



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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Community Options
Serving the Canberra region

Select Committee on End of Life Choices
ACT Legislative Assembly

Dear Committee Members,

Re: Inquiry into End of Life Choices in the ACT

We appreciate an opportunity to make a submission to the Select Committee's inquiry into End of Life Choices in the ACT. We trust that this submission provides some insight and information for the Select Committee in relation to this inquiry and highlights issues that ACT residents face in relation to accessing services required for them to exercise their choice and preference for receiving end-of-life care.

We would also like to thank you for your consideration of information provided in this submission and would like to welcome the Select Committee's very timely inquiry into the matter of end of life choices in the ACT. We would also like to offer our full cooperation to the Select Committee in this inquiry. As such, we would welcome the opportunity to provide further information or answer any questions the Select Committee may have in relation to this submission.

Should you have any questions in relation to this inquiry or would like to receive additional information, please do not hesitate to contact me on (02) [REDACTED] or at [REDACTED]

Yours faithfully

[REDACTED]

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Community Options
Serving the Canberra region

**ACT Legislative Assembly Select Committee's Inquiry into End of
Life Choices in the ACT**

Community Options Submission

22 March 2018

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List of Acronyms

ADL – Activities of Daily Living

ATSI – Aboriginal and Torres Strait Islander

CASP – Community Assistance and Support Program

CASP – Community Assistance and Support Program

CHSP – Commonwealth Home Support Program

HCP – Home Care Packages

NDIA – National Disability Insurance Agency

NDIS – National Disability Insurance Scheme

TCH – The Canberra Hospital

1. Introduction

The ACT Legislative Assembly's Select Committee (the Select Committee) resolved to inquire into the end of life choices in the ACT with the particular reference to a number of issues including: "(1) current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care." As a provider of in-home support services to older people, people with disabilities and people with health conditions including those diagnosed with terminal (end-stage) illnesses, Community Options is pleased to forward this submission. We trust that this submission provides some insight and information into the Select Committee's inquiry above and highlights some of the issues in relation to limitations of existing services and the medical community to support people in exercising their choice and preference to receive end-of-life care in their own home.

2. About Community Options and Palliative Care Program

Community Options is one of the major providers of in-home and community based support services to older people and people with disabilities with complex support needs residing in the ACT. We provide services to a number of target groups including ACT residents diagnosed with terminal (end-stage) illnesses. In 2012, we established a pilot palliative care project in response to an increasing number of referrals from ACT hospitals and other ACT Health services for case management and in-home support (non-clinical) to people with terminal (end-stage) illnesses who expressed their wish to die at home.

Since its establishment in 2012, Community Options has provided support to more than 800 ACT residents diagnosed with terminal (end-stage) illnesses. Majority of referrals to the Community Options Palliative Care Program come from: the Canberra Hospital; Clare Holland House (both in-patient hospice and the Home Based Palliative Care Team); and Calvary Hospital. The Community Options Palliative Care Program complements the existing palliative care system in the ACT, and home based palliative care services in particular. Namely, our Palliative Care Program works in conjunction with the Home Based Palliative Care Team of Clare Holland House. Through this arrangement, Community Options delivers practical, in-home care and support (non-clinical support with activities of daily living); whereas, clinical home based palliative care services (health services including nursing care for pain and other physical symptom management) are delivered by the Home Based Palliative Care Team from Clare Holland House.

In supporting people under the Palliative Care Program, Community Options relies on a number of funding sources; including:

- ACT Health grant assistance for case management services delivered through this Program to ACT residents of all ages diagnosed with terminal (end-stage) illnesses;

- ACT Health Community Assistance and Support Program (CASP) for in-home support (non-clinical) services delivered to people diagnosed with terminal (end-stage) illnesses aged under 65;
- Commonwealth Home Support Program (CHSP) for in-home support (non-clinical) services delivered to people diagnosed with terminal (end-stage) illnesses aged 65 and over.

3. Key Issues with Delivery of Home Based Palliative Care in the ACT

While the attached evaluation report of our palliative care project has further information on service delivery activity through our Palliative Care Program and the community views and preferences on end-of-life care, we would like to highlight the major issue for the purpose of the Select Committee's inquiry into end of life choices in the ACT; namely:

- *Increasing number of people in the ACT wish to receive end-of-life care in their own home; yet, not everyone is able to fulfil this wish due to a lack of services available in the community*

Both research evidence and our service delivery experience suggest that the vast majority of people, who have considered the end-stage of their lives or who are at the stage of facing these decisions, want to die at home. Yet, according to Palliative Care Australia (2011)¹, only a relatively smaller segment of the population in Australia (16%) actually dies at home, and the majority of people (84%) die in hospitals (54%), hospices (20%) and nursing homes (10%). As such, there is a general consensus that a home setting is both a community preferred and a more cost-effective setting for managing the end-of-life care for people diagnosed with terminal (end-stage) illnesses (Daveson et al 2013; Higginson 2013), yet the healthcare system in Australia continues to bear the high cost of managing the end-of-life care particularly during the last year of life.²

It is our service delivery experience that part of the reason why many ACT residents continue to end up having to receive the end-of-life care in hospital instead of home is a lack of practical, in-home support services that are required in conjunction with clinical palliative care services to delivery best possible end-of-life care outcomes in a home setting. Namely, the biggest gap we have identified in consultation with other providers of in-home palliative care services such as the Home Based Palliative Care Team at the Clare Holland House is the

¹ Palliative Care Australia (2011). Media Release 'We Need to Talk about Dying – Survey. Retrieved from: <http://www.palliativecare.org.au/>.

in-home and overnight respite care that is often required by families to be able to practically continue caring for their family members, particularly during the very end-stage of their lives.

The practical, in-home and overnight (in-home) respite care can play a crucial role in preventing the hospital admission for non-medical reasons during the last few weeks of people's lives. Unfortunately, overnight (in-home) respite care services are non-existent in the community and in-home support services that we are currently providing under our Palliative Care Program desperately require expansion to match the increasing demand for services. In addition, there is a desperate need for the ACT Government and ACT Health in particular to assess the implications of the national disability and aged care reforms for future sustainability of health services in the ACT³. Namely, the national disability and aged care reforms, and introduction of My Aged Care system in particular, have already placed significant constraints on our ability to adequately respond to demand for in-home support services for people with end-stage illnesses.

While little information is available regarding a funding model or an implementation approach for Stage 2 of the national aged care reforms, the Australian Government has announced its clear intention to consolidate the CHSP and Home Care Packages (HCP) funding and move to an individualised funding model for consumers from 1 July 2020. More information about these national aged care reforms is available at: <https://agedcare.health.gov.au/increasing-choice-in-home-care>.

This plan to move to an individualised funding model will have a detrimental impact on our Palliative Care Program and will most likely result in significant delays and lack of access to essential in-home support services required for delivery of sustainable end-of-life care outcomes in home settings for many ACT residents. Namely, should the CHSP and HCP programs merge on 1 July 2020 as expected, older ACT residents (aged 65 and over; or 50 years and over for people who come from Aboriginal and Torres Strait Islanders [ATSI] backgrounds) who are diagnosed with terminal (end-stage) illnesses will no longer be able to access in-home support with Activities of Daily Living (ADL) promptly under CHSP (as they currently do) and will face significant delays due to the access requirements under the Commonwealth Home Care Packages (HCP) program. As a result, older ACT Residents diagnosed with terminal (end-stage) illnesses will have to undergo the following process through My Aged Care:

³ This matter has been addressed in a greater detail in the Community Options' submission to the ACT Legislative Assembly Standing Committee on Health, Ageing and Social Services' Inquiry into the Sustainability of Health Funding in the ACT available on: <https://www.parliament.act.gov.au/in-committees/standing-committees-current-assembly/standing-committee-on-health,-ageing-and-community-services/5.-inquiry-into-the-future-sustainability-of-health-funding-in-the-act>.

- Following a referral being sent to My Aged Care, the Contact Centre conducts screening of the referral and sends a referral to the Aged Care Assessment Team (ACAT) for an assessment for approval of home care under the Aged Care Act 1997;
- The timeframe for the ACAT assessment is up to 21 days following receipt of referral;
- Following the assessment and approval of home care under the Aged Care Act 1997, the client will need to join a national queue, Home Care National Prioritisation system;
- The waiting period for allocation of a home care package through the national queue varies and can take several months particularly for high level packages required by people diagnosed with terminal (end-stage) illnesses;
- Once the home care package is assigned through My Aged Care national queue, the client requires to research and engage an appropriate provider of home care and sign a home care agreement with the provider;
- The client has 56 days from the date a package was assigned to them to enter into an agreement with a provider. If more time is required, an extension of 28 days (84 days in total) can be requested by calling the My Aged Care contact centre.
- Clients also have to have a formal income assessment conducted through the Department of Human Services (DHS) for determination of their home care fees. The DHS income assessment also takes quite some time;

On the basis of the processes and requirements for access to individualised funding under the Home Care Packages program described above, it can be assumed that access to in-home support services required for ACT residents to choose a home setting for managing their end-of-life care will take several months as a minimum. Given the circumstances of this target group, such delay in access to services will most likely mean that people will have to stay in hospital for their end-of-life care contrary to their wishes and preferences.

4. Conclusion

Both research evidence and our service delivery experience suggest a need for a clear strategy and action from the ACT Government and ACT Health in particular to improve ACT residents' ability to exercise their choice to receive end-of-life care in their own home. It is critically important that appropriate measures are taken to address the increasing gap in in-home and community-based services required for achieving safe and sustainable end-of-life care outcomes in home settings for many ACT residents. Without these vitally important services, many ACT residents are unable to exercise their choice to receive end-of-life care at home resulting in the ACT Health system unnecessarily bearing the high cost of palliative care in hospital and other institutional settings.



Community Options
Serving the Canberra region

Pilot Palliative Care Project Evaluation Report

Date: September 2013

Canberra, ACT

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Précis

An increasing number of people confronting end stage illness are expressing their wish to die at home. Community Options has observed this trend over a number of years in the normal course of its business.

With funding provided by the ACT Government Health Directorate Community Options has undertaken a pilot project providing community based palliative care to some ninety six people. The project ran from August 2012 to mid-September 2013.

The accompanying report describes the project, lists key findings and makes a number of recommendations aimed at improving end-of-life care for the terminally ill in the Australian Capital Territory and increasing support for their families.

Evidence is produced to support the findings and references provided to support the main premises of Community Option's position.

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Introduction

Community Options Pilot Palliative Care Project has been undertaken with funding assistance provided by the ACT Government Health Directorate. During May-September 2013, the pilot project was evaluated against its aims and objectives. This report summarises key evaluation findings and provides information about the project and service activities. The report also outlines recommendations based on the project evaluation findings.

Background Information and Rationale for the Development of the Pilot Project

In recent years, Community Options has seen a strong demand for community-based palliative care¹ and an increasing number of people diagnosed with end-stage illnesses expressing their wish to die at home. The demand for palliative care services is expected to further increase over the next five years due to a number of factors including the ageing population and the incidence of cancer in the ACT.² It has become evident that in the ACT there is a big gap in the availability of targeted community-based support and non-clinical home based palliative care services for people diagnosed with end-stage illnesses and their families. In addition, the lack of specialist community based support services for these people may serve as a contributing factor to a large and disproportionate percentage of people dying in residential care establishments.

The gap in non-clinical community-based support services for people with end-stage illnesses and their families in the ACT has placed increasing pressure on Community Options' service delivery. Namely, during the 2010/11-2012/13 financial years, Community Options experienced a steady increase in referrals for short to medium-term community-based support services for people diagnosed with end-stage illnesses and their families. Community Options saw a pressing need for an increase in its service capacity in order to respond to an increase in referrals for personally tailored and coordinated services to people diagnosed with end-stage illnesses and their families.

In view of the increased demand Community Options sought approval from the ACT Health Directorate to use unspent grants to implement a pilot palliative care project during the 2012/13 financial year. In July 2012, a short-term Palliative Care Coordinator position was created. In August 2012, Ms Joy Dizon was appointed as the Pilot Palliative Care Project Coordinator. In August-September 2012, the project commenced. In June 2013, the ACT Government Health Directorate approved an extension of the pilot project until 30 June 2014.

Pilot Palliative Care Project Scope

Project Goals

The pilot project aims to respond to an increasing demand for community-based palliative care and the wish of the terminally ill to die at home through provision of targeted in-home non-clinical support services to them 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

¹ Palliative care in this report is defined as 'providing the best quality of life possible when people are dying.' This definition is in accordance with the community's perception of palliative care. Namely, according to Palliative Care Australia, 73% of survey respondents defined 'palliative care' as 'providing the best quality of life possible when people are dying' qtd. in Palliative Care Australia (2011). Media Release 'We Need to Talk about Dying – Survey. Retrieved 5 May 2013 from: <http://www.palliativecare.org.au/>

² ACT Government Health (2013). Palliative Care Services Plan 2013-2017.

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 from acute care settings 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.

Pilot 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 Home and Community Care (HACC) services and other programs available in the community;
- Complex needs requiring a complex service/case management response that cannot be met within existing HACC programs;
- HACC eligibility criteria: older and younger people with functional disabilities living in the community who require assistance with performing everyday tasks;
- ACT residence.

Project Evaluation

The Pilot Palliative Care Project evaluation conducted over the period of May 2013 to September 2013 included a number of evaluation activities, such as obtaining client feedback collected through surveys, stakeholder feedback, interview with the Palliative Project Coordinator and analysis of client demographic and service delivery data. The pilot 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 as a result of the project evaluation activities outlined above.

Pilot Project Data Summary

From the commencement of the Pilot Palliative Care Project to mid-September 2013, Community Options received a total of 124 referrals for support services and case management to people diagnosed with end-stage illnesses. Most of 124 people referred to the project were visited either in the hospital, hospice or their own homes. In 28 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) Extended Aged Care in the Home (EACH) 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 medical conditions of people referred to the project.

Table 1: Referrals to the Pilot Palliative Care Project by Source for the period of August 2012 – mid-September 2013

Referral source	# of referrals
The Canberra Hospital (TCH) Oncology Ward	28
Other TCH Wards	30
Home Based Palliative Care Team	17
Clare Holland House	22
Calvary Hospital	10
National Capital Private Hospital	7
Community nurses/ACT Health Directorate	4
Self/family	1
Other community services	5
Total	124

Table 2: List of medical conditions/diagnoses for clients supported through the pilot project for the period of August 2012 – mid-September 2013

Medical Conditions/Diagnoses	% of total
Bowel cancer	11%
Lung cancer	14%
Malignant blood disorder	8%
Malignant brain tumours	6%
End stage medical conditions (COPD, cardiac failure, CVA, Motor Neurone Disease)	6%
Ovarian/cervical cancer	8%
Head and neck cancer	4%
Other cancer types (malignant melanoma, prostate cancer, liver cancer, thyroid cancer, renal failure, chondrosarcoma)	43%
Total	100%

During the 2012/13 financial year, through the Pilot Palliative Care Project Community Options delivered a total of 1,742 hours of service to people with end-stage illnesses and their families. As Table 3 below shows, people with end-stage illnesses aged under 65 received 49% of all services provided through the project; whereas, people with end-stage illnesses 65 and over received 51% of all services provided through the project. On the other hand, as the data in Table 4 below demonstrates, 42% of clients who received services through this project were aged under 65 and 58% of clients were 65 and over. This data suggests that people with end-stage illnesses aged under 65 are slightly higher consumers of services as compared to people with end-stage illnesses 65 and over. The data in Table 3 below also shows that case management service was a significantly high percentage of all service provision for people with end stage illnesses in both under 65 and 65 and over age categories, 62% and 63% respectively.

Table 3: Client service delivery snapshot for the period of August 2012 – June 2013

Type of service provided	Level of Service Provided (Hours)	Percentage of total
Palliative Care Services to Clients under 65		
Case management	528	62%
Personal care	157	18%
Social support	93	11%
Domestic assistance	72	9%
Total	850	100%
Palliative Care Services to Clients Aged 65 and Over		
Personal care	295	33%
Case management	558	63%
Social support	22	2%
Domestic assistance	17	2%
Total	892	100%

Table 4: Clients supported through the Pilot Palliative Care Project by Age during the period of August 2012 – mid-September 2013

Age Group	# of clients	% of total
≤ 40	2	2%
41-50	5	5%
51-60	24	25%
61-70	28	29%
71-80	25	26%
81-90	12	13%
Total	96	100%
<65	40	42%
≥ 65	56	58%

Table 5: Demographic information about clients supported through the Pilot Palliative Care Project

Demographic category	% of total
Clients from CALD backgrounds	18%
Clients who lived alone	4%
Gender: male	49%
Gender: female	51%

Support services provided to people with end-stage illnesses through the Pilot Palliative Care Project can be classified according to three categories:

High level support: Approximately 40% of clients supported through this project received high level support. Many clients in this category presented with complex care needs, which involved End of Life care (EOL), hoist lift transfers with the assistance of two support workers, and required a high level of case management and coordination. Daily support was provided to assist with personal care, pressure area care, and social support. Clients' conditions and support circumstances were frequently reviewed. With some clients, daily contact with family members and the Home Based Palliative Care Team was necessary to allow for changes in the support to be made as required.

Medium level support: Approximately 30% of clients received medium level support. Many clients in this category did not require high level of support but had complex social and family circumstances. Clients often required three to five days a week of personal care assistance, meal preparation and social support. There was also a need for a moderate degree of case management and coordination involvement to ensure the sustainability of support services. Clients' support services were reviewed every two to four weeks.

Moderate to low level support: Approximately 30% of clients received moderate to low level support. Many clients in this category required a low level of personal care assistance. With some clients, entry to the program was through this level of support, with the initial request for domestic assistance or meal preparation. However, support service provision often increased gradually as clients' conditions deteriorated. There was also a need for moderate to low level case management involvement for this client group. Clients' support services were reviewed every two to four weeks.

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

- Safe and sustainable discharge from acute care settings to home was accomplished for the majority of clients referred to the project;
- 35 clients passed away at home (preferred setting);
- 2 clients received EACH packages;
- Clients and family members reported improved quality of life and reduced carer stress and pressure;
- Clients and family members reported a high level of satisfaction with service provision through the pilot project.

Client Feedback

In May 2013, client surveys³ were sent to an initial sample of nine families who received services through the Pilot Palliative Care Project. The initial sample of nine families represented 19% of all families supported through the project as at May 2013. The initial sample selection criteria included:

- The families selected for survey sample must have received support through the pilot project for a minimum period of two weeks;

³ Addendum: Client Satisfaction Survey Template

- Sensitivity: to exclude from sample families where the Palliative Care Project Coordinator reasonably believed it would be insensitive to send a client satisfaction survey and to allow time for grief recovery.

Due to no sensitivity issues raised as part of the palliative care project client surveys, the second round of the surveys was conducted in June 2013. During the second round, surveys were sent to an additional ten families who received services through the Pilot Palliative Care Project. In total, nineteen families were surveyed. This represented approximately 25% of all families who received services through the pilot project as at June 2013. The initial sample selection criteria applied to the selection of the sample in the second round of surveys.

A total of six out of nineteen families responded to Community Options' survey on the consumer experience with services provided through the pilot project. This represented a 32% survey response rate. General feedback regarding surveys was overwhelmingly positive demonstrating a high level of satisfaction and the need for support services offered through the pilot project. 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. Families who responded to surveys stated that the offered support services were very helpful, 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 by families for improvement of support services through the pilot project was the extension of those services for one week after the person with an end-stage illness passed away. This would 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] manage 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 an 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

As part of the evaluation, a feedback session with major referring agencies was held on 7 May 2013. The session aimed to gain feedback from referring agencies and other stakeholders regarding the pilot project and identify opportunities for improvement to better capture the needs of the target group. In addition to oral feedback provided at the feedback session, written feedback on the project was also provided. The following referring agencies provided feedback: The Canberra Hospital, Clare Holland House, Calvary Hospital, and Phillip Health Centre Cancer Counselling Service. Representatives of the ACT Government Health Directorate also attended the feedback session.

As part of the feedback session, Mr Brian Corley (Community Options Executive Director) gave a presentation on the Pilot Palliative Care Project. The presentation included background information, project aims and objectives, target group demographic information and service delivery data.

Following the presentation, Ms Penny Hall (Community Options Client Services Manager/Deputy Director) facilitated the discussion with the referring agencies and other stakeholders. General feedback received from referring agencies regarding the project performance and its ability to support clients with end-stage illnesses and their families in the community setting was overwhelmingly positive.

The referring agencies who participated in the feedback session expressed strong support for the program. According to the referring agencies, people with end-stage illnesses are increasingly choosing to die at home; whereas, palliative care services existing in the ACT are operating at full capacity and are unable to meet an increasing need for in-home palliative care. In addition, according to the referring agencies even where a family would prefer to use residential palliative

care facilities, such as Clare Holland House, it is often the case that places are unavailable and families are left with the only option of managing end-of-life care at home or seek admission to hospital.

One of the key elements of feedback received from the referring agencies was the importance of the targeted case management service in supporting people with end-stage illnesses. Namely, the face-to-face meetings with clients and their families in hospital or hospice settings were identified as the key element in achieving positive outcomes for clients with end-stage illnesses and their families. According to referring agencies, the likelihood of cancellation of in-home support without face-to-face client meetings and targeted case management service was significant.

Other positive elements of the pilot project included reliability in service provision, appropriateness of support and maintaining client focus. According to the referring agencies, the pilot project may also have a positive impact on reducing the number of 'social admissions' to hospital whereby people are admitted to hospital for non-medical reasons and largely due to lack of practical in-home support which improves their ability to cope at home. Referring agencies also reported that services offered through the pilot project were crucially important in achieving a safe transition of people with end stage illnesses with complex needs from hospital to home.

Some comments made by one of the referring agencies in relation to the needs of people with end-stage illnesses and their families and services provided through the pilot project are quoted below:

"The impact of caring for a loved one at home through the end of life stage is multifarious and is deeply impacted by the context in which such care occurs. Some carers have young children who also require their care, others may be caring for their loved one without the help and support of any other family members, others may be unwell or have pre-existing physical or mental health issues. Taking extended and indefinite periods of time off work can have huge financial repercussions for families and couples, providing substantial financial stress and losses. Most carers report getting very little sleep, having little or no time to care for themselves personally and therefore finding their own health declining and experiencing significant stress while at the same time needing to adjust to the understanding that their loved one is dying and all the implications this will have for their own future and that of their family. In addition to this pre-existing family conflicts and dynamics will often contribute even further to the stress and distress of the primary carer.

The services provided through the Community Options pilot project provide vital support to carers managing end of life for a loved one in the home 24 hours a day, seven days per week. Having someone help with the housework or meal preparation or give the primary carer some much needed time out can contribute significantly to a family's ability to cope with the high demands of end-of-life care in the home, reducing overall stress and distress significantly. In addition the flexibility built in to the program allows carers to choose those kinds of services which they feel will be most helpful to their family and context.

As a social worker working with a number of families managing end-of-life care for their loved ones in the home I believe the services offered through the Community Options Pilot Project provide vital practical support to people caring for their loved ones in the home, through the end stage of life. I would love to see the project made permanent.

Thank you for the support that you provide to our clients.”

The referring agencies were also asked to identify any gaps in services required for the target group. Identified gaps included: longer-term support for people with chronic illnesses such as people with motor neurone diseases (MNDs), overnight support to relieve pressure from carers, gap in community based services and resources for people aged under 65, medication prompting and administering, injections, nursing, physiotherapy, massage therapy and other allied health services. The referring agencies also identified a group of people with end-stage illnesses who had not been admitted to hospital and captured by the pilot project but who required in-home support offered through the project. Finally, the referring agencies identified gaps in Home Based Palliative Care’s capacity to respond to the needs of people with end stage illnesses.

Among other issues with referrals to Community Options, the following were identified:

- Pre-referral discussion with Community Options is important; however, provision of information in referral documentation may be repetitive and time-consuming;
- Difficulty to identify the timeframe of support during the referral stage: it was noted that often the medical team informed the client and the family members of the timeframe and the details of the disease prognosis; however, clients and/or family members may not consent for this information to be passed on to Community Options;
- Pre-palliative clients: due to the short- to medium-term nature of support through the Palliative Care Project, clients who are diagnosed with end stage illnesses with the timeframe longer than the available support experience difficulty accessing services longer-term.

Feedback from Brokerage Service Providers

Community Options service model, which was introduced by the Commonwealth Government of Australia in 1990, is based on an intensive case management and brokerage approach to delivery of services to people with complex needs including people with end-stage illnesses. This service model allows Community Options to rapidly respond to referrals and tailor support to individual client’s needs and requirements. Under this model, Community Options purchases in-home support services through carefully selected and quality approved brokerage providers. The Palliative Care Project Evaluation included feedback sessions with three major brokerage service providers engaged for the delivery of in-home support to people with end-stage illnesses: ACT Nursing Services, Domiciliary Nursing Services and All About Care. The section below summarises feedback received from the brokerage agencies regarding the Community Options Pilot Palliative Care Project.

The referring agencies provided positive overall feedback regarding the project and its contribution to improvement in quality of life outcomes for people with end-stage illnesses and their families. Some of the key points made by the referring agencies include:

- **Relationship with Community Options:** All three referring agencies acknowledged that effective relationship with Community Options plays an integral part in achieving successful and sustainable service outcomes for people with end-stage illnesses. While two agencies have expressed satisfaction with the level of support and all aspects of cooperation with Community Options while delivering services through this pilot project, one of the agencies has raised concerns regarding the safety and sustainability issues caused by the rapid

response and high turnover nature of this project. Namely, the brokerage agency claimed that people with end-stage illnesses being discharged home are often medically unstable and their physical conditions rapidly deteriorate during the short-term service provision which often may raise work health and safety concerns for employees of the brokerage agency. In addition, the agency believes that providing support for this target group requires higher level and more intensive administration thus consuming increased organisational resources. The agency thus believes that the cost of support service for this target group should adequately reflect additional resource requirements.

- **Support Workers' Training:** All three agencies identified the importance of providing targeted training for support workers engaged for delivery of in-home palliative care support services for people with end-stage illnesses. Minimum qualifications held by support workers are Certificate III or IV in Disability Support and Aged Care. The brokerage agencies acknowledged the importance of adequately addressing the emotional part of providing support to people with end-stage illnesses in ongoing training and other professional development opportunities. An optional palliative care module offered through the Certificate III and IV courses was also identified as potentially an important and useful part of training for workers providing support to people with end-stage illnesses and their families.
- **Grief and Bereavement Support:** All three agencies raised 'grief and bereavement issues' experienced by support workers as the most challenging part of providing services through this pilot project. The brokerage agencies also identified the importance of providing the grief and bereavement support to support workers as part of ongoing training courses as well as individually tailored debriefing opportunities to provide an understanding of the impact of grief and loss and mitigate the emotional impact of end-of-life care on support staff.
- **Other Suggestions:** One of the brokerage agencies also suggested that allowing an extension of support services for an additional two weeks to the family after the passing away of the person with an end-stage illness could greatly benefit the family members and could potentially allow for the closure and healing for both the family members and support staff. The support could be tailored around the domestic or any other required tasks, such as organising removal of hospital beds and other care equipment.

Feedback from the Pilot Palliative Care Project Coordinator

Ms Joy Dizon, the Project Coordinator, was interviewed on 12 September 2013. The aim of the interview was to seek feedback from the Coordinator regarding her experience of working with people with end-stage illnesses and their families, referring agencies and other stakeholders in the capacity of the Pilot Palliative Care Project Coordinator. The interview questions focused on a number of areas, such as working with the target group; service gaps; training and other professional support requirements. The feedback collected from the Project Coordinator during the interview is summarised below:

- **Target group:** Ms Joy Dizon identified the case management service, particularly the practice of initial home visits with clients and their families, as an essential factor which contributes to achieving successful service outcomes and sustainability of service provision. The Coordinator stated that conducting a home visit not only provides a 'face' to the program but also contributes to best possible service outcomes for individual clients and families - a prerequisite for the overall project success. Ms Dizon commented that initial home visits also minimise potential service delivery risks, such as client safety, and helps build rapport with clients and their families. The home visit also serves the educational purpose as detailed information is provided to clients and their families about available services and how to navigate the service system.

Among the specific needs and circumstances of the target group, Ms Dizon identified the following: people with end-stage illnesses who are referred to the Pilot Palliative Care Project mostly have higher level of support needs and require intensive case management and coordination service response to ensure safety and sustainability of service outcomes following discharge from hospital. People with end-stage illnesses who access services through this project also tend to deteriorate over the course of service delivery and thus require intensive monitoring of their support and gradual increase in services. Among benefits to clients the Coordinator identified: effective service outcomes, improved quality of life, safe and sustainable discharge options, integrated referral pathways, reduced stress and pressure associated with caring for someone with an end-stage illness and, ability to receive end-of-life care at home.

Ms Joy Dizon also discussed cultural values and beliefs which sometimes impact end-of-life care choices made by clients and their families. The importance of understanding these differences and respecting these choices without jeopardising the service outcomes for clients was highlighted as crucially important.

- **Relationship with stakeholders:** Ms Dizon identified effective relationship with the referring agencies and other stakeholders including the Clare Holland House hospice and home-based palliative care team as key to achieving effective outcomes for clients with end-stage illnesses and the overall project success. The Coordinator reported that over the course of the implementation of the pilot project, a close partnership based on trust and effective relationship was built with the referring bodies and other stakeholders, including hospitals and Clare Holland House.
- **Service gaps:** Ms Dizon identified a number of service needs for people with end-stage illnesses and their families including:
 - A number of families caring for people with end-stage illnesses may benefit from overnight care and weekend support to relieve pressure and provide respite opportunities to the primary carer. This group includes those families with lack of other available informal support and those with young children;
 - More respite opportunities for carers of people with end-stage illnesses;
 - Home modifications;

- Social support and community access opportunities for people with end-stage illnesses who are bed bound;
 - Quick and easy access to allied health services, including podiatry, physiotherapy, and massage therapy;
 - Hairdressing services.
- **Training and professional support opportunities:** Ms Dizon reported that professional training and development opportunities, including palliative care workshops and conferences, can greatly benefit the Coordinator in fulfilling his/her role and responsibilities. The need for the Coordinator to have access to debriefing and professional counselling was also highlighted.
 - **Other improvement opportunities:** Among improvement opportunities, Ms Dizon identified the need to improve communication between the referring agencies and Community Options and providing support workers with access to targeted training on grief and loss, such as Program of Experience in the Palliative Approach (PEPA) available through Clare Holland House. Namely, the Coordinator suggested that it would be useful to establish a closer relationship between Clare Holland House and the Palliative Care Project. The closer relationship was identified as being particularly important for the purpose of improving communication of information regarding mutual clients, particularly around hospital re-admissions and improving the referral pathways. This could be achieved through the development of a Memorandum of Understanding with the key project stakeholders including Clare Holland House, TCH and Calvary Hospital. It was also suggested that a closer relationship could be formed with Clare Holland House by the Palliative Care Coordinator attending meetings at Clare Holland House on a regular basis.

De-Identified Case Study

Below is a (descriptive) case study of a client supported through the Project. The case study was provided by the Pilot Palliative Care Coordinator. The case study outlines the client's needs and social circumstances and requirements for support. The case study also delineates the services provided through the pilot project and outcomes achieved for the family. For the purpose of confidentiality, the names in the case study have been changed.

Lucy was a 54 year old lady who was first referred to the Project by a Home Based Palliative Care (HBPC) nurse in May 2013. The client's major concerns were pain and mobility. Lucy had a history of breast cancer which had spread to her bones and lungs. She was on continuous oxygen therapy. Lucy was frail, although able to mobilise slowly with the aid of a walking stick. She had difficulties moving her arms and shoulders due to bone pains. She already had many falls at home due to her declining mobility.

Lucy lived in a private rental house with her partner Paul and their two cats. Lucy was on a Disability Support Pension and Paul was unemployed. Lucy was a heavy smoker and continued to smoke throughout the period of our service.

Lucy came to Canberra twelve years ago, leaving behind the few friends and relatives she had in Victoria. She had no close friends in Canberra. Her partner, Paul, had been providing all her care while also looking for employment when he could.

Support requested

A case meeting was held at Lucy's home attended by Lucy and Paul and the Palliative Care Project Coordinator. A support plan was developed incorporating Lucy's request and her current needs. The bathroom was well set up for her needs.

Support was set up for up to 10 weeks providing 5 days per week of personal care and 1 hour weekly of domestic assistance.

The client fee was waived as Lucy and Paul were struggling financially.

The brokered agency was instructed to provide 1 regular and 1 back-up skilled support worker with some background experience in palliative care and high care needs clients.

The referral from the HBPC nurse also requested the installation of a personal alarm. This was discussed at some length with Lucy and Paul. The rented house had no landline which was necessary for the alarm installation. Lucy was adamant that she did not want a landline or a personal alarm. But she had her mobile phone which she kept with her for most of the time.

The outline of the support plan was given to the HBPC team for their information. The support was provided for 3 weeks at which time Lucy was admitted to the hospice for symptom management.

Period of service

During the first week of support, Lucy rang Community Options (CO) every day. She would ask a variety of questions including: 1) what time the worker would come (this had been explained to Lucy during the first meeting and when the support was first set up); 2) who she needed to contact for more prescriptions for her pain medications; 3) what she could do with an abscess on her face; and many other questions.

Each time Lucy was reassured and her questions answered. The role of the HBPC team was explained to her in relation to her questions of clinical nature (medications, wound management, pain). Lucy was then happy for the Palliative Care Project Coordinator to contact the HBPC team on her behalf. The information was immediately passed on to the HBPC team, who in turn always responded promptly after being contacted.

At the Hospice

Lucy was admitted to Clare Holland House (CHH) after being assessed at home by the HBPC doctor that her pain levels cannot be adequately managed in the community. According to the HBPC nurse Lucy was requiring 24 hour monitoring and supervision and that this admission to the hospice will most probably lead to End of Life Care.

After a week of her admission to the hospice the Palliative Care Project Coordinator visited Lucy. She looked extremely frail and was bent over to one side, and she had a syringe driver in place. She could

only mobilise with the use of a wheel chair. Despite her frailty Lucy was determined to go home. She expressed frequently that she wanted more than anything to be at home with Paul and her cats, in her familiar environment.

New referral

Two weeks after her admission to the hospice a new referral was received from Clare Holland House. Lucy was discharged home as per her wish. HBPC nurses were required to visit daily to monitor her condition and change the morphine syringe. Lucy also went home with loaned equipment: a hospital bed, a pressure mattress, a commode transporter, and wheel chair.

The Palliative Care Project Coordinator arranged for a home visit on the same day referral was received to review the home support situation and discuss a new support plan.

New Support Plan

Lucy required daily visits to assist with her shower or bed sponge, provide pressure area care, wash and dry her hair, change to clean clothes, and provide other social support. The weekly domestic support was reinstated. After a week it appeared that Lucy was settling back to her home and care routine.

A frequent review of Lucy's support was necessary as her condition varied from day to day. Twice weekly contact with the client or her partner were made to gain an update of their situation and if support was adequate and effective. Twice weekly contact was made with the brokered agency to find out if workers were managing with their work and if there were any issues arising. Once weekly contact was made with the HBPC nurse to obtain an update of Lucy's general condition. The review was also required when Community Options was made aware of any increase to her morphine dose which affected Lucy's ability to stay awake for longer periods. The support workers were able to plan accordingly as to how best they could assist Lucy on certain days.

Lucy's partner had been unable to find employment as she was requiring 24 hour supervision at home and had been unable to leave her on her own. A hospice volunteer was eventually introduced to them who was able to stay with Lucy for few hours per week to enable Paul to go out to do the shopping and pay bills.

Both Lucy and Paul declined any increase to her daily support. They were very appreciative of all the support that was provided to them. Apart from the daily visits by the support workers the HBPC nurses were also visiting every day. The time that they can be alone was becoming very precious to them.

“One-off” Assistance Provided through the Pilot Palliative Care Project

During the winter period Lucy needed to keep warm at all times. This meant the use of gas to keep the house warm and especially in the rooms that Lucy stayed in for most of the day. A recent gas bill for \$490 arrived which caused Paul a great deal of anxiety as to how he could pay for it. Most of Lucy's DSP paid for their rent and bought food supplies. They had previously accessed financial support from the Eden-Monaro Cancer Support group and had been told they had reached their funding limit.

In addition to support services, Community Options was able to provide a “one off” funding assistance to pay the ACTEW AGL gas bill. This was done immediately to the grateful relief of the client and her partner.

The Outcome

After nearly six weeks of being home, Lucy’s condition deteriorated further. The support continued to be delivered daily. The HBPC team were visiting every day and sometimes more often as Lucy started to lose her consciousness.

On 12 August 2013, Lucy’s partner contacted the Palliative Project Coordinator to say that Lucy passed away that morning at home. He expressed his appreciation for the support that she received throughout, and more so that she was able to fulfil her wish of remaining where she wanted to be.

Overview of Palliative Care Services Available in the ACT

Palliative care services in the ACT are available for people diagnosed with end-stage illnesses such as cancer, motor neurone disease, HIV/AIDS and end-stage heart, and lung or kidney failure through hospitals, Clare Holland House, Home Based Palliative Care Team and aged care facilities. The section below provides a summary of palliative care services available in the ACT.

Clare Holland House

Clare Holland House is a publicly funded specialist palliative care provider in the ACT. Clare Holland House is a short-term facility offering specialist palliative care including the provision of a comprehensive, interdisciplinary palliative care service that collaborates with general practice and community nursing to achieve quality end of life care. This service also offers a 24 hour home based service and outpatient appointments at Clare Holland House.

Clare Holland House Inpatient Unit (Hospice)

The Clare Holland House hospice is a 19-bed inpatient facility which provides palliative care specialist and medical services.

Home Based Palliative Care

The Home Based Palliative Care team provides clinical palliative care services to people with end-stage illnesses and their families. The Home Based Palliative Care team also provides information and support to the family on how to care for the person with an end-stage illness, equipment required to support the person with an end-stage illness to stay in the home setting as long as possible, 24 hour telephone advice and bereavement service. The Home Based Palliative Care services do not entail provision of in-home (non-clinical) support services.

Palliative Care in Hospital

Palliative care services can be provided in hospitals. The Canberra Hospital employs a specialist palliative care nurse who provides advice, support and guidance for people with end-stage illnesses. In addition, palliative care physicians are able to provide advice on palliative care needs of people with end-stage illnesses.

Palliative Care in Aged Care Facilities

Aged care facilities in the ACT provide palliative care services to its residents.

The ACT Palliative Care Society Inc. Volunteer Program

Volunteers are available to provide services to people with end-stage illnesses and their families both in the community and within the palliative care inpatient unit at Clare Holland House. Services provided by volunteers in the community include home visits, companionship to carers and direct social support to the person with an end-stage illness. Services provided by volunteers in the palliative care unit include assistance during meal times, transport, shopping and other forms of social support.

Conclusion

As a result of the evaluation of the Community Options Pilot Palliative Care Project, a number of findings and recommendations have emerged. While key findings and recommendations are detailed below, particular attention needs to be paid to the significant role of the case management service in ensuring quality service outcomes for people with end-stage illnesses and their families, establishing integrated pathways between palliative care services and the community care system, and for overall successful implementation of this project.

Key Findings

- **Integrated pathways between palliative care and community care system:** The implementation of the Pilot Palliative Care Project demonstrated the need for integrated pathways between palliative care, hospital and community care system to achieve best possible quality of life and service outcomes for people with end-stage illnesses. The evaluation of the project demonstrated that a strong relationship between palliative care and the community care system is key to improving end-of-life care for people with end-stage illnesses. Namely, the novelty of this pilot project in the ACT community care system was the specialist approach to providing targeted home-based community care services to people with end-stage illnesses. Services provided through the pilot project complement the existing clinical home-based palliative care services and provide opportunities for people with end-stage illnesses to receive end-of-life care in their own homes.
- **Services provided through the pilot project improved possibilities for people to exercise greater choice and control regarding their end-of-life care:** The research evidence on community preferences for end-of-life care as well as Community Options clients' expressed preferences suggest that for the vast majority of people home is a preferred setting for receiving end-of-life care and dying. This suggests that the community sector has an equally important role in the palliative care services. Specialist community based palliative care services can fill in the service gaps through provision of flexible, targeted and coordinated service options to people with end-stage illnesses and their families. In addition, services provided through the pilot project greatly improve possibilities for people to exercise greater choice and control regarding their end-of-life care.
- **Improved quality of life outcomes for people with end-stage illnesses including reduced carer stress:** Research evidence suggests that quality of life during the final stage of life is more important for people with end-stage illnesses than prolonging life. On the other hand, the evaluation of the pilot project, particularly feedback from carers of people with end-stage illnesses obtained through surveys, suggests that services provided through this project greatly contribute to improvement of quality of life outcomes and reducing stress associated with caring for a family member with an end-stage illness. Both reviewed research evidence and the client survey data also suggest that services provided through this

project have a great potential for improving quality of life outcomes including people with end-stage illnesses experiencing less symptomatic distress, better physical health and lower depression scores compared to people receiving residential palliative care services. Research evidence also suggests that home-based palliative care services greatly reduce the likelihood of people with end-stage illnesses being concerned about 'being a burden to others,' which is reported to be second most significant concern expressed by people with end-stage illnesses after pain.

- **Improved discharge outcomes for people with end-stage illnesses and reduced likelihood of social admissions to hospital:** Discharge planning for people with end-stage illnesses is a complex process and requires an active collaboration between Community Options case managers and hospital discharge planners to ensure safe discharge, sustainable service options and best possible quality of life outcomes for people with end-stage illnesses.

The case management to people with end-stage illnesses is based on an active assistance and planning approach to ensure that community support is safe and sustainable. The evaluation of the pilot project demonstrated that the palliative care project case manager's active involvement in the discharge planning for people with end-stage illnesses and provision of specialist targeted community support can significantly reduce the likelihood of 'social admissions' to hospital whereby people are admitted to hospital for non-medical reasons and largely due to lack of practical in-home support which improves their ability to cope at home.

- **Importance of culturally sensitive practices in palliative care:** Both the research evidence and information obtained from the Palliative Care Coordinator suggest that people from CALD backgrounds may often have qualitatively different views and expectations for end-of-life care and culture can significantly shape people's views on illness, suffering, end-of-life care and dying. This suggests the importance of implementing culturally sensitive practices in palliative care focusing particularly on the social context of care in the home.
- **Cost-effectiveness of home-based palliative care:** The information obtained through evaluation of the pilot palliative care project suggests that services provided through the pilot project not only improve quality of life outcomes for people with end-stage illnesses and their families but also reduce healthcare costs associated with hospital admissions and receiving palliative care services in residential settings, such as hospice and hospitals. Namely, not only do home-based palliative care services represent the preferred care option for people with end-stage illnesses but also a cost-effective end-of-life care method.
- **Professional support and development opportunities:** The project evaluation suggested that to ensure the long-term project success it is important to establish a formal training and professional support program for the Palliative Care Project Coordinator and facilitate the direct support staff's access to training opportunities. A most important element of this program should be professional debriefing, counselling and training opportunities on grief, loss and bereavement.
- **The role of the case management service in achieving quality of life outcomes for people with end-stage illnesses and other project outcomes:**

The evaluation of the pilot project strongly demonstrated that the case management service plays the key role in achieving best possible quality of life outcomes and successful implementation of the pilot project. Namely, the case management services provided by the

Palliative Care Project Coordinator represented 62% of all service provision through the pilot project and played a significant role in achieving the following:

- Rapid service response to people with end-stage illnesses following hospital admission;
- Sustainable and safe discharge options and best possible service outcomes for people with end-stage illnesses and their families including reduced pressure and stress;
- Integrated referral pathways between community care service system, hospital system and clinical palliative care services;
- Integrated and coordinated service options including linking people with people with end-stage illnesses and their families with available community services and resources;
- Intensive service monitoring for people with end-stage illnesses who tend to deteriorate rapidly over the course of service provision requiring an increase in support services;
- Information and education provided to families including assistance with the navigation of the service system;
- Improved capacity for people to receive end-of-life care at home;
- Culturally sensitive service provision;
- Cost-effective end-of-life care service options.

Recommendations

As a result of the findings of the evaluation of the Pilot Palliative Care Project, the following key recommendations have emerged:

- **Establish the Palliative Care Project on a permanent basis:** The evaluation of the pilot project strongly demonstrates the need for establishing the project on a permanent basis. This can be achieved through securing permanent funding for one permanent full-time case management position. The funding proposal for the establishment of the position is included in Addendum 3. The specialist palliative care case manager will work closely with people with end-stage illnesses and their families, hospitals, Clare Holland House Home Based Palliative Care Team, community nurses and broadly with aged and disability community service providers. The case manager will link people with end-stage illnesses and their families with existing Community Options and other community services and resources required to achieve safe and sustainable service outcomes for people with end-stage illnesses.
- **Establish formal pathways for training and other professional support:** It is strongly recommended that a targeted training and professional support program is established for the palliative care case manager. It is recommended that professional debriefing and counseling opportunities are provided through this program. It is also recommended that Community Options facilitate support workers' access to targeted training on grief, loss and bereavement, such as PEPA.
- **Formalise partnership with the palliative care system:** The project evaluation also suggested that integrated pathways between the community care and palliative care systems is key to achieving best possible end-of-life care for people with end-stage

illnesses. Therefore, if the project is established on a permanent basis, it is strongly recommended that the partnership between Community Options and the palliative care system including hospitals and Clare Holland House is formalised through a Memorandum of Understanding.

Literature Review

Palliative care services and people's end-of-life care preferences have drawn considerable public attention and scholarly interest in recent years both in Australia and world-wide due to ageing populations and rising incidence of cancer and other life-limiting conditions. A number of research and scholarly articles have been published on various aspects of palliative care services and choices for end-of-life care. This section provides an overview of published literature on palliative care services and issues faced by people as part of their end-of-life care particularly around quality of life and social considerations during the final stages of life.

Home – a preferred place of death, home based palliative care services and quality of life:

A high preference of people to die at home instead of in residential institutions is strongly supported by research evidence. While most people express a preference to have end-of-life care at home and most would also prefer to die at home, the majority of people die in residential settings such as hospitals, nursing homes and in-patient palliative care units. People with end-stage illnesses receiving home-based palliative care services demonstrate less symptomatic distress and experience greater quality of life than people receiving in-patient palliative care services.

Foreman (2006) conducted a population survey to assess people's preferences for place of death in South Australia. Foreman found that in face of a terminal illness such as cancer, 70% of respondents would prefer to die at home, 19% would prefer to die in hospital, 10% would prefer to die in a hospice and less than 1% would prefer to die in a nursing home.⁴

McNamara and Rosenwax (2007) examined accommodation settings at the time of death for people in Western Australia.⁵ The study found that while most people would prefer to die at home, over half of Western Australians died in hospital. The study also showed that people with cancer and other life-limiting conditions who accessed community-based specialist palliative care were seven times more likely to die in their usual place of residence.

Gomes et al (2012) conducted a European Union population-based survey which examined people's preferences for place of death cross-nationally, namely in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. This study found that the vast majority (at least 75%) of survey respondents in all countries with the exception of Portugal (only 51%) indicated a preference for a home death if they were to die with cancer or another serious life-limiting condition.⁶

⁴Foreman, L. et al (2006). Factors predictive of preferred place of death in the general population of South Australia. *Palliative Medicine*, June 2006 vol. 20 no. 4447-453

⁵McNamara, B. & Rosenwax L. (2007). Factors affecting place of death in Western Australia. *Health & Place*. Volume 13, Issue 2, June 2007, Pages 356–367.

⁶Gomes B., et al (2012). Preferences for place of death if faced with advanced cancer: A population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of Oncology*, 2012 Aug;23(8):2006-15. Epub 2012 Feb 16.

According to the results of an independent survey commissioned by Palliative Care Australia in 2011 to assess the community views of dying and palliative care, of those Australians who had considered the end stage of their lives, 74% stated that they wanted to die at home.⁷ According to the same survey, only 16% of people actually die at home; whereas 84% of people die in hospices (20%), nursing homes (10%) and hospitals (54%).

Peters and Sellick (2006) examined the symptom experience, physical and psychological health, perceived control of the effects of cancer and quality of life of people with terminal cancer receiving inpatient and home-based palliative care.⁸ The study also examined factors that contribute to quality of life for people with terminal cancer. The study found that people receiving home-based palliative care services experienced significantly less symptom severity and distress, lower depression scores, and better physical health and quality of life than those receiving inpatient treatment. People receiving home-based palliative care also reported significantly greater control over the effects of their illness and medical care. The study finally found that better physical health, greater control over the effects of cancer and lower depression scores were associated with better quality of life outcomes.

End-of-life care preferences in a multicultural context:

It is generally recognised that the topic of end-of-life care preferences for people from Culturally and Linguistically Diverse (CALD) backgrounds is significantly under researched and people from CALD backgrounds may often have different views and expectations for end-of-life care and culture can fundamentally shape people's views on illness, suffering, dying and decisions about medical treatment at the end of life including reluctance to accept hospice (Kagawa-Singer & Blackhall, 2001; LaVera, et al 2002; Owens & Randhawa, 2004)⁹. In addition, people from CALD backgrounds may often lack knowledge and information about the nature of the palliative care services which can also influence choices for end-of-life care. Finally, a number of studies (Kagawa-Singer & Blackhall; LaVera, et al; Owens & Randhawa) also highlight the importance of implementing culturally sensitive practices in palliative care focusing particularly on the social context of care in the home.

A study conducted by Fukui et al (2010) shows qualitatively different views on end-of-life care in the Japanese culture. The study found that 44% of survey respondents would prefer to die at home in the context of serious life-limiting conditions, 19% would prefer to die in a residential palliative care unit, 15% would prefer to die in an acute care hospital and 12% would prefer to die in a nursing home. Fukui concludes that the results of the study highlight the importance of providing education on home care services to people with end-stage illnesses who currently prefer hospital based palliative care services.

⁷Palliative Care Australia (2011).Media Release 'We Need to Talk about Dying – Survey. Retrieved from the World Wide Web: <http://www.palliativecare.org.au/>.

⁸Peters, L. & Sellick, K. (2006).Quality of life of cancer patients receiving inpatient and home-based palliative care. *Journal of Advanced Nursing*, Volume 53, Issue 5, pages 524–533, March 2006.

⁹Kagawa-Singer, M. &Blackhall, L.J. (2001). Negotiating cross-cultural issues at the end of life: "You got to go where he lives." *JAMA*, December 19,2001—Vol 286 (23).

LaVera, M. et al (2002).Strategies for culturally effective end-of-life care. *American College of Physicians-American Society of Internal Medicine*.

Owens, A. &Randhawa, G. (2004). 'It's different from my culture; they're very different': Providing community-based 'culturally competent' palliative care for South Asian people in the UK. Blackwell Publishing Ltd.

Kagawa-Singer & Blackhall (2001) argue that while 'patient autonomy,' the primary focus of decision making at the end of life which reflects the European American (white) medical model and cultural values, includes the right of patients to be informed about their condition and choosing or refusing the life-prolonging medical treatment. Patients and families from other cultures may not necessarily share these values and may often choose aggressive life-sustaining medical treatments due to their cultural, religious or spiritual beliefs. Kagawa-Singer & Blackhall also argue that the risk of healthcare professionals stereotyping by generalising individual beliefs to the whole ethnic group is serious. However, failure to take cultural values and beliefs held by people from different backgrounds can be a violation of rights and a form of cultural imperialism resulting in mistrust, anger and even the removal of the patient from medical care.

Kagawa-Singer & Blackhall (2001) found that families of people with life-limiting conditions from other cultural backgrounds play a much more significant role in decision-making about treatment options who also consider that it is more appropriate and humane to withhold information about the condition and the prognosis from the patient. Finally, Kagawa-Singer & Blackhall claimed that people from CALD backgrounds are often reluctant to accept hospice (25% of US population was multicultural; whereas, less than 17% of people enrolled in hospices in the US in 2001 were from a CALD background and very few of these were from Asian American backgrounds) partly due to a notion that it can be seen as a failure on the part of the carer to adequately care for their family member and 'filial piety' whereby children are expected to care for their parents in gratitude for their parents' caring.

Concerns of people with end-stage illnesses:

Research studies show a number of concerns expressed by people with end-stage illnesses, such as pain, breathlessness and insomnia. It is noteworthy that a number of studies found that 'being a burden to others' and 'being alone' were the most significant concerns expressed by people with end-stage illnesses. A number of studies also demonstrated that to most people quality of life is prioritised over extending life in the face of a life-limiting condition.

A study of end-of-life care of cancer patients in Europe conducted by Bausewein et al (2013)¹⁰ demonstrated a high level of public concern with social aspects of end-of-life stage, such as being a 'burden to others' and being alone. Namely, the study shows that the public is not only concerned about medical symptoms associated with cancer, such as pain and breathlessness, but also about 'being a burden' to others. It is noteworthy that 'being a burden' to others was ranked by research participants as the second most significant concern after pain in most countries examined in this study.

Another research article (Higginson et al, 2013)¹¹ which examined people's priorities for end-of-life care concluded that people were mostly concerned with the improvement of quality of life for the time they had left and only a minority of people who participated in the study reported prolonging life as most important. Namely, the study showed that most people (ranging from 57% to 81%) who participated in the survey prioritised quality of life over prolonging life by choosing 'improve quality

¹⁰Bausewein C. et al. 'Burden to others' as a public concern in advanced cancer: a comparative survey in seven European countries. *BMC Cancer*, 2013; 13: 105.

¹¹Higginson I.J., et al. (2013). Priorities for treatment, care and information if faced with serious illness: A comparative population-based survey in seven European countries. *Palliat Med*. 2013 Jun 14.

of life for the time they had left' as the most important factor, only 2%-6% stated that extending life was most important, and 15%-40% indicated that quality of life and extending life were equally important.

Daveson et al (2013) examined the public views in Europe about end-of-life care in the face of serious illness.¹² The study found that the public are concerned about the prioritisation of quantity of life over quality of life. In addition, the study found that the public recognises the importance of improved quality of end-of-life and palliative care for people with end-stage illnesses, especially for elderly people and families.

Palliative Care Services: Cost-effectiveness

Cost-effectiveness of palliative care services, particularly home-based palliative care services, is well supported by research evidence. According to Higginson, from 150,000 deaths registered in Australia annually, it is estimated that 120,000 people may require palliative care.¹³ On the other hand, studies show evidence of palliative care services resulting in fewer hospital admissions and accordingly in lower healthcare costs. Daveson et al (2013) also argues that while care in the last year of life accounts for up to 20% of all health care expenditure with the expenditure being highest for those with cancer; the healthcare system continues to bear the high costs despite evidence showing that palliative care can help reduce costs associated with hospital admissions during the last year of life.¹⁴

¹²Daveson, B.A., et al (2013). Learning from the public: Citizens describe the need to improve end-of-life care access, provision and recognition across Europe. *European Journal of Public Health*.2013 Jul 1.

¹³Higginson, I.J. qtd.in Murray, R. (2013). Australia a leader of the pack. Retrieved September 9, 2013 from:

<http://www.ehospice.com>.

¹⁴ Ibid.

Addendum: Client Satisfaction Survey

Dear

Community Options developed a pilot project to respond to an increasing need to support people with end stage illnesses and their families in the community. Under this pilot project, Community Options has been providing practical assistance with activities of daily living aimed at achieving a greater quality of life and reducing stress levels for people with end stage illnesses and their families.

After approximately eight months of operation, the pilot project is being evaluated against its aims and objectives. The key element of this evaluation is to gain feedback from families who have received support through this pilot project. The enclosed questionnaire was designed to obtain your feedback regarding services provided under the pilot project. Your feedback will help us better understand your experience as a consumer in this pilot project, the needs of people with end stage illnesses and their families, and identify areas for improvement. Your feedback will also assist in identifying funding priorities and securing long-term funding.

All the information you provide will be strictly confidential and will be used only for planning purposes. While the aggregated de-identified results of this evaluation will be shared with our funding bodies and other relevant stakeholders, your personal or any other identifying information will not be disclosed to a third party. You may also choose to complete the questionnaire and leave the name section blank. In this case, we guarantee the anonymity of information, i.e. even a person collating the survey data will not be able to identify you.

Your participation in this evaluation is entirely voluntary. If you wish to participate in this evaluation, please complete the enclosed questionnaire and return it to Community Options using the enclosed stamped addressed envelope. Alternatively, you can contact us on (02) 6295 8800 if you wish to be interviewed by Community Options instead of completing this questionnaire.

We thank you in advance for your feedback and taking the time to participate in this evaluation.

Yours sincerely

Brian Corley
Executive Director

Questionnaire

Client Name (optional): _____

Question 1

Please provide general comments below regarding your experience with services provided through the Community Options pilot project.

Question 2

Do services provided through this pilot project contribute to improvement of quality of life? (Please circle the relevant answer) **YES/NO**

If YES to above, please provide comments below on how exactly these services contribute to improvement of quality of life.

If NO to above, please provide comments below on what could be done through this project to achieve a greater quality of life.

Question 3

Do services provided through this pilot project contribute to reducing the stress levels associated with caring for a family member with end stage illnesses? (Please circle the relevant answer) **YES/NO**

Question 4

In your experience what is the most useful element of support offered through this project?

Question 5

In your experience what is the least useful element of support offered through this project?

Question 6

What would you do if services offered through this pilot project were not available?

Question 7

Please provide feedback below on three aspects of service provision:

Overall quality of support received:

Quality of communication with Community Options during the service provision:

Quality of support staff and whether you believe that the support staff is adequately trained to provide specialised community support to people with end stage illnesses and their families:

Question 8

Do you have any other suggestions for improvement of services offered through this pilot project?

Question 9

Do you have any other feedback or comments?

If you wish to receive the final report on this evaluation please indicate here by circling the relevant answer: **YES/NO**

Thank you for participating in this evaluation and taking the time to complete the questionnaire. Your feedback is important to us and will help us better understand the needs of families receiving support through this pilot project and improve services that we provide.