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Carers NSW submission to the Inquiry into Palliative Care in Australia

Carers NSW appreciates the opportunity to contribute to the Inquiry into Palliative Care in Australia. This submission will focus on the issue of palliative care from the perspective of carers and will focus on those areas which have particular relevance for carers and family members of persons with a life limiting illness.

Carers NSW has received feedback from several carers who are caring for a person with a life limiting illness, or who have done so in the past, which has informed this submission.

About Carers NSW

Carers NSW is an association for relatives and friends caring for people with a disability, mental illness, drug and alcohol dependencies, chronic condition, life limiting illness or who are frail. Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

The core work of Carers NSW is to:

- be the voice for carers in NSW
- undertake research, policy development and advocacy
- provide carer services and programs
- provide education and training for carers and services providers
- build capacity in the sector.

Carers NSW's vision is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by their communities and by governments.

About carers

Carers are the main providers of care in the community, and have been described as the 'invisible workforce' by the National Health and Hospital Reform Commission. It is estimated that carers provide 74 per cent of the assistance required by aged people and people with

disabilities.[i] Carers perform an important role in the palliative care system, particularly in providing support for people receiving care in the community.

The 2009 Survey of Ageing, Disability and Carers (SDAC), undertaken by the Australian Bureau of Statistics, provides a snapshot of carers and their role:

- 12 per cent of the Australian population are carers (2.6 million people).
- There are 771,400 primary carers (the person who provides the most informal assistance to an individual).
- 66 per cent of primary carers care for 20 hours or more per week.[ii]

1. Carers in the context of palliative care and end of life

Palliative care is provided in both community and institutional settings, including the home of the patient and/or their carer, hospitals, hospices and residential aged care. Wherever palliative care is provided, the carer plays a key role in supporting the patient, although it is when caring takes place in the community that they tend to provide a more intense level of care and support. Studies have shown that most Australians would prefer to die at home, which in many cases requires community palliative care services. One survey found that of those Australians surveyed who had thought about where they would like to die, 74 per cent said that they wanted to die at home.[iii]

Governments and health services realise the potential cost savings of community palliative care as opposed to care provided in expensive institutional settings. However, the success of palliative care in the community relies on the support of informal carers who, even when assisted by formal services, often provide much of the day to day care. Despite the importance of carers in the provision of palliative care, Carers NSW was disappointed to note that the Terms of Reference only referred to carers in relation to advance care planning.

The role of caring for a person with a life limiting illness and providing care for someone nearing end of life can be both deeply rewarding and extremely challenging, and carers require support themselves in order to sustain this role. Carers deserve recognition for their work and respect for their knowledge and experience.

Carer recognition is especially important in palliative care, as often carers of people who are dying feel disempowered and undervalued in their role as a carer by the health services and professionals they are dealing with.[iv] A study by Keesing et al of carers of people who were dying in WA found that carers felt they were not recognised as key parties in the process and they found it difficult to advocate for their own needs and those of the person they were caring for.[v]

The Commonwealth *Carer Recognition Act 2010* and the National Carer Strategy provide a national framework for improving the rights and recognition of carers in Australia. In line with the principles of the *Statement for Australia's Carers*, carers 'should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.'[vi] With consent from the patient, services and health professionals must work in partnership with carers in order to ensure the best possible outcomes for the patient, must respect the relationship between carers and the persons requiring care, and must recognise the unique knowledge of carers.

Recommendation 1: Carers NSW recommends that the Commonwealth *Carer Recognition Act 2010* and the National Carer Strategy inform the development and implementation of palliative care policies and services.

1.1 The role of carers in palliative care

Caring for a person with a life limiting illness is often physically, psychologically and emotionally demanding. In many cases carers are providing care for someone in their home, but carers may also be supporting a person in a hospital, aged care facility or hospice. Carers have varied roles and experiences. Their responsibilities may include managing medications, providing transport, personal care and emotional support and assisting with decision-making. Caring in the context of palliative and end of life care can be particularly intense due to the deteriorating condition of the patient and their often high care needs. Carers are also experiencing feelings such as grief and fear, and other family members such as children may require additional support to cope with the situation. Carers may also be trying to maintain paid employment.

One carer who spoke to Carers NSW about her experiences gave an outline of her activities as a carer for her husband with a life limiting illness. These included arranging and transporting her husband to appointments with specialists, implementing the advice and instructions from various health professionals, such as monitoring his diet and assisting him to do his exercises, personal care such as showering and providing emotional support.

Many carers report that caring is always their priority and that they have little time or energy to undertake other activities such as paid employment, spending time with relatives and friends, sport and hobbies.[vii] Participation in such activities can provide a sense of identity and contribute to overall wellbeing. Being unable to engage in activities other than caring can contribute to poorer health outcomes.[viii]

2. Support for carers

Support for carers is critical to helping carers to maintain their caring role for as long as they wish to do so, and also to minimise the potentially negative impacts on the carer. Carers can be seen as both clients and providers of palliative care, which incorporates offering a support system to help the family cope during the patient's illness and in their own bereavement,[ix] while carers are also involved in providing care for the patient.

While palliative care provided in the community has many benefits, it is crucial that carers are provided with appropriate support in order that providing this care does not come at a cost to their own health and wellbeing. Currently, many carers do not receive adequate support from palliative care and other services, resulting in high levels of stress for carers and the risk of hospitalisation of the patient when carers can no longer cope. In some cases patients and carers have to wait until a care package becomes available, which could take weeks or months. One service provider explained to Carers NSW how patients and families often struggled to access the support that they had been assessed as eligible to receive due to the limited number of care packages available.

Carers have needs for support related to managing their caring role. This can include respite services, domestic assistance, training and attention to their own health. In a recent study of carers providing home-based palliative care in Sydney, carers identified the key areas in which more support from formal services would be helpful as information and advice (44 per cent), financial assistance (38 per cent), respite care (35 per cent), and assistance with household tasks (27 per cent).[x] Respite care is crucial for many carers in enabling them to continue providing care while also engaging in other activities and minimising the negative impacts on their own health and wellbeing.

Other kinds of support can also benefit carers, such as emotional support to assist in coping with the person's illness and bereavement. For instance, LifeCircle provides support to carers of people with a life limiting illness who wish to die at home through a mentoring

program. Mentors are volunteers with personal experience of caring for someone at the end of life who offer comfort, guidance and on-going support to people who are caring for someone who is dying.[xi] They also help people access community support services. This helps carers cope with their role and increases the likelihood of the individual being able to die at home.

One of the priorities in the National Carer Strategy is that carers should have access to appropriate and timely information which makes it easier for them to get support. Other priorities include that carers are supported with appropriate, timely and accessible services and that the health and wellbeing of carers is improved.[xii]

2.1 Improving access to and quality of support for carers

Support for carers, including those providing palliative care in the community, needs to be improved in order to improve outcomes for both patients and carers. This requires increased funding for services such as respite care and other community support services to reduce waiting lists and allow more clients to access services.

However, while increased funding is important, the way services are provided also needs to change. Carers NSW believes there needs to be a fundamental shift in the way that services are delivered, so the service system is more closely aligned with the needs and choices of both the carer and the person requiring care. Carers are often frustrated by the inflexibility of services, which can make them inaccessible or of limited benefit. For instance, carers often struggle to access adequate and flexible respite that meets their needs. A carer caring for her husband with a life limiting illness explained to Carers NSW that she could only access one hour of respite at a time, which was not enough time for her to do anything.

The NSW Government is in the process of introducing person centred approaches in the disability sector which could serve as a model for introducing similar changes in other fields such as palliative care.

In order to improve access to services for carers there also needs to be increased awareness of the various services and supports available among carers, as well as service providers, social workers and GPs. This is especially important in reaching 'hidden carers' including Aboriginal carers, carers from culturally and linguistically diverse backgrounds and other carers who do not identify as carers and therefore may currently miss out on support.

Recommendation 2: Carers NSW recommends that services for patients receiving palliative care and their carers be delivered in line with the principles of person centred approaches.

Recommendation 3: Carers NSW recommends increased funding for support for carers providing palliative care in the community.

Recommendation 4: Carers NSW recommends improved access to information for carers and service providers about the various services available for carers.

3. The factors influencing access to and choice of appropriate palliative care that meets the needs of the population

There are a number of factors which influence whether different groups can access appropriate palliative care. Access to palliative care services is crucial to the health and wellbeing of both the person in need of palliative care and their carer. However, there is great variation between the type and availability of services from area to area, with rural and

regional areas particularly disadvantaged. Nonetheless, even within metropolitan areas carers are often isolated and there are barriers to accessing services, including waiting lists and lack of appropriate services that meet the needs of the particular situation.

Carers NSW is pleased that the Terms of Reference have identified a number of population groups which face particular barriers to accessing care. Carers NSW is focused on the needs of carers, therefore this section will consider access to services for carers in the context of palliative care.

3.1 People living in rural and regional areas

As with other services, populations in regional and rural areas often have difficulty accessing appropriate palliative care due to a number of factors, including limited choice of services and the distance and cost of travel to access services.

Carers living in regional areas identify a lack of transport and local services as a major concern. Carers often need to travel vast distances to access the health services in regional centres due to the absence of local health services. Australia wide, 45.3 per cent of carers in outer regional and rural areas have difficulty accessing services, compared to 29.4 per cent in inner regional areas and 25.7 per cent in urban areas.[xiii] Almost 40 per cent of carers in remote areas named distance as the main reason for not being able to access services, compared to 17.1 per cent of carers in urban areas.[xiv]

Patients and their carers often have to relocate to metropolitan areas for lengthy periods of specialist treatment. This can lead to severe financial pressure as families struggle to meet the costs of accommodation, travel and treatment while also facing the loss of paid employment.[xv] Relocation can also mean that patients and carers are isolated and removed from informal support networks such as extended family and the community.

Nonetheless, Carers NSW is aware that in some regional areas there are well resourced palliative care services that provide quality services to patients and their families. In some cases a stronger sense of community in rural areas can result in additional informal support being provided for the patient and their family by neighbours and friends.

Recommendation 5: Carers NSW recommends that funding for palliative care services in rural and regional areas be increased in order to improve access for patients and carers.

Recommendation 6: Carers NSW recommends that financial and other support for patients travelling from rural and remote areas to cities be improved.

3.2 Aboriginal people

Relatively few Aboriginal people access palliative care compared to the non-Indigenous population. This is because Aboriginal people with a life limiting condition face many barriers to accessing palliative care, and instead are often supported by their family and community. Aboriginal health and community services also provide valuable support, although they may not be funded or trained to provide palliative care.[xvi] This may affect the quality of care that is provided and therefore the quality of life for the patient and their family. In addition, Aboriginal carers are more likely to need assistance with core activities themselves, which limits the capacity of the carer to provide care and look after their own needs.[xvii]

Aboriginal people often have different cultural understandings and values which influence the types of services they are willing to access. This includes different understandings of concepts such as kinship and family relationships, caring, place, healing, communication

styles and death and dying. These differences are particularly significant in the context of palliative care, when a loved one is dying and spiritual and cultural rituals can be particularly important.

Many Aboriginal people are reluctant to access mainstream health services. This is often linked to past experiences of discriminatory policies and practices directed towards Aboriginal people, such as removal of children and a lack of rights and choices, the impacts of which continue to shape the lives of Aboriginal people today.[xviii] Mainstream services may also be perceived as culturally inappropriate, as they may be unfamiliar with the values and traditions of the local Aboriginal communities or engage in practices which appear insensitive. For these reasons, Aboriginal people often prefer to use specific Aboriginal community services, although in the case of palliative care this is often not available.

Improving the cultural appropriateness and sensitivity of mainstream organisations could help to increase the uptake of palliative care services by Aboriginal people. The Practice Principles developed by the National Palliative Care Program provide a useful guide. A key element of the Practice Principles is the concept of cultural safety, which emphasises respecting and empowering the cultural identity and wellbeing of an individual. This requires palliative care professionals and staff to reflect on their own culture and values, and those of their organisation, and how these influence the services they provide.[xix]

The three principles for improving the practice of palliative care services in relation to support for Aboriginal communities are:

- involving Aboriginal and Torres Strait Islander organisations and staff in the planning, provision and monitoring of palliative care
- sensitive communication
- training for all staff in cultural safety focusing on the needs of Aboriginal peoples.[xx]

In some cases, it is the preference of the patient that their family, or a particular member of the family, provide care. As mentioned earlier, there is often limited access to formal services for Aboriginal people and there is a need for care that is culturally sensitive. In such cases, direct employment of family members to provide care services is one possible solution. This could be considered in some situations; however supports and standards need to be incorporated into this provision, such as relevant training and appropriate financial accountability measures.

3.2.1 Additional issues for Aboriginal people from regional, rural and remote communities

In addition to cultural barriers, many Aboriginal people live in regional, rural and remote locations and therefore encounter the barriers of distance and lack of services that other carers in these locations experience.

Many Aboriginal people travel to cities or major towns for treatment for diseases such as cancer and kidney disease. Problems such as the distance required to travel to access services can be especially difficult for Aboriginal people who are more likely to be dependent upon payments from Centrelink or have a lower income.[xxi] A study conducted in South Australia found that Aboriginal carers coming to Adelaide from remote areas to support someone undergoing treatment were often isolated and confused.[xxii] Adjusting to living in the city and finding their way from place to place can be very stressful, especially for those who are unfamiliar with the area.

Patients and carers travelling to cities for treatment rely heavily on family members living in the area. Relatives can provide accommodation, both short and long term, as well as assisting with a range of other needs including transport, groceries and emotional support.

> *We stayed with my sister for five days… Just as well we had somewhere to stay, we couldn't afford $80 a night. We still have to pay all the expenses for home as well.*[xxiii]
>
> *I used to catch a taxi everywhere I wanted to go… and then [my cousin] told me about this free bus that pulls up in front of the hospital so I started jumping on that to go around the city… so that was good.*[xxiv]

Patients and carers without family support often find their time in the city much more stressful and face a much higher financial burden due to reliance on formal accommodation. More support is needed for carers and patients that are receiving treatment away from home, especially if they do not have the additional support of family members living in the area.

Most people wish to return to their communities after or between treatments, especially if they are suffering from a life limiting illness, as they would prefer to die at home within their community. However, returning to their community is often difficult when quality health and palliative care is only available in urban and regional centres. People choosing to return to their home in the final stages of an illness need to be assured that professional care is available. Without professional services and support, carers will be left to care on their own with limited resources, or alternatively patients may be denied the opportunity to return to their home and their community.

However, with the support of health services and the community it is possible for people to return to their communities to receive palliative care. In the example below the carer was supported by palliative care services as she cared for her husband at home, until he was transferred to the local hospital:

> *They told us in the city hospital that there was nothing more they could do. We wanted to bring him home… I took him home for about three months with help from palliative nurses… they gave me a bed in the hospital in the room with him so in the last – you know, we'd been together – 43 years we were.*[xxv]

Recommendation 7: Carers NSW recommends that funding for culturally appropriate palliative care services for Aboriginal people be increased.

Recommendation 8: Carers NSW recommends that palliative care providers receive training in the principles of cultural safety and working with Aboriginal peoples.

Recommendation 9: Carers NSW recommends that the possibility for Aboriginal carers to be directly employed to provide care be considered where appropriate.

Recommendation 10: Carers NSW recommends that support for Aboriginal people who wish to return home after treatment be improved in order to improve the quality of life for the patient and their carer/s.

3.3 People from culturally and linguistically diverse backgrounds

People from culturally and linguistically diverse (CALD) backgrounds often face additional barriers to accessing appropriate palliative care. There is great diversity within the CALD

population which encompasses many religions and cultures. Approaches which suit one community may be inappropriate for others which may have different values and experiences. Barriers to accessing services include differences in language, communication styles, religion and understandings of death and dying.

Cultural issues around death and dying for diverse cultural groups can affect their willingness to seek palliative care. In many cases the health sector does not have adequate knowledge of such issues, which is crucial in order to provide services that are sensitive to the needs and values of different groups and to ensure that different groups have equity of access to quality services. Carers NSW supports Palliative Care Australia's call for improved education in this area, and community consultations and capacity building in relation to end of life care.[xxvi]

Cultural differences also affect the expectations of the role of carers and family in supporting the patient. Different understandings of the family, the role of women and attitudes towards receiving services compared to mainstream Australian culture can mean that carers are less likely to seek support even if they are having difficulty caring for a person with a life limiting disease.

A lack of knowledge about the health system in Australia or awareness of services available can also limit use of services. Recent research from Queensland has shown that even people from established CALD communities are unfamiliar with health systems and experience difficulties accessing health care.[xxvii]

Recommendation 11: Carers NSW recommends increased awareness of the ways in which cultural differences impact the experiences of patients and carers from CALD backgrounds in the context of palliative care.

3.4 People with disabilities

People with a disability and their carers often face additional barriers to accessing health care and services that meet their needs. This is especially the case for people with intellectual disability, who may not be offered the same treatments as patients without intellectual disability. In the context of palliative care, this can lead to the individual with disability suffering pain and distress at end of life which could have been relieved through palliative care. Carers NSW commends this Inquiry for investigating access to palliative care for people with disabilities.

A literature review conducted in 2004 identified barriers to access to palliative care for people with intellectual disability.[xxviii] These included the failure to diagnose a condition as medical professionals frequently attribute symptoms to the person's disability, rather than looking for an underlying medical condition, and the fact that people with a disability may have difficulty communicating pain or symptoms.

From the carer perspective, the lack of support for their family member or friend can make caring for a person with a disability and a life limiting illness even more difficult. Carers may be unaware that the person they are caring for is entitled to access palliative care services which could assist in meeting their care needs as well as improve quality of life by managing symptoms and providing support such as counselling.

4. Advance care planning

With the consent of the care recipient, it is important that carers are involved in advance care planning for the persons they are caring for. Decisions about the type and place of care will

likely affect the nature of the carer's role, and may result in a considerable increase in their workload. Involving the carer in planning helps ensure that the impact of any decision on the carer is considered, and that the carer understands and can support the decisions of the consumer. This is also in line with the principle of working with carers as partners in care.

Carers NSW supports moves to include advance care plans in personal electronic health records, in order that they can be more easily accessed by health professionals. Hopefully this would also make it easier for individuals and GPs to complete advance care plans, and lead to an increase in the number of plans completed.

5. The availability and funding of research, information and data about palliative care needs in Australia.

In order to improve support for carers of people with a life limiting illness there needs to be further research into effective ways of supporting carers. There is also a need for greater research into the needs of different groups, especially carers from CALD backgrounds, and Aboriginal carers. There is also a lack of information about the needs of carers of persons with a life limiting illness who identify as gay, lesbian, bisexual, transgender and intersex (GLBTI).

Recommendation 12: Carers NSW recommends further research into the needs of carers and the most effective ways of supporting carers, including the needs of diverse carers.

Conclusion

Carers NSW appreciates the opportunity to provide a submission to the Inquiry into Palliative Care. If you require any further information about Carers NSW submission please contact Louise Bradley on (02) 9280 4744

Yours sincerely

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Endnotes

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