



National Disability Services

NDS Submission

Palliative Care in Australia





National Disability Services

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About National Disability Services

National Disability Services is the peak industry body for non-government disability services. Its purpose is to promote and advance services for people with disability. Its Australia-wide membership includes around 700 non-government organisations, which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.

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Introduction

In 2008–09, 19,048 (6.8 per cent) of the 279,374 users of NDA-funded services were aged 65 years or over.¹ Apart from people with sensory disabilities, this current cohort of people with disability who are ageing is the first to have survived into ‘old age’ in significant numbers since data have been collected. Greater longevity of people with severe disability will see this figure grow markedly over coming decades.

Generally, the prevalence of disability increases with age. The average male (in 2003) can expect to experience 18.6 years of life with a disability (5.4 of which are expected years of life with a severe or profound disability). Females can expect 20.7 years of life with a disability (8.3 years with a severe or profound disability).² Indeed, in 2010 an estimated 705,200 people aged 65 and over live with severe or profound core activity limitation and this figure will more than double over the next two decades.³ Of these, some will have lived with severe disability since their early years; others will have acquired disability as a result of ageing.

The correlation between ageing and disability highlights the need for the interfaces between disability services and health, allied health and aged care services to be workable for older Australians with disability. Supporting people ageing with a disability requires cooperative action across governments and across departments because administrative responsibility for health, aged care and disability services is split.

NDS members, particularly those providing accommodation support to people with disability—in their own home, in group homes or in institutions—increasingly report they are supporting people who are living with a life-threatening condition and/or at the end of their life. A significant proportion of these people have cognitive impairment or communication difficulties.

NDS welcomes the opportunity to provide input to this important Inquiry.

¹ Australian Institute of Health and Welfare 2011, *Disability Support Services 2008-09*, Canberra: AIHW, Table 3.1, p. 13.

² AIHW 2006, *Life expectancy and disability in Australia 1988-2003*.

³ AIHW 2008, *Australia's Welfare 2009*, Table A4.2.

Factors influencing access to appropriate palliative care

In 2008, research undertaken by Verso Consulting (for NDS Victoria)⁴ identified a range of barriers that operate to reduce the likelihood that people with disability will be well supported as they age. These were grouped into categories:

- policy (e.g. some services not being available to group home residents);
- program (the impact of program guidelines and management);
- practice (e.g. limits being applied at the level of service delivery);
- personnel (e.g. staff skills and levels of staffing);
- personal (e.g. the availability of informal supports or income level); and
- place (e.g. variable access to services for people living in different accommodation types).

Commonly, these barriers arise when people with disability try to access aged care or health services—such as obtaining an Aged Care Assessment or government-funded allied health services—but they also arise when people with disability need palliative care. In recent years, Victoria has undertaken significant work to improve access to palliative care for people with disability⁵. During the course of the project, it became clear that barriers were arising at each of these levels:

- one type of organisation funded to provide palliative care interpreted policy in such a way that people living in group homes were ineligible;
- some individual palliative care services assumed that as people with disability were receiving funding from a different government department all their needs would be met by that department;
- disability organisations were sometimes poorly informed about available palliative care options;
- many palliative care staff did not feel equipped to work with some people with disability, particularly those with cognitive impairment or communication difficulties;
- many disability support workers were not confident in supporting people with disability at the end of their life;
- many people with disability, particularly those living away from family, did not have family and friends actively advocating for their needs.

Concerted and diverse actions are required to improve access to palliative care for people with disability. Flexibility in approach is essential, as the following example from Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council (Aboriginal Corporation) demonstrates.

⁴ NDS Victoria 2009, *Interface barriers: Impediments to 'ageing in place' for Victorians with a disability Stage 1 report*.

⁵ See

[http://docs.health.vic.gov.au/docs/doc/4758F8FEB4320819CA25796C00084A6D/\\$FILE/disability_palliative_care_guide.pdf](http://docs.health.vic.gov.au/docs/doc/4758F8FEB4320819CA25796C00084A6D/$FILE/disability_palliative_care_guide.pdf)

NPY Women's Council

NPY Women's Council provides a range of human services and advocacy to indigenous people living in the remote, cross border region of the Northern Territory, Western Australia and South Australia. Its services include a Domestic and Family Violence Service, Youth Service, Child Nutrition Team and Tjungu (together) Team. This Team provides services for people who are frail aged and people with disabilities and their families and carers and includes Case Management and Advocacy and Carer Respite programs.

NPY's Carer Respite Programs are funded by the Commonwealth Department of Health and Ageing. Within the scope of these Programs NPY provides support for people from the NPY Lands who require palliative care. NPY Women's Council Directors and Members are very supportive of the importance of people being able to access resources to ensure that they are able to return to country if possible and see family before they die.

Palliative Care for Indigenous Australians from the cross-border region involves a complex range of issues including but not limited to:

- Respectful and culturally appropriate service delivery
- Extremely remote locations
- Travel
- Importance of connection to country and family
- Positive working relationships with Alice Springs Hospital
- Positive working relationships with remote community Health Services and Clinics
- Listening to the needs and wants of the palliative client and their family
- Access to Traditional Healers

NPY Women's Council is uniquely placed to deal with requests for support in flexible, timely and responsive manner. In order to provide a culturally appropriate service it is critical that we are able to access advice and support from our Directors and Members who are all indigenous people from the cross border region.

The other critical factor is being able to listen to what palliative clients want to do and to respond flexibly to those requests. It has been our experience that there is no single formula for responding to these needs other than flexibility. Women's Council is able to provide for a range of needs for the palliative client in a very practical way. Generally we can assist with transport, we can provide practical items such as swags, blankets and food and we can liaise with community clinics to ensure that adequate medical support is available while the client is at home with family.

Case study: Taking BL home to country to pass away

NPY received a referral from NT Palliative Care team and Purple House Renal Dialysis Unit requesting assistance to return BL to her remote community to pass away. After being on dialysis for 15 years doctors had decided she could receive no more treatment. She had only a short time to live.

BL had lived in a hostel in Alice Springs during this time and had had little contact with family and had only been out on the lands once for a visit. To return her home, there were many things to put in place:

- **Locate family:** Because BL had been in Alice Springs for so long she had lost touch with most of her family. NPY located her daughter and one sister in a remote WA community and two other sisters in nearby communities. These family members were willing to take on the responsibility of caring for her and were very happy to have her come home. Her sister agreed to take time from her work at the school to care for BL.
- **Liase with remote clinic staff:** Because of shortage of staff, the remote clinic was dubious about having BL back in community to 'finish up'. Assurance was given that NPY would support the clinic and keep in daily contact. NPY communicated with the Renal Doctors from hospital to ensure all medications and notes would be available. The Royal Flying Doctor Service would be used to fly BL to community. After much negotiation the clinic staff agreed to accept the patient.
- **Discharge Planning:** Royal Flying Doctor Service was notified. Confirmed with family that they would be at airstrip to meet plane. Confirmed with clinic staff that they would meet plane. Liaised with doctors and renal nurses to organise final dialysis treatment before she flew out. Confirmed with staff that all medications were ready to go with her.
- **Family Support:**
 - Organised for new bedding and mattress to be sent out for BL.
 - Spoke with remote Centrelink team and set up carer payment immediately for main carer.
 - Gave purchase orders for fuel to family members from other communities so they could drive over to visit BL.
 - Contacted prison in Perth so BL's son could have phone link up with his mother.
 - Gave purchase order for community store so family could buy extra food.
- **Final Days:** When BL flew into community there many family members present to meet the plane. BL was happy and aware of her surroundings. Family went out hunting to find goanna and cooked for her; grandchildren came and slept with her; and she and her sister told stories each night around the fire. NPY telephoned the clinic daily to offer support and NT Palliative Care nurse was also in constant contact.

BL spent 8 days in her community and died peacefully surrounded by family.

The effectiveness of palliative care arrangements

Across Australia, the access that people with disability have to palliative care varies markedly, as does the effectiveness of that access. In 2008, British researchers surveyed palliative care professionals to identify the main challenges in providing palliative care to people with an intellectual disability⁶. The challenges raised were strongly correlated with communication issues:

- person not able to fully understand their illness;
- communication;
- difficulties in assessing pain;
- difficulties in assessing other symptoms; and
- the length of time it took to gain the person's trust.

These same professionals identified the following initiatives as needed to improve the care they were able to provide:

- training on intellectual disability;
- a disability link person in the palliative care service;
- access to background information on the person with disability;
- resources to help provide support; and
- contact details of local disability services.

There is clearly a need to strengthen partnerships between disability organisations and palliative care services if the best care and support is going to be provided for a person with disability who is nearing the end of life. In materials developed for the Victorian project⁷, it is suggested that stronger partnerships be fostered by: having regular contact; being available; providing a key contact person; and organising reciprocal learning opportunities. They also point to the need for disability organisations to assist palliative care providers by giving them knowledge of the person with disability, including:

- how the person communicates and makes health decisions;
- background information;
- what can be provided within the 'accommodation support'; and
- other available local disability services.

The importance of this cannot be overestimated. For instance, pain management is a critical part of palliative care. In some circumstances palliative care staff will need to work with pain scales for people who are non-verbal; good working relationships with disability staff will be essential to assist the interpretation of non-verbal responses.

To provide good palliative care, disability organisations need to be committed to providing end-of-life care, have access to additional aids and equipment as required

⁶ Tuffrey-Winjne, I et al (2008): Palliative care provision for people with intellectual disabilities: a questionnaire survey of specialist palliative care professionals. *Palliative Medicine*, 22: 281-290

⁷ [http://docs.health.vic.gov.au/docs/doc/4758F8FEB4320819CA25796C00084A6D/\\$FILE/disability_palliative_care_guide.pdf](http://docs.health.vic.gov.au/docs/doc/4758F8FEB4320819CA25796C00084A6D/$FILE/disability_palliative_care_guide.pdf)

(and staff able to operate any necessary medical equipment), be able to control pain and manage other symptoms, offer good information and support for staff as well as family and friends, have an area that can be organised to meet the needs of the person dying and their family and friends, and have in place a good care plan. The limited funding currently available for accommodation support makes this difficult to put in place. Additional funding must be readily available to support people with disability who wish to die at home.

NDS is aware that supporting a person with disability to die at home, when that home is shared by other people with disability (often including people with cognitive impairment) can result in significant grief and loss being experienced by all residents (and by staff). Good palliative care practice includes providing psychosocial support to the individual and to significant others. To assist this work, more materials should be made available in Easy English or picture-based formats to improve the advice and support available to those who have cognitive impairment. A 2007 Scope publication, *Supporting people with disabilities coping with grief and loss – An easy to read booklet*⁸, goes some way to meeting this need but more comprehensive materials to suit a range of circumstances are needed.

Some people with disability, particularly those with cognitive impairment and/or communication difficulties, experience trauma when hospitalised (often a more frequent occurrence near end-of-life). Good coordination between the disability sector, hospital and medical staff and palliative care services is essential to improve treatment and minimise distress. This is often best managed by regular support workers continuing to be available to assist the person with disability. Unfortunately, funding is not generally provided to allow this to occur. Thorough discharge planning and arrangements (including information provision) also need to be undertaken.

The Australian Centre for Grief and Bereavement has been funded by the Victorian Government to provide a secondary consultation service for professionals working with people who may have suffered a loss (useful for staff such as supervisors of group homes) who need to provide information for other residents, staff and family members who need assistance with managing grief and loss. It can also provide counselling to fellow residents of the group home. This is a practical approach which could be mirrored in other jurisdictions.

⁸ <http://www.scopevic.org.au/index.php/site/resources/supportingpeople>

The adequacy of workforce education and training arrangements

A strong finding of the Victorian palliative care project was the need to improve the education and training of disability support workers in palliative care and on grief and bereavement. This training is aimed at making workers more aware of what palliative care service offer, how to work more effectively with these services, and how to support the person who is nearing the end of their life as well as family members, friends, co-residents and staff.

There is also a need to improve the knowledge and skills of palliative care staff, particularly in how to work with people who have cognitive impairment or communication difficulties.

Advance care planning

Advance care planning should not be ignored with people with disability; many will be capable of making choices (though some will need support) and expressing preferences about the end of their life. Where appropriate, the person's family and friends should be included in these discussions.

NDS encourages future extension of the personally controlled electronic health record to enable it to record information that will assist health care staff to work with a person with disability (such as how to communicate) and provide information on advance care planning (such as health care preferences, name of the substitute decision maker, and refusal of treatment decisions).

Recommendations

Build on outcomes of the Victorian Disability Residential Services Palliative Care project by implementing similar projects in other jurisdictions.

Make available additional funding to support people with disability who wish to die at home—such as funding for additional staff, medical support, training, specialised aids and equipment.

Develop a range of specialised resources on palliative care, grief and loss to use with people with cognitive impairment or communication difficulties.

Provide training for palliative care staff in disability.

Provide training opportunities for disability workers in palliative care, grief and loss.

Fund programs to provide consultation services to people with disability who need assistance with managing grief and loss. These services should also be funded to provide secondary consultation services for disability staff seeking information, advice and referral options.



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