Inquiry into Palliative Care In Western Australia

The establishment of the joint select committee of the Legislative Assembly and Legislative Council of the WA Parliament into palliative care in Western Australia is a welcome step to initiate and drive change in the community aged care sector. It presents an opportunity for community aged care service providers to create a vision for the future to provide services to clients to meet their needs to the end of their life. (Terms of Reference (1).

TPG Aged Care has been operating in the community aged sector for 22 years. In 2017 we gained Approved Provider status and began delivering services to clients under the federally funded Home Care Package Program in our own right. Since then we have successfully assisted people to die at home but there have been times when this is not possible. Whilst frustrating, it has afforded our staff the opportunity to understand that cultural change is required to fulfill our goal of working with people, in a manner of their choosing, to the end of their life. The $6.3 million boost to expand community based services across both metropolitan and regional Western Australia to better meet demand has had little or no impact on our capacity to deliver effective palliative care services. (Terms of Reference (2)

The report of the Joint Select Committee on End of Life Choices, My Life, My Choice, identified gaps in the system that reflect our experiences and are impediments to moving forward and the State Government made funding announcements in The gaps impacting directly on our ability to achieve our goals are the:

- low uptake rate of Advanced Health Directives (AHD)
- understanding that palliative care is more than just care during the terminal phase of life
- present limitations of community palliative care
- late introduction of palliative care
- inability to meet client choice because of the lack of services to address the broad needs of clients during the terminal phase of their life

Taboos around the concept of death and dying are entrenched in our community as too is the understanding of the word 'palliative'. Timely information provision and education is essential to improve the successful and effective delivery of palliative care in the community. Whilst the importance of Advance Health Directives forms part of our assessment processes client focus is only upon their immediate needs and there is a failure to follow up on completing a directive with their medical practitioners or others.

Advanced Health Directives need to become an essential component of end of life plans to prevent the trauma and frustrations experienced by people preventing them from dying a 'good death' in their place of choice. Professionals working in the aged care sector have identified that an AHD is not something that you can develop in one session. It is also identified that success is more probable if information and education is provided by a person that has developed a relationship with the person over time and provided the opportunity to build trust in the relationship.

As a result of the limitations of and outmoded model of community palliative care available to community service providers we researched and implemented new processes within the funding available to us through the federally funded Home Care Package Program. The following Case Study provides evidence of the way people can be maintained in their own home whilst living with

chronic co-morbidities. Regrettably, we were unable to fulfill our client's goal of remaining in her home "until the end" because of the lack of funds available to provide her with 24/7 care in the terminal stage of her life.

Mary (not her real name) was born in 1922 and started receiving services through the Home and Community Care Program in 2015 at the age of 93. She lived alone and her only support was provided by her 72 year old son who had his own chronic health issue. In November 2017 she transitioned to a Level 4 Home Care Package after she was diagnosed with left eyelid and left limbic malignant melanoma, a left eye tumour and suffered with seizures and experienced bouts of depression.

An extract from her assessment plan indicates that her goals were to:

- remain in her own home "until the end"
- not want to go to respite or be transferred to hospital
- maintain level of independence and control over her life
- maintain current mobility
- go out at least weekly
- forego treatment requiring clinical intervention

Strategies to achieve goals by building on abilities and overcome difficulties:

- Provide appropriate support services to assist client living alone at home for as long as possible
- Allow client to be involved with doing as much as she is able
- Provide transport for social support services to go out regularly
- Assist with ADL's

Services provided within her budget were:

- daily services to assist with personal care and medication prompts
- social support and shopping
- nursing services to assist with the management of the left eye tumour

In February 2018 the tumour grew and Mary's Ophthalmic Surgeon recommended an operation and chemotherapy, which was refused. In August 2018 the Case Manager consulted with clinicians (GP and Nurse Practitioner) at Collaborative Health who agreed to work with Mary to assist with her clinical needs. She was able to visit the surgery in Joondanna and also completed an Advance Health Directive at this time.

This practice was followed until January 2019 when her condition deteriorated and her care could not be maintained within the capacity of the HCP budget and the Case Manager encouraged her to take advance of hospice care once arrangements were made for the care of her dog, Henry. Mary died on her own 10 days later.

As a result of this and other end of life experiences where we were unable to achieve the client's goals we embarked on research to optimise our ability to develop and implement a more holistic, person centred palliative care model. We were chosen to participate in an ELDAC (End of Life Directions in Aged Care) Linkage Project with the Queensland University of Technology (QUT) under an agreement with QUT and the Commonwealth of Australia.

The aim of the ELDAC Program was to improve quality of end of life care (EOLC), prevent unnecessary hospital admissions and shorten hospital stays, through improving collaboration between primary, aged and palliative care services, and the palliative care and advance care

planning (ACP) skills of aged care staff and GP's. Project meetings included staff of Palliative Care (WA) and Silver Chain.

We were supported by ELDAC facilitators to develop and implement our own palliative care and advance care planning objectives. Our participation in the project resulted in the development of a collaborative partnership with a GP and NP from Collaborative Health and a Pharmacist from the Joondanna Pharmacy who are committed to the development and trial of a collaborative approach to palliative care delivery in the community. A Pilot Proposal (see proposal outline attached) has been developed to commence after the successful end of the COVID pandemic.

TPG Aged Care Aims:

- Increase client uptake of Advance Health Directives by acquiring funding to implement a project using the resources of a Client Liaison Co-ordinator with backup from a Nurse Practitioner focussing on four groups:
  - HCP clients receiving care at low level care under Level 1 and 2 packages
  - HCP clients receiving high level care under Level 3 and 4 HCP clients to increase uptake
- Initiate palliative care at the outset of initial diagnosis of an incurable disease utilising the financial resources available under the Home Care Package Program
- Seeking support to fund the provision of 24/7 care support during the terminal phase of life to prevent unwanted transitions to hospice and/or hospital
- Incorporate the services available under the collaborative team approach to enable users to get to know and trust their support team members comprising GP's, Nurse Practitioners, Pharmacist, allied health professionals, nurses and well trained committed support workers who are instrumental to the successful delivery of palliative care services

Expected Outcomes:

- The development of a model of care that is transferrable across service providers in the metropolitan area and regions
- Increase the number of clients completing AHD's in each category
- Capture and document staff time spent on achieving completions in each category
- Reduce the number of hospital referrals
- Increase the number of clients able to achieve their goals and wishes to remain in the own home until the end of life

Summary:

Cultural change is required to fulfill our goal of working with people to achieve their goals and wishes at the end of life. In our experience there has been little change resulting from the announcement of increased funding to community palliative care services in October 2019. We

urge the Joint Select Committee into Palliative Care to allocate funding to a wider range of service providers to ensure that care is provided by support teams who are familiar to clients over a longer time frame to achieve improved social, clinical and financials outcomes for people at the end of life.

We would value the opportunity of making a verbal submission to the Joint Select Committee to support your deliberations.

Palliative Care Pilot Proposal (updated 23/01/2020)

Aims

- To provide end of life care to TPG clients in the community using a collaborative multidisciplinary team
- Reduce hospital admissions
- Provide in home end of life care in line with client goals and wishes

How we will achieve this:

Role clarifications

TPG

Identify clients in the appropriate geographical area of JMC
Arrange to meet and outline proposal
Discussions around AHD - identify goals and discuss values
Arrange transport to consultations as required
Liaise with JMC to prevent unnecessary home visits by NP/GP
Primary contact: Linelle Peacock (Linda and Erica)

JMC

Initial consult with identified clients
Assist with AHD
Liaise with TPG to achieve client goals
Provide after-hours service (in collaboration with locum and TPG)
Home visits if required
Primary contact: NP Shannon Tassell

Joondanna Pharmacy

Accept client referrals
Carry out client medication reviews
Provide Webster packs to clients
Provide medication profiles to TPG
Fill prescriptions for emergency medications and end of life care
Primary contact: Wesley Williams, Pharmacist

Process

- Finalise client letter
- Approve palliative care documentation - policy, procedures and assessments
- Undertake staff education
- Identify clients
- Meet clients and provide information - written and verbal