

**SENATE COMMUNITY AFFAIRS COMMITTEE INQUIRY INTO THE
PROVISION OF PALLIATIVE CARE IN AUSTRALIA**

**SUBMISSION FROM THE CENTRE FOR CEREBRAL PALSY
WESTERN AUSTRALIA**

Palliative care is specialised care and support provided to people (adults and children) with an active, progressive and advanced disease or illness for whom there is little or no prospect of cure. Palliative care needs to be holistic and focus on enabling people to have the best quality of life possible until their death. Being a holistic approach to care, palliative care needs to address the physical needs of the patient, including prevention and relief of pain as well the emotional, social, cultural and spiritual needs of the patient, and their carers and families.

ABOUT THE CENTRE FOR CEREBRAL PALSY

The Centre for Cerebral Palsy was founded in 1951 and is a leading non-government agency serving over 1300 clients with cerebral palsy and their families throughout Western Australia. It provides a range of services including accommodation, respite, employment and alternatives to employment, assistive devices and other services to its clients (adults and children) and their families. The range of services The Centre provides is demonstrated in the following data from the 2009/10 financial year. During this period, the Centre:

- provided therapy services to 480 children in the Perth metropolitan area;
- supported 85 children in country WA;
- provided therapy services to 253 adults in the Perth metropolitan area;
- provided alternative to employment day activities for 117 adults;
- provided respite for 42 adults;
- provided respite for 159 children;
- supported 116 adults to live in our nursing home, hostels and group homes;
- provided independent community living to 7 adults;
- provided supported employment for 70 people with disabilities in our business services arm;
- supported 63 people in their endeavours to attain and retain open employment, including 8 people into new jobs; and
- Provided work experience for 35 students from supported education units at 16 schools and colleges.

The Centre has an operating budget of \$33 million, employs 600 staff and receives the support of over 200 volunteers. These factors demonstrate the

need for an agency such as The Centre to be prepared to provide high quality services to an increased clientele.

A realisation that The Centre has celebrated in recent years is that people with cerebral palsy are living much longer than previously thought possible. Advances in medical and health care, technological advances and the increased ability for people with disabilities to live, participate and mingle in the community enjoying a good or reasonable quality of life are some of the factors that have contributed to this trend. While the need for, and response to, palliative care already exists for people in main stream population, it should also be acknowledged that there is an emerging need for an appropriate palliative care system for people with disabilities.

This submission focuses on people with disabilities, and specifically those individuals with cerebral palsy who require a palliative care response that meets their specific 'end of life' needs, wishes and desires.

The right of people to choose their care preferences

The many policy changes in the disability sector in recent years point to a rights based approach, enabling people with disabilities to make decisions and to have maximum choice. People with disability are now able to choose their care preferences, which should also include preferences relating to palliative care. Through the person centred planning process, The Centre is developing mechanisms whereby each adult client is afforded the opportunity to make known their palliative care preferences at a time they, with the support of the families, can make informed, rational decisions. Clients of The Centre are encouraged and given opportunity to develop Advance Health Directives which clearly state what level of intervention they wish to receive should their health deteriorate at any time. They record all of their wishes including resuscitation options, hospitalisation and preferences in regard to receipt of palliative support in their place of residence. Some clients and their families opt not to use this opportunity, preferring instead to postpone decisions relating to palliative care until the situation is such that they have to make decisions. Whilst respecting everyone's right to delay these decisions, experience supports that informed decision making ahead of any serious decline in health does ensure the best possible options for quality of life at the appropriate time. The Centre believes that all clients in their supported accommodation service should have control over their preferences for care and discussed all options including palliative well before required. Consideration should be given to making this process standard for all permanent residential support providers for people with disability across the sector.

It is generally accepted that palliative care has been organised around the needs of terminally ill cancer patients. While acknowledging the needs of terminally ill cancer patients to be treated with the utmost respect and addressed accordingly, equally there needs to be recognition of models of palliative care to be as flexible in accommodating the multiplicity of non-malignant situations with which individuals requiring palliative care present. Early planning is vital to enable preferences of individuals to be respected, and their quality of care maximised.

Settings for providing palliative care

A majority of clients who live in The Centre's group homes regard it as their home. This is the case for those who have close family with whom they have good relations. Many of them have spent most of their adult lives in the homes and have not known any other permanent home. In recent years The Centre has evaluated its processes relating to palliative care and is in the process of making the necessary changes to enable clients who require palliative care to be provided these services in their places of residence, if this was indeed their preference. While acknowledging that some clients may opt for receiving palliative care in other settings, several factors make an individual's home a preferred setting for their end of life choices, particularly for people with profound disabilities. These factors include:

- Receiving palliative care in a person's own home where they are surrounded by people who know them well including family, other residents and care staff. This is particularly important in the case of non-verbal individuals who are not always able to articulate their wishes. Support staff have usually supported individuals for a long period and know how best to communicate with them;
- The deterioration of an individual's condition is usually not a surprise, and is often expected, enabling support staff to work alongside allied Health Professionals to recognise when palliative care is appropriate and to ensure that it is respectful and with dignity;
- An individual's familiarity with the surroundings enables the individual and their families to be mostly free from stress and anxiety;
- Clients who require a high level of manual handling which many of the Centre's clients do are most comfortable when handled by staff who know them and their situations well,
- It is less expensive than a hospital setting.

While acknowledging the need for some palliative care to be provided in hospitals and hospices, The Centre strongly advocates for enabling palliative care to be provided in an individual's home, particularly for individuals with profound disabilities, unless individuals specifically request otherwise.

However, to enable palliative care to be provided in community settings, and particularly in peoples' homes, it is critical that all people concerned including people requiring palliative care, their family members and significant others, and all levels of support workers have access to good education programs on all aspects of palliative care. This is because the notion of palliative care can be a hard matter to discuss with people who do not require it. People requiring palliative care and their families will be more responsive to planning for palliative care if they were informed and educated about these matters. Equally, staff supporting individuals will more readily engage with planning for and implementation of palliative care if they too were more informed and educated about these matters. Consideration should be given to developing interactive internet based education programs as an alternative to training programs delivered on a face to face basis.

Procedural and personnel safeguards

As previously stated, The Centre provides its clients the opportunity to state their preferences for palliative care considerably before this type of care is required by them. Individuals and families opting to use this opportunity are supported to develop an Advance Health Directive. The Centre has adopted measures to minimise potential risks associated with their development. Previously, it was possible for The Centre's staff to witness an advance health directive. Acknowledging the potential for risks associated with staff witnessing the directives, The Centre's staff are no longer allowed to witness these directives. It is now obligatory for the directives to be witnessed by a medical doctor and someone outside The Centre which can include a family member. The Centre ensures that the process for developing a health care directive engages the client, family, health and medical professionals and other personnel of significance to the individual to enable an individual's wishes to be articulated, debated as necessary, be made known to all concerned and be ready to be implemented without contradiction or confusion, when it is necessary. These processes not only afford greater accountability but also ensure that personal philosophical positions of staff and all other individuals do not impact on the health directive.

The Centre calls upon the services of Silver Chain, a community and health service to provide nursing care to the clients being provided palliative care, particularly to administer all medication, including pain management. Support workers are not allowed to administer medication at any stage. The relationship with Silver Chain is critical to The Centre being able to provide palliative care in the homes of individuals. The Centre urges formal partnerships be developed between disability organisations and community and health services to make the provision of palliative care in the community a viable option. It is therefore important to ensure that resourcing to these operations not only continue but be increased.

Disability organisations currently providing palliative care or which are intending to provide this type of care need easy access to palliative medical specialists. The Centre has been fortunate in having access to such a specialist. However, it may be necessary to gauge their locations to determine their availability and organisations' access to them.

Cultural need

Aboriginal people and people from culturally and linguistically diverse backgrounds may have cultural needs that are often overlooked in the provision of palliative services. It is acknowledged that some people from CALD backgrounds do not speak English and would require an interpreter. Less well known is that one in five Aboriginal people also do not speak English and require an interpreter. However, the provision of an interpreter in either case is merely the tip of the iceberg and does not fulfil the cultural obligations of care providers, including that of medical and health professionals.

Topics of discussion, and questions or statements that are considered 'standard' from an Anglo-Celtic perspective may be inappropriate or taboo in other cultural contexts. For example, in many cultures 'death' and 'dying' are taboo topics which need to be approached sensitively. It is also likely that kin and family will play a more central role during the phase of providing

palliative care than they would in an Anglo-Celtic context. Equally, after death rituals will vary significantly between cultures. It is crucial that these differences be recognised and sensitively observed throughout the provision of palliative care

Despite public hospitals being committed to culturally sensitive practices in theory, they fall considerably short in practice. Hospitals are often unable to balance clinical practice with cultural need, with the former always getting an undue prominence in service provision, even where the cultural element may be of great importance to the receiver of services. It might also be the case that mechanisms for making an individual 'comfortable' in a clinical sense might contradict being comfortable in a cultural sense. This type of contradiction can cause irreparable harm to the emotional and psychological wellbeing of an individual and needs to be avoided as far as possible.

Complexity surrounding these issues is exacerbated by the fact that cultures are not homogenous. An important aspect of providing culturally sensitive services is to engage the individual and their families in articulating their cultural need and preferences. Each hospital may have many iterations of Aboriginal and cultural plans, it is unlikely that yet another iteration would fix the cultural issues. The translation of theory into practice usually depends on individual carers and health professionals. It is well established that with age people's links to their culture increases; since palliative care is mostly provided to an ageing population, some mechanism needs to be established to move the cultural agenda from the individual to the collective. For some people a cultural context may be an essential aspect of dying with dignity. Ensuring that palliative care is primarily provided in a community setting may contribute to cultural sensitive practice being observed in palliative care. Community settings such as in a person's home will ensure that those around an individual requiring services are aware of cultural and religious needs.

Funding

The Centre's residential adult clients are funded by the State's Disability Services Commission (DSC) on an individual basis. Each year there are two opportunities for The Centre to assist clients requiring additional funds to apply for increased funding. This option for increased funding is available for clients receiving palliative care. On the other hand, block funding rather than individual funding is provided by DSC for clients requiring therapy and health services. All of The Centre's services for children are located in the therapy and health services program. Increases in funding to this program are through growth funding, based on 'blocks', which means there is currently no option for receiving more funding assistance for children in palliative care, even though there is a recognition that they require additional and extended support and services. Although children and palliative care are not a logical mix, the reality is that some children who have life limiting conditions as a result of congenital abnormalities or early neurological insults will require palliative care. Two of The Centre's young clients are recipients of palliative care and live with family at home. They require a multiplicity of direct and indirect support and services. Direct services include the provision of equipment, usually more equipment than children with a disability typically require; peg feeding, oxygen, 24 hour positioning

and emotional support for the family. Indirect support includes assisting families to access available support, which can consume many hours of a social workers' time. There are strong links with health services, however, the continuation of therapy service provision by the Centre's allied health professionals is a cost impost on the organisation. Given the many needs of children in palliative care, consideration should be given to establishing a fund specifically for this purpose, which families can access when required.

Workforce training

Palliative care can generate considerable emotion with which some staff and family members struggle to cope. Currently, training in the area of palliative care is largely for specialist health professionals. This need is critically important and needs to continue. It may be opportune to include more elements of the non-clinical aspects needs, including culturally sensitive practice and engaging families into specialist training. However the area of training that needs considerable reinforcement is in the area of non-specialist training which community workers including residential support workers can access. While this group of workers would not administer clinical or medical procedures, they, along with family spend the most time with an individual in palliative care. As in the case of education programs, making them interactive internet based is likely to be well received, particularly since palliative care in the community is still not an entrenched factor. As a result, community support workers either may not consider it important to spend the time required to attend this training or they may not be supported by their supervisors to do so.

Given the potential risks associated with palliative care, it is also important for the Executive of community organisations and all managers to be vigilant at all times. They too may require training on areas for vigilance including pointers to identifying risks. Currently, The Centre's staff have a choice on whether they want to support individuals receiving palliative care. Those that opt out are temporarily placed elsewhere in negotiation with them. However The Centre recognises that much more needs to be done to prepare staff to support individuals in palliative care.

Conclusion

The Centre strongly supports the Senate's initiative to conduct an inquiry into palliative care. At a time when The Centre is in the process of developing processes and procedures for providing palliative care in its residential settings, the inquiry's findings are likely to provide directional support. The Centre hopes that the findings of the Inquiry would generate leadership, including policy and practical support for community settings to be better equipped to provide palliative care, particularly for marginalised groups such as people with disabilities.

Judy Hogben
Chief Executive Officer
The Centre for Cerebral Palsy
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