Parliamentary Committees
Health and Community Services Committee

Wesley Mission Brisbane wishes to make a submission to the Inquiry by the Health and Community Services Committee of the Qld Parliament into palliative care services and home and community care services in Queensland

Overview

Aged care facilities are the final residential home for many Australians. Residents whose home is a Wesley Mission Brisbane (WMB) aged care facility (RACF) often wish to die in their home. Our community based clients wish to die in their homes too. Both RACF residents and home based clients most often wish to avoid going to hospital if at all possible when they reach their end-of-life. The increasing frailty and grand age of both RACF residents and our community based clients has resulted in a palliative approach informing the care provided by WMB. This is also reflected in shorter length of stay for recent RACF residents requiring high levels of technical and clinical care. The increasing frailty of our residents, with most having dementia and/ or cognitive impairment, has resulted in a high number of residents requiring and receiving palliative care that supports them to and die with peace and dignity in our age care facilities. Therefore RACF and Community Aged services need to be viewed as integral players in the delivery of palliative services to Australians.

If this approach can be successfully implemented in Queensland through improved access to training, flexible and adequate funding and a multidisciplinary approach there will be ever increasing improved outcomes and quality of life at end-of-life for residents, more sympathetic and supportive approaches for family members and a substantial reduction in costs associated with using the hospital care system.

WMB currently:

- Provides residential aged care for 940 residents,
- Delivers 205 Community Aged Care packages,
- Delivers 85 Extended Aged Care at Home packages,
- Delivers 80 Extended Aged Care at Home Dementia packages,
- Operates multidisciplinary allied health centres where our professional staff provide support for residents within WMB's RACF and also for older people living in their home, and
- Funds a Palliative support team of specialised Clinical Nurse Consultants (CNCs) as part of the clinical support team. These CNCs offer advice, support, resources and education addressing end-of-life decisions and care.

Innovations that have built capacity

Wesley Mission Brisbane has implemented two programs and service that have built capacity to provide quality palliative and end-of-life care;

1. The WMB RACF Bethesda Caring Centre participated in a research study (2007- 2009) with Brisbane South Palliative Care Collaborative (BSPCC) along with 5 other Brisbane RAC's to trial the use of the RACF End-of-life Care Pathway (EoLCP). The results of the WMB program demonstrated that when clients are placed onto the RACF EoLCP (once it has been determined that they have entered the terminal phase of life) they are less likely to be transferred to hospital for end-of-life care and the outcomes for them and their families are significantly improved (1).

   WMB's goal was to translate the Brisbane South Palliative Care Collaborative evidence into practice and implement the utilisation of the RACF EoLCP in all its' RACF's. We were able to achieve this by running a project from March 2010 to June 2011. The 600K project was funded by the Department of Health & Ageing Local Palliative Care Grants Program Round 5. It was based upon the "Palliation in Dementia Care" course run by Qld Dementia Training Study Centre/ Queensland University of Technology, the BSPCC project (1) and the Guidelines for a Palliative Approach in Residential Aged Care" (2). The project activities and outcome aligned with Palliative Care Australia's Consensus Statement that "assisting people to not only live well but to die well too, free from pain, in the place of their choice, with the people they wish to be present and above all, with dignity" and the Australian Standards for providing quality palliative care for all Australians.

   The WMB Project Officer, two Clinical Nurses and BSPCC Palliative Care Nurse Specialists delivered education to the majority of staff working in our aged care services. Over 1,000 staff attended education, received workplace mentoring and support. Staff's knowledge, competence and confidence in end-of-life care was demonstrated in the uptake of the EoLCP in all WMB RACF's (average 50%) and positive staff survey results. A major component of the project was to up skill senior clinicians to be the experts in a palliative approach to care. WMB now has specialised Clinical Nurse Consultants and Palliation Advisors to continue to implement and support the use of EoLCP and ensure the best possible end-of-life care in all our aged care services. As a result of this project the number of transfers of residents at end-of-life rapidly decreased and this transfer rate remained low throughout the project and continues to be minimal today.

   Provision has been made in WMB Aged Care in the community to incorporate the provision of a palliative approach and end-of-life care. WMB has extended the provision of end-of-life care for their community clients in Queensland by adapting the RACF EoLCP for use in the home setting. This supports elderly people to stay at home for as long as possible as most people say they want to die at home (3).

Whilst the project has concluded it is evident with the increasing frailty of residents and older people in their own homes and the high staff attrition rates in the industry an ongoing program of palliative care education is vital across the aged care sector.

References
1. Residential Aged Care End-of-lifeCare Pathways Project, funded by Department of Health and Ageing, Authors: Julie Thomson RN Project Officer; Fiona Israel RN MCouns, Manager; Dr Margaret Charles PhD, Senior Lecturer, Sydney University.
2. National Health and Medical Research Council & Edith Cowan University. (2006, May). *A palliative approach. In Guidelines for a palliative approach in residential aged care.* Canberra: Australian Government Department of Health and Ageing.
3. National EOL Framework Forum. (2010, May). *Health system reform and care at the end of life: a guidance document.* Palliative Care Australia

2. The ongoing provision of a Palliative Support team of specialised CNCs is another innovation implemented at WMB as a result of the very positive outcomes of the year long project reported in 2011 and is a sustainable approach to palliative care for our RACFs.

Factors that would enable effective and efficient service delivery.

A number of factors need to be addressed to enable effective and efficient service delivery. These include:

1. an holistic model guiding a multidisciplinary palliative service
2. flexible, responsive funding models that can respond quickly to meet the rapid deterioration and end-of-life needs of all people; community and RACF based.
3. education and support for the elderly and their family to address advanced health directives and end-of-life decisions prior to them being needed, and
4. ongoing training and professional development education and training for care staff and health professionals in order to meet the complex needs of the person and their family requiring palliative and end-of-life care.

1. **An Holistic model of multidisciplinary palliative care would enable effective and efficient service delivery**
   - Currently there is a lack of holistic models of care guiding multidisciplinary teams who can provide palliative care. The professional boundaries inhibit an holistic view.
   - There is increasing community and family expectations around expert, highly skilled care in RACF including palliative care.

2. **Flexible funding arrangements would enable effective and efficient service delivery**
   - More flexible funding arrangements would facilitate the use of multidisciplinary teams who can provide palliative care
   - More flexible and responsive funding arrangements are required so that end-of-life care can be funded as required to avoid unwanted transfers to acute hospitals or RACFs

- Funding for ongoing provision of outreach and in-home palliative services to older people
- Funding for the provision of bereavement support and services
- ACFI funding is difficult to change quickly and end-of-life can be over before a reviewed funding application is submitted

Currently aged care funding focuses on ongoing resident care and acknowledges some aspects of palliative care however a review of the funding for the intensive support required in the end-of-life phase is recommended. This is needed to ensure that the intensive and time consuming support and hospice care needed by residents, community based clients and their families can be delivered.

3. **The use of advanced health directives would enable effective and efficient service delivery**
    - There is a need for increased awareness among the elderly and their families of the value of an advanced health directive
    - There is a need for increased knowledge, skills and confidence among care staff in addressing conversations around the wisdom of writing an advanced health directive

When a resident in an RACF or a community based aged care recipient deteriorates quickly they are often transferred to the acute setting because of the lack of instruction from the resident, family or GP. This may contravene the unspoken wishes of all these people. The lack of instructions from the elderly person or their families leaves very few options to care staff when a person's health suddenly deteriorates particularly overnight.

The medical model that guides health service provision through a person's life is that hospitals are where you go when you are very ill. Death is often viewed by family as increasing illness and therefore there may be an expectation from family to transfer a resident to hospital. This may not be the resident's view but without a written advanced health directive or stated health directive this conflict is likely to arise as a result of a health crisis out of hours. This indicates the need for future services to be aimed at education and support of families and the older person early in the process failing health.

4. **Ongoing training and professional development for care staff addressing end-of-life matters would enable effective and efficient service delivery**
    - Palliative and end-of-life care is provided by Personal Carers, Assistants in Nursing, Enrolled Nurses and Registered Nurses in both RACFs and the community. All need palliative care education and professional development and training.

- Increased knowledge, skills and confidence among care staff in addressing end-of-life care would improve the quality and outcomes of palliative care
- Increased knowledge, skills and confidence among care staff in addressing collaborative, multidisciplinary palliative care would improve the quality and outcomes of palliative care
- Training and professional development in supportive communication and counselling skills in required for staff to enable them to provide a greater repertoire of support to residents/clients and families through the end-of-life process.
- Training of mentors and train-the-trainers is required to provide ongoing professional development and training all care staff.

All residents at WMB can have end-of-life care that reflects a palliative approach. However the level of expertise among staff is not consistent. The quality of the service and care provided reflects the knowledge, skill set and confidence of the staff on duty.

WMB has participated in a program to develop of palliative advisers across the organisation. In order to maintain the education and expertise of the staff funding needs to be provided to resource the team. A rolling program of palliative training is required to address staff turnover and loss of skills.

The lack of RNs confidence and skills around end-of-life assessment and communication with other health professionals results in barriers to optimal care. Where multiple providers are delivering care communication can breakdown and continuity of care lost. The knowledge, skill set and confidence of health professionals, regardless of professional qualification varies widely.

The multi-cultural nature of the staff mix in aged care brings important cultural insights however training needs to be accessible to all staff including those from a culturally and linguistically diverse background.

Currently there is a good understanding of palliation in people with dementia in WMB. However many people in RACF and the community die of other causes. Palliation in older people with cancer, end stage respiratory, cardiac, diabetes, and neurological diseases remains poorly understood and therefore poorly developed. The palliative approach for the 87 year old women with end stage breast cancer is very different from the journey of the 57 year old women. Age is the only discernible difference between the women. Their experience is very different.

5. **Ongoing training and professional development for GPs addressing palliative care including;**
    - Advanced-health-directives

- Specialised equipment such as syringe drivers
- Advanced pain management
- A palliative approach including expectations and instructions for care out of hours

It is out of scope of practice for registered nurses to prescribe medications and limitations around out of hour's medical review and very limited home visits adversely impacts on WMB's ability to provide optimal pain management and a peaceful quality palliative pathway to all our people.

Discharge from hospital may occur outside GP clinic hours and continuity of care can be problematic when relying on out of hour's services.

There is a general reluctance by afterhours GP services to prescribe narcotics. Often advising the requestor to transfer the RACF resident to hospital or seek support from usual GP in the morning. The Residential Aged Care Facility Clinical Resource Manuel (Metro South Health Service District) recommends on pages 11-07, 11-10, 11-12 that drugs be given as prescribed. However if the drugs have not been prescribed they cannot be given.

When a doctor is not confident to prescribe specialised equipment eg syringe drivers they recommend that the palliative team be called in. This places the resident on a waiting list and increases the likelihood of out of hour's crisis and transfer to hospital or death without adequate pain relief.

Current barriers to optimal Palliative care

1. There is currently no accessible outreach palliative service for RACFs or community based clients in area North.
2. There is a waiting list for services from the area South outreach palliative service.
3. A general community reluctance to acknowledge the palliation process in people who are 'just old'. This results in the residents needs being met in an ad hoc way rather than a supported and resourced palliation program.
4. A general community reluctance to acknowledge the palliation process in people with dementia.
5. There is also a general reluctance by the community at large to talk about death and dying until a crisis arises.

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