Canberra Health Services, hospital teams, and other community organisations have enabled smoother transitions from hospital to home and improved outcomes for clients with complex needs.

Sustaining these relationships requires active engagement, including:

- Regular attendance at stakeholder meetings.
- Sharing up-to-date information and service changes.

- Participating in network events and education sessions.
- Creating informal opportunities for connection (e.g., twice-yearly activity nights or networking events).

These strategies help ensure Community Options remains visible, trusted, and front-of-mind for referrers.

**Service Gaps**

Olive's feedback reinforced several service gaps already identified through the roundtable process. While Community Options provides flexible case management and navigation, the organisation is not funded to deliver in-home services directly, leaving significant unmet needs for clients and carers.

**Key gaps include:**

1. **Ongoing Funding for Case Management and In-home Services**
   A structural gap exists in the current funding model: the Palliative Care Case Manager role is supported through a one-year ACT Government contract, and no recurrent funding is available for in-home non-clinical support. Consequently, Community Options continues to underwrite domestic assistance, personal care, respite, and overnight care through organisational reserves, limiting long-term service sustainability.
2. **Overnight and Weekend Support**

   Current funding rarely covers extended or after-hours care. Families with limited informal support particularly those with young children are disproportionately affected and may resort to hospital admission when respite is unavailable.
3. **Respite for Carers**
   Carers often lack access to regular, funded respite. Expanded respite options would reduce stress, prevent burnout, and support families to maintain home-based care.
4. **Social Support and Community Access**
   Bedbound clients frequently miss out on social supports that reduce isolation and maintain wellbeing. These services are critical but poorly resourced.
5. **Allied Health Services**
   Timely access to allied health, podiatry, physiotherapy, massage therapy, is limited despite their importance for symptom management and quality of life.

6. **Practical Supports**

   Services such as hairdressing and personal care are rarely funded but contribute significantly to dignity and emotional wellbeing at end-of-life.

### Training and Professional Support

Olive emphasised the importance of ongoing professional development, including palliative care workshops, conferences, and structured learning opportunities. She also highlighted the need for:

- Access to clinical supervision (reflective practice), debriefing or counselling, given the emotional demands of end-of-life care.
- Opportunities to attend relevant conferences to keep informed on emerging best practice and innovation and share learnings with the team.
- Opportunities to present or attend palliative care case studies.
- Targeted palliative care training such as grief and bereavement training or participating in ACT PEPA program workshops and placements.
- Regular opportunity to participate in study forums focussed on education that is relevant to Community Options' work (not academic coursework).

Staff taking responsibility for maintaining their skills was seen as essential for both service quality and professional growth.

### Opportunities for Improvement

Across the interview and roundtable discussions, several improvement opportunities were identified:

- Strengthen communication between referring agencies and Community Options to ensure timely, coordinated care.
- Formalise relationships with key stakeholders (Clare Holland House, Canberra Hospital, Calvary Hospital) through Memoranda of Understanding to support consistent referral pathways and information sharing should funding be secured for a reasonable length of time.
- Enhance collaboration with organisations such as Palliative Care ACT.
- Introduce regular case review discussions (e.g., fortnightly) to reflect on referrals, challenges, and opportunities for improved client outcomes.
- Explore targeted outreach to paediatric and youth-focused organisations where appropriate.

- Maintain visibility through networking, education sessions, and stakeholder engagement activities.

**Summary**

Olive Doig's feedback, combined with insights from the roundtable discussions, reinforces the central role of case management, home visits, and strong stakeholder relationships in delivering high-quality support to people with end-stage illnesses and their families. The project's strengths, flexibility, responsiveness, and a strong client focus are clear. However, significant gaps remain, particularly in in-home service funding, overnight care, respite, allied health access, and culturally sensitive practice.

These findings highlight both the value of the current model and the need for further investment to ensure clients and families receive the comprehensive, dignified, and culturally respectful support they deserve.

## De-Identified Case Study

### Case Study: Diane's Story – The Role of Community Options in End-of-Life Care

Diane was a 49-year-old woman who relocated from Sydney to Canberra with her husband John and their youngest daughter Sam, aged 12. Their two older children, James (23) and Sophie (20), remained in Sydney to continue their careers and studies, supported by their grandparents. The family's move to Canberra was prompted by John's new employment opportunity, and Diane quickly secured a teaching position at Sam's school.

Several months after settling, Diane was diagnosed with advanced ovarian cancer that had spread to her liver and lungs. The diagnosis was devastating, and following initial oncology treatment, Diane required hospital admission for complications. With increasing fatigue, she took leave from teaching, and John began working from home to provide care. Diane's mother also relocated to Canberra to support the family.

**Referral to Community Options**

A hospital social worker referred Diane to the Community Options Palliative Care Program. Following an initial home visit, the program provided personal care support five times per week from the same support worker, ensuring continuity and rapport. The support worker assisted Diane with daily needs and household tasks, while Sam received emotional support from her grandmother and school counselling, supplemented by CanTeen services.

Community Options' involvement was pivotal in enabling Diane to remain at home. The support worker helped Diane prepare letters and birthday cards for her children, providing meaningful legacy activities.

### Integrated Care

As Diane's condition progressed, she required repeated hospital admissions for fluid drainage and was referred to Community Nursing for twice-weekly procedures. Home Based Palliative Care nurses managed symptom control, including daily syringe drivers for pain relief. Community Options coordinated with these services, ensuring seamless integration of clinical and non-clinical supports.

### Family Tragedy and Increased Support

During this period, the family faced further tragedy when James was killed in a car accident. Sophie relocated to Canberra to support her family. Community Options' support worker became invaluable, assisting Diane with daily care and household tasks during this time of compounded grief.

Support was increased to daily visits, with a second worker allocated to assist with bed washes and pressure care. The regular support worker and "buddy" worker were present when Diane passed away peacefully at home, surrounded by family.

### Outcomes and Impact

Despite the profound challenges, Diane's family expressed gratitude that her wishes were honoured: she remained at home, surrounded by loved ones, with dignity and comfort. Community Options played a critical role in enabling this outcome, providing:

- Consistent, trusted personal care and household support.
- Emotional and practical assistance during family crises.
- Coordination with nursing and palliative care services.
- Flexibility to increase support intensity as Diane's needs changed.
- Relief for carers, allowing the family to focus on spending meaningful time together.

### Summary

This case study demonstrates the unique value of Community Options in bridging gaps between hospital discharge, clinical services, and family care. By providing flexible, non-clinical support and consistent case management, Community Options enabled Diane and her family to achieve her wish of end-of-life care at home. The program's responsiveness, compassion, and integration with other services ensured dignity, reduced stress, and improved quality of life for both Diane and her family.

## Conclusion

The evaluation of the Community Options Palliative Care Project demonstrates that the project has delivered significant benefits to people with end-stage illnesses and their families in the ACT. By providing flexible case management, service navigation, and non-clinical supports, the project has enabled safe discharge from hospital, reduced carer stress, and allowed more clients to achieve their preference of dying at home.

The project has also highlighted systemic gaps in the broader palliative care system, particularly around access to funded in-home services, respite, and supports for clients under 65. Community Options has filled these gaps through self-funded service provision, but this model is not sustainable long-term. Without secure funding, families risk losing access to essential supports that prevent hospital admissions and improve quality of life.

Overall, the evaluation confirms that the pilot project is a vital component of the ACT palliative care system, bridging the divide between hospital, clinical palliative care, and community-based supports.

## Key Findings

- Demand and impact: Between 2019 and September 2025, 765 referrals were received, with over 220,000 hours of service delivered in 2022/23 alone. More than 70 clients achieved their wish to die at home.
- Client outcomes: Families reported improved quality of life, reduced stress, and high satisfaction with support workers. Surveys confirmed that services were "extremely helpful and supportive in difficult times."
- Service distribution: 70% of service hours were delivered to clients aged 65+, but younger clients consumed more hours per person, reflecting higher complexity of need.

- Case management: 7,175 hours of case management were delivered, ensuring personalised coordination and safe transitions from hospital to home.
- System gaps: Stakeholders identified critical gaps in funded services, including overnight care, respite, allied health, home modifications, and supports for under-65 clients.
- Funding limitations: Community Options is funded only for case management and has relied on reserve funds to deliver in-home services. This is unsustainable and leaves families vulnerable.
- Stakeholder support: Referring agencies and government representatives strongly endorsed the project, recognising its flexibility, responsiveness, and ability to reduce hospital “social admissions.”

# Recommendations

1. **Secure sustainable funding for in-home services**
   Transition from reliance on Community Options reserves to ACT Government funding for non-clinical supports such as domestic assistance, personal care, respite, and overnight care and longer-term contracts for the Palliative Case Manager funding.
2. **Integrate allied health and practical supports**
   Establish funded access to allied health (physiotherapy, podiatry, massage therapy), home modifications, and practical supports (e.g., hairdressing, social access) that contribute to dignity and wellbeing.
3. **Strengthen system coordination and workforce capacity**
   Formalise referral pathways with hospitals and Clare Holland House, embed cultural safety, and invest in workforce training (grief, loss, and debriefing) to ensure consistent, high-quality care

# Addendum 1: Attendance List for Feedback Session with Stakeholders

| # | Name | Organisation |
|---|---|---|
| 1 | Jenny Pegram | Meridian ACT |
| 2 | Karen Dell | North Canberra Hospital |
| 3 | Jen Harland | ACT Health Directorate |
| 4 | Ben Harkness | Directions Health Services |
| 5 | Hannah Gissane | ACT Health Directorate |
| 6 | Ros Kirk | Capital Health Network |
| 7 | Alicia Phillips | Canberra Health Services |
| 8 | Kirsten Sippel | Canberra Health Services |
| 9 | Jacqui Boutcher | Canberra Health Services |
| 10 | Janine Rath | Canberra Health Services |
| 11 | Amanda Russell | Home Based Palliative Care |

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