



The University of Sydney

**CDDS**

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**Developmental**  
**Disability**  
**Studies**



**Department  
of Ageing,  
Disability &  
Home Care**

**PALLIATIVE CARE IN PEOPLE WITH CONGENITAL OR ACQUIRED  
INTELLECTUAL DISABILITY AND HIGH NURSING SUPPORT  
NEEDS  
A literature review**

**REPORT TO THE DEPARTMENT OF AGEING, DISABILITY AND  
HOME CARE**

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The report represents a review of the literature and is not intended as a statement of policy.

## **Introduction**

The need for quality palliative care services is well accepted in the general population. It is becoming increasingly evident that the same need exists in people with intellectual disability, especially in those who also have high support requirements. Any response to these needs has to take into consideration the general principles of palliative care provision including an ethical decision making framework, and the specific needs and circumstances of people with intellectual disability.

This literature review seeks to outline the definition of palliative care, when and how decisions about palliative care are made, how these findings apply to people with intellectual disability, and the implications for government and service providers. There is a paucity of evidence based literature in the area of palliative care for people with intellectual disability. Therefore, principles drawn from the general palliative care literature and recommendations based on expert opinion are presented.

## **The population**

In NSW in 2003, between 250-300 people with intellectual disability (congenital or acquired, mainly secondary to Traumatic Brain Injury) and high nursing support needs were cared for in Department of Ageing, Disability and Home Care (DADHC) funded residential settings. Another 15 children in this situation were cared for at home and approximately 30 people under the age of 30 years were in nursing homes (DADHC).

## **What is palliative care?**

The World Health Organisation states that the role of palliative care is to improve “the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement.” Implicit in this definition is the understanding that palliative care is not merely the cessation of curative treatment. It is an active process, where problems are anticipated and addressed, and the impact of the illness is minimised. (Therapeutic Guidelines, 2001)

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;

- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. (WHO)

By its very nature, palliative care delivery is a multidisciplinary practice, involving among others, general practitioners, medical specialists, including pain management specialists, therapists, nurses, psychologists, social workers, ministers and others providing pastoral care, and family and friends.

### **When does palliative care begin?**

The NSW Palliative Care Framework (2001) states "Palliative care is generally provided to people of all ages whose condition has progressed beyond the stage where curative treatment is effective and cure is attainable, or to those who choose not to pursue curative treatment". However, this transition point is not always easy to identify. Literature makes reference to "cross-roads" where treatment is re-evaluated (Lin, 2003) and this may be the most common time for treatment to adopt a more palliative focus. This point, however, appears to have no clear definition and is based on "gut feeling" or may be precipitated by some other event within the individual's family. Frequently, prognostic information is lacking, with prognosis based on "best guess" from clinical experience (Lin, 2003). Thus, every case becomes slightly different and clear-cut definitions are almost impossible.

### **Decision Making in Palliative Care**

Decision making occurs at several levels – a key decision is about when palliative care is to commence. In the general population, this decision is usually based on factors such as: the individual's desire to continue with curative treatment; cultural views on illness, dying and social roles; family and work commitments; age and presence of other illness. (Therapeutic Guidelines, 2001). The individual, family members and other involved individuals may have differing views about the planned course.

Other areas of decision making include the setting of practical and functional goals by the patient, treatment options, deciding where care will be received, and the setting of Advance Care Directives. Advance Care Directives are completed by patients to address the situations where they can no longer make decisions about their health care (e.g. if they are unconscious or confused). A patient may also appoint a proxy to make such decisions on their behalf. Advance Care Directives are discussed in greater detail below.

A retrospective case review of doctors' end of life decisions (van Thiel et al, 1997) suggests that palliative care decisions occur later in the course of an illness in people with intellectual disability. The authors infer that this may be because the "handicaps are not usually progressive lethal diseases [and] also that doctors may be more reserved in deciding to hasten death in such patients".

Little high quality evidence exists about factors which affect end of life decisions. A study by van Thiel found that the most important reasons cited by doctors for making 'non-treatment' decisions in people with intellectual disability were - no chance of improvement (21%), pain and suffering (16%), needlessly prolonging life (18%) and futility of medical treatment (16%). Nine percent believed it to be the wish of the patient, and 5% cited the wishes of relatives or patient representatives. Doctors' intentions appeared to take into account the probability that death would be hastened (75%).

A person with intellectual disability and high medical support needs may be incapable of making such decisions and an ethically sound means of substitute decision making must be established. Nelson (2003) makes a clear statement that any palliative care decisions should be made in the best interest of the patient, rather than in the interests of the hospital, the physicians, the legal system or someone else.

### **Key principles of palliative care**

The NSW Health Palliative Care Framework (2001) outlines the key principles of palliative care service delivery. These can be summarised as follows:

- The patient and his or her carers are the focus of care
- There should be timely access to a range of disciplines and services
- Services should be delivered in a culturally appropriate context
- Services should be in a setting that is appropriate to the needs of the patient and family
- Services should include a focus on bereavement support / follow up for the patient, family, friends, informal and formal carers
- Education for the patient, family and carers, as well as clinicians is an important element
- Monitoring of patient characteristics and outcomes is important in improving the quality of care

### **Implications for people with intellectual disability and their carers**

#### **Initiation of palliative care**

As discussed above, the decision about when to initiate palliative care in people with intellectual disability and high nursing support needs is complex. The need for palliative care may not be easily recognised in an individual who has had significant life long medical problems. Thus the provision of such care may be unnecessarily delayed or never initiated. The result is that the individual may suffer needless pain and/ or distress at the end of life. An understanding of the term "terminally ill – a person who has less than one year to live" (Ng & Li, 2003) may assist practitioners in decision making regarding end-of-life care.

#### **Place where palliative care is to be given**

Decisions need to be made regarding where people will receive end of life care. In the general community, it is accepted that "ideally, palliative care services should be provided wherever patients reside." (Therapeutic Guidelines, 2001, p.13). The

increasing trend for community living means that people with disabilities have the right to die in their home. This may be in the family home or in the group home in which they have been accommodated. Issues then arise, not only about the care of the dying person but also about the care needs of those who live in the same group home. Often staff members have been associated with the residents for long periods of time and their needs also must be addressed. Co-residents with intellectual disability may also experience the same grief and loss, but may find it difficult to express their distress (Botsford, 2000).

### **Quality of care**

Review of the literature (Tuffrey-Wijne, 2003) highlights some concerns about the quality of palliative care offered to individuals with intellectual disability. Diagnostic overshadowing (the phenomenon of attributing symptoms to the disability, rather than looking for an underlying physical or mental health problem), may affect decisions made regarding palliative care. People who have intellectual disabilities may not be able to communicate suffering or pain and its potential cause may be overlooked. Similarly some people with intellectual disability may have pain insensitivity or indifference that complicates diagnosing an acute episode or deterioration in an existing condition.

### **Care Plan and Advanced Care Directives**

In caring for people who have ongoing high care needs, the development of a comprehensive care plan, addressing all areas of assessed care needs, may avert many difficulties at times of crisis. Care Plans should be initiated early in care process, be person-centered, involve the client, family and every health care professional involved in the care of the client. Regular review of the plan, as circumstances change, is essential. The use of Advance Care Directives included in a Care Plan may be helpful in implementing a person's preferences for care at the time of end-of-life decision making.

As mentioned previously, Advance Care Directives (Friedman, 1998) are written instructions from a person that either articulate in advance the person's medical treatment preferences or appoint another person to make health care choices on his or her behalf in the event of future incapacity. There are two types of Advance Care Directives:

- Instruction directives – these are written documents containing instructions to health care professionals about any type of health related interventions that an individual does or does not want to receive in the event that they are unable to make a choice for themselves. The most common type is a living will.
- Proxy directives – these are written documents that nominate and empower another individual to act in relation to health care decisions when the person is unable to make the choice for themselves. This is in essence surrogate decision-making. The person may give the surrogate decision-maker written instructions or may rely entirely on the judgement of the surrogate to make the decisions. This form of Advance Care Directive may be more suitable for a person who has an intellectual disability because it only requires the person to be able to nominate a person they trust to make their decisions for them. In contrast, Instruction

directives require a higher level of cognitive functioning, that of thinking and planning in advance.

Ethical principles involved with Advance Care Directives are:

- Beneficence – healers must do everything possible to promote health and well being of their patients.
- Nonmaleficence – the avoidance of intentional harm and injury.

These two may conflict with the concept of autonomy. Autonomy is defined as “a form of personal liberty of action in which the individual determines his / her own course of action in accordance with a plan chosen by himself / herself.” (Friedman 1998).

When applying these principles to people with intellectually disability, this conflict becomes more obvious. Historically, personal choice for people with intellectual disability has been limited by a society that assumes that others know best. There has been some shift from that position, but end-of-life care offers particular difficulties. Competence is a legal concept and must be determined legally. Often however, physicians refer these decisions to family members who are those most intimately involved in the care of the person with a disability. Some ethicists believe that family members have the right to be involved in decision making because of their substantial, financial, emotional and physical investment in caring for the individual (Friedman, 1998). Cultural factors and family belief systems also impinge on decision making.

Friedman (1998) quoting Kapp (1991) suggests that individuals must be assessed for competence in a particular decision-making context, rather than in a global context. “Many individuals, although not capable of making entirely autonomous, authentic decisions completely on their own, are nonetheless able to muster enough powers of comprehension and rational thinking when given the proper degree of assistance, encouragement and support by others.” When assessing capacity, affective states must also be considered. Depression for example, can impact on the person's ability to make appropriate decisions.

Some constraints apply to the use of Advance Care Directives. Involving close family may result in pressure on the person to follow a certain course of action, or family members may disagree about the proposed course of action. Decisions within the family or by health care providers, to accept or reject or limit expensive treatment may be made on economic grounds.

Surrogate decision making has two standards:

- Substituted judgement standard – surrogate uses inferred or direct knowledge when making decisions
- Best Interest standard – used when the surrogate is unable to make a substituted judgement. This may be because the surrogate is unaware of the person's preferences or because those preferences are unclear, or the person was never able to make that decision. The risk in this circumstance is that the values of the surrogate may be imposed on the disabled person and autonomy is violated.



Advance Care Directives should be made jointly by the person involved and their guardian, in conjunction with the person's treating physician. Ideally, the formulation of an Advance Care Directive would be co-ordinated by the Palliative Care Team. In order to facilitate this process, information and training must be provided in the use of Advance Care Directives. Family members and clients should be informed of their rights and responsibilities in the area of advance care planning. Information on making surrogate decisions should be provided to family members and staff, addressing the balance between autonomy and beneficence. Information on legal, ethical, psychological, religious and cultural perspectives should be included. Legal requirements between states may vary. Training in capacity should be made available to suitable health care workers. Such information and training should be sought from the appropriate medical and /or palliative care staff.

Safeguards should be in place to facilitate the development and use of Advance Care Directives and Care Plans. Reference should be made to ethics committees in hospitals, universities and the Guardianship Tribunal. These agencies may also assist where there are conflicts of interest between clients, family members and staff of health care facilities.

### **Staff education and training**

Palliative care requires a set of skills not normally held by people who work with people with intellectual disabilities. A study to assess the skills and needs of carers of people with intellectual disability was undertaken by Ng and Li (2003), using a formal questionnaire designed and developed from a framework of palliative care. This was a pilot study with small number of responses (25/40) from "qualified care practitioners" (the majority having some type of nursing qualification). Responses from "unqualified care practitioners" were too low to be included in the analysis. The respondents answered questions about their knowledge and skills in the area of palliative care.

The study highlighted a lack of knowledge, particularly in psychosocial aspects (e.g effective communication with the dying person and bereavement support) and skills in the care of the dying person. While this study surveyed support staff with nursing qualifications, it is probable that similar results would be found in support staff generally.

### **Needs of family, support workers and carers**

Support workers in group homes seldom have formal training or experience in caring for a dying person. Reid (1998) notes that support workers commonly express fears about finding the patient dead unexpectedly, fear of not knowing what to say, and fear of breaking the bad news. They also have concerns about supporting other residents within the home, and anxiety related to management of pain and other associated symptoms.

Read (1998) suggests that support workers have support needs which include:

- Practical help and guidance on issues such as medication
- Psychological support to effectively manage their feelings of fear and anxiety
- Advice and support regarding breaking bad news
- Educational opportunities

Family members also require advice and support, even if the person with the disability is not living with them. Friends and co-residents who also have an intellectual disability may have difficulty in understanding fully what is happening, but have similar needs for explanation and support. (Read, 1998).

### **Recommendations for improving end of life care for clients of residential services:**

1. Where possible, keep the person in his or her own home.
2. Involve the Palliative Care Service as soon as possible after the diagnosis of a terminal condition is made. A Palliative Care Service can provide information, practical advice and support in the home, and where required, suitable in-patient care.
3. Where the person's health needs are no longer able to be met within the home, discuss suitable alternatives (e.g. hospital, palliative care facility) in consultation with the individual, family/guardian, treating physician and the Palliative Care Team.
4. Ensure that decisions about commencing palliative care, treatment options and Advance Care Directives are made in an ethical decision-making, collaborative framework. Ensure that all stakeholders are involved in the decision making process. These decisions should be made in advance, not at a time of crisis.
5. Provide support staff training to encompass:
  - Concepts of palliative care, assessment and care of the dying person.
  - Social, cultural, family and religious issues
  - Knowledge of community resources.
  - Skills in communication with the dying person and their family members
  - Legal issues including Advance Care Directives, substitute decision making. While these issues are the responsibility of the person's guardian, treating physician and the Palliative Care Team, support staff need to be aware of the relevant issues.
6. Ensure that family members and staff have access to support and counselling to help them during the bereavement process
7. Ensure support for co-residents and co-workers of the dying person. Help people cope by:
  - Actively seeking out non-verbal rituals
  - Respect both the avoidance and choice of photos and mementos
  - Minimise major changes for at least one year
  - Postpone assessment of skills and behaviour
  - Assist appropriate searching behaviour to support emotional recovery
  - Support formal observances of anniversaries
  - Seek consultation with specialists in bereavement if behavioural changes occur (aggression, regression, mutilation, self-injury, wandering or tearfulness)

(Botsford, 2000.)

8. Areas for future development

- Use of qualitative methodologies in research to explore the needs of support workers, people with intellectual disability
- Develop a conceptualisation that will enhance understanding of death and dying
- Ensure equal access to appropriate health care services based on accurate assessment of care needs
- Establish ethic committees or end-of-life committees to support decision making in regard to Advance Care Directives and end of life care
- Encourage the development and use of Care Plans to ensure that the care provided is planned, assessed and evaluated, and reflects the client's current needs and preferences.

## References

Botsford, Anne L. (2000). Integrating End of Life Care into Services for People with an Intellectual Disability. *Social Work in Health Care*. 31:35-48

Friedman, R.I. (1998). Use of Advance Directives: Facilitating Health Care Decisions by Adults with Mental Retardation and their Families. *Mental Retardation*. 36(6):444 - 456

Nelson LJ. (2003) Respect for the developmentally disabled and forgoing life-sustaining treatment. *Mental Retardation & Developmental Disabilities Research Reviews*. 9(1):3-9

Ng, J. and Li, S. (2003). A survey exploring the educational needs of care practitioners in learning disability settings in relation to death, dying and people with learning disabilities. *European Journal of Cancer Care*. 12:12-19

Lin RJ (2003) Withdrawing life-sustaining medical treatment--a physician's personal reflection. *Mental Retardation & Development Disabilities Research Reviews* 9(1):10-5

NSW Health (2001) NSW Palliative Care Framework

Read, S. (1998). The palliative care needs of people with learning disabilities. *British Journal of Community Nursing*. 3(7): 356 – 361

Therapeutic Guidelines. Palliative Care (Version 1).Therapeutic Guidelines Ltd., Melbourne:2001

Tuffrey-Wijne, I. (2003). The palliative care needs of people with intellectual disabilities: a literature review. *Palliative medicine*. Vol 17: pp 55 - 62

Van Theil, GJMW, van Delden JJM, de Haan, K, Huibers, AK (1997) Retrospective study of doctors 'end of life decisions in caring for mentally handicapped people in institutions in the Netherlands. *BMJ* 315:88-91

World Health Organisation. Palliative Care. (Web site)  
<http://www.who.int/cancer/palliative/en/>. Accessed 10<sup>th</sup> May, 2004

## Resources

Palliative Care Australia - [http://www.pallcare.org.au/pca\\_aboutpalliativecare.html](http://www.pallcare.org.au/pca_aboutpalliativecare.html)