

## **Inquiry into Palliative Care in Australia**

### **Context**

Baptistcare is a Christian faith-based, Community Benefit (not-for-profit) Charity that is celebrating its 40<sup>th</sup> anniversary this year in 2012. It operates under the Western Australian Associations Incorporations Act 1987. It provides services predominantly to older Australians, in addition to those living with a disability and those struggling with mental health illnesses, together with support for their families. All three client groups access residential, home and community-based services. Baptistcare operates in the Perth metro area, in rural and regional Western Australia and often in remote locations. Approximately 65% of our activity is in regional WA. We employ approximately 1400 people and have over 20 different service locations. Baptistcare is Western Australian and is a member of a national board called Baptist Care Australia (BCA), which acts as a representative and advocacy body at a national level. Baptist Care Australia has a membership comprising all the Baptist community service organisations which operate in every State and Territory around Australia. BCA is set up under the ASIC Rules and Regulations.

Therefore, the Inquiry into Palliative Care in Australia is something of great interest to Baptistcare and to Baptist Care Australia.

Baptistcare Incorporated believes that a number of principles should be taken into account when considering issues in relation to Palliative Care:

- End of Life palliative care and support needs to be available to all who are diagnosed with a terminal illness, no matter the setting within which they are living;
- Palliative care services need to be tailored to the distinct needs of the individual;
- Palliative care services should be inclusive, involving family and others who are integral in the life of the individual, along with service providers;
- Palliative care service delivery should be well coordinated and integrated, with timely and appropriate planning of not only clinical care, but also other aspects that meet the needs of the individual; for example spiritual, respite, counselling (including for the family), family carer support and household tasks;
- Palliative care should be recognised as part of the normal scope of practice in the provision of residential and community aged care, as well as for people living in the community (including younger people) with a terminal illness,
- Education for palliative care should focus on symptom management and person-centred service delivery;
- Commonwealth funding should recognise additional requirements for care and support during the end of life phase of people in palliative care;
- Rural GPs would benefit in accessing improved palliative care networks and resources;
- Differences in culture should be recognised as a normal part of palliative care planning and palliative care services tailored accordingly;
- A palliative approach to care should be recognised and commenced before the end of life stages.

Baptistcare's perspective is informed by its experience in the provision of residential aged care, disability services, community aged care and mental health services, including in rural locations..

### **The factors influencing access to Palliative Care:**

1. Discussions and planning with the client and family about what to expect, what resources and supports might be needed/available before the client or family reach a crisis point or end of life stage, are not resourced and given the necessary time and commitment.

Some GPs are reluctant to make a palliative diagnosis which delays a palliative approach being coordinated with the most appropriate services/professionals in the client's community.

Timely referral and coordination also needs to factor in remote and rural communities and the possible delays/waiting time to access visiting specialists.

A solution may be for the GP networks to be provided extra funding for Palliative Care support, which might include mentoring and coaching from an experienced colleague. In smaller communities where sole practitioner GPs operate, the need for support is even greater as the GP is often on call, working long hours, and there are high and unreasonable expectations from the community placed on the GP.

2. There is no system involving engagement of an independent and trained professional, as a matter of course, to assist and work with the individual and their family on developing a tailored approach around the individual's palliative care in the early stages of diagnosis.

Furthermore, recipients and families frequently complain about having to provide the same information over and over again and of poor communication between providers.

Entry to Palliative care services via a more structured approach involving service delivery coordination and support would streamline access to appropriate services and support, improve communication and efficiencies, while providing an improved and more person-centred outcome for the individual.

3. The availability of e-health, electronic health records and other communication technology is essential to the coordination of care and support.
4. Interventions and assistance are not generally person-centred. With a primary focus on clinical care and symptom management, there is inconsistent consideration of the individual needs of the person experiencing the illness or their family. This includes issues such as age specific requirements, spiritual beliefs, personal preferences of the individual and their cultural beliefs and practices.

With the changing demographics, there may need to be a greater emphasis on access for the family and client to translators who have knowledge of palliative care and are able to translate information from health professionals that reflects the intent of the original message.

5. Nursing staff need to be able to have prompt access and assistance with the community care provider when the resident is initially diagnosed, to facilitate careful and clear assessment and planning of clinical care, ensuring concise and consistent palliative management.
6. In all our service delivery areas of Disability and Community Care, Residential Care and Mental Health, there is an ongoing shortage of qualified clinical staff.

In rural areas, this can be exacerbated by the distance between towns, and the capacity to respond to unplanned/unforeseen changes. Staff turnover and attrition is, and will continue to be for the foreseeable future, an issue for service providers to ensure that knowledge and skills are not just maintained but continuously improved.

7. Timely access to enough equipment in rural communities is an issue with costs of hiring and transport from metropolitan or larger towns creating further hurdles for the coordinating service.
8. Staff in residential aged care try to ensure residents are effectively managed in the residential care facility. It is our experience, however, that at least a third of palliative care residents are admitted to hospital prematurely because there are insufficient staff who are appropriately trained and supported to deliver best practice care in the resident's home. The availability of the GP to attend the aged care home is a critical factor in providing support to the resident, their family and staff.

Sometimes it is perceived that the only way to access 24 hour expert care and support is for the resident to be admitted to an Acute Health Service. For some residents, being transferred out of their 'home' is not what they had envisaged would happen and the clinical feel and routines of a hospital setting can increase their distress and discomfort.

#### **Funding arrangements:**

Residential Aged Care relies on the Aged Care Funding Instrument (ACFI) to determine funding entitlements. This is focussed on achieving an appropriate assessment of a resident's care needs and this should afford the correct level of funding for clinical care.

Baptistcare as a faith-based organisation believes strongly in the provision of end of life services that meet clinical, spiritual and relational care expectations as we walk the journey with the resident or client and their family.

However, the funding given to the care provider frequently remains insufficient. This is a particular issue when a resident has been assessed as having a high domain in complex care and also has a palliative care diagnosis. The cost of providing individualised, 'one on one' care, is prohibitive and is not recognised in the ACFI, as it is usually (relatively) short term. It is however very intense and falls to the service provider to deliver this higher level of service without appropriate funding.

By way of example, it is worth noting that the Grasby syringe drivers are to be phased out this year (2012), with no funding provided by the Commonwealth to purchase replacement equipment. The implication for Baptistcare has meant that we have had to purchase eight Niki syringe driver alternatives, with a need to buy six more this year. This organisation has had to carry the cost of buying this new equipment.

In a community setting, whether Community Aged Care or Disability Services, the same situation occurs where there is no recognition of additional costs associated with relatively short, but intense, palliative care service delivery.

Generally, people in this situation, despite often having a desire to remain in their own home, end up being admitted to a Hospice or Hospital.

#### **Effective and efficient use of resources in the various settings:**

Facilities located in the larger regional cities and towns and surrounding environs manage palliative residents, with the support from Silver Chain or other government-funded organisations.

However, these outside services can only be accessed when an individual is in the terminal stages and not at diagnosis, which is a significant deficit for service providers, the community and families.

Some GPs at facilities are skilled in providing excellent palliative care and support to staff but, where the GP support and management is not ideal, the resident's care is compromised.

More clinical support and education for nurses, carers and GPs, is required to ensure best practice pain and symptom management.

Small rural communities are at a major disadvantage with challenges in relation to geographic isolation and distance and with limited access to care providers.

Given this and the general desire for people to remain in their own home, there is an opportunity to better develop palliative care services in the community; particularly in relation to the early diagnosis, use of technology such as e-health and telemedicine, and multi-skilling/better education of staff.

Such enhancements should also recognise the highly specialised requirements of people living with a disability, cultural differences and other specialised requirements (for example, people who are terminally ill, suffering a mental health condition).

#### **Palliative care workforce:**

Currently, Baptistcare does focus on providing palliative care for our residents, utilising GPs and other outside agencies. Baptistcare does not have specific Palliative Care teams but we are accessing a Palliative Care Project 'Talking about End of Life' which has been funded and managed by the WA Department of Health.

Taking part in this project will allow an identified team of clinical staff at each aged care facility to access evidenced-based education, resources and support. These teams of staff will then facilitate palliative care at their sites and be an important resource for other staff members and families.

Palliative care training initiatives, directed at person-centred and integrated service delivery would be advantageous in improving Palliative Care outcomes for individuals across all settings.

This should form part of a Palliative Care programme, focusing on early support, coordination and advanced care planning. Ideally this should be led by appropriate health professionals who have the ability to work with the individuals, families, and other health providers to provide Palliative Care planning for an individual throughout their journey and across the different settings of community, community care, residential care and/or Hospice and Hospital.

#### **Standards:**

There needs to be full integration of the palliative care standards with the aged care accreditation and other standards (including Disability, Mental Health, etc).

#### **Advanced Care Planning:**

The roll out of advanced care planning offers those living with a terminal condition the opportunity to make decisions which affect their care. People suffering a terminal illness, their families and significant others need assistance and to be engaged in advanced care planning, to ensure end of life wishes are determined and met.

#### **Technology**

Care recipients frequently raise frustrations at having to repeatedly tell their story and provide the same information to different services and providers.

There is an opportunity to improve coordination and communication through the use of modern Information and Communication Technology. Whilst being cognisant of privacy concerns, there is a significant opportunity to decrease this burden with better use of technology, including electronic databases/records, electronic health cards and tele-health.

General communications can also be enhanced, especially in rural areas, by the introduction of video call technology/telehealth and use of electronic records.

Any such initiatives do however need to be developed with strong safeguards around data security and confidentiality.

## **Conclusion**

The provision of Palliative care services is an area that presents significant opportunities for improved outcomes for individuals and their loved ones.

Palliative care is an area where person-centred service provision should be at the fore.

Palliative Care should not be considered solely in the setting of residential aged care. Palliative care services should also be developed around younger people, including those living with a disability and/or living in the community, as well as those suffering a mental health condition.

These services should also include consultation, engagement and support for families.

In particular, palliative care discussions and planning, should be focused on the needs of the individual and his/her family, and commence at an early stage following the diagnosis of a terminal illness.

Currently, palliative care service planning does not generally occur until an individual with a terminal illness is approaching the end of life stage. This planning is not always particularly well coordinated and communication between the various parties is limited, with care recipients and their families having to tell their story and provide information several times over.

There is an opportunity to improve coordination of Palliative Care, that is sensitive and responsive to the unique needs of the individual, including cultural spiritual, age and environment. Such early engagement and planning should be undertaken by health professionals and others with the capacity to work with the individual and their family around holistic requirements, whilst working with other health professionals who provide speciality services (eg GP's, Clinicians, etc).

In doing so, a focus should also be on education of health professionals around palliative care, support networks, multi-skilling (especially with regard to those providing services in rural areas) and the adoption of modern technology to assist communication, service coordination and to streamline dissemination of information.

The Federal Government should also recognise the additional cost of providing one on one support for Palliative Care within residential aged care and other settings, in relation to the end of life stage.