

Acknowledgements

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Introduction

This paper was commissioned by Alzheimer's Australia to promote discussion by people with dementia, their families and carers of the issues that may be faced as people with terminal dementia move towards death. A palliative care approach will also be appropriate when a person with dementia has another terminal condition.

This paper

- Sets out why palliative care can be important as death approaches;
- Describes how a person with dementia can be assisted to die in comfort and with dignity;
- Emphasises that flexibility is needed to respond to the unique needs of the individual; and
- Emphasises the importance of involving the family and carers and attending to their separate needs throughout this critical time.

Palliative Care and Dementia Care

According to the World Health Organisation (WHO):

Palliative care is the active total care of patients whose disease is not responsive to curative treatment ...The goal of palliative care is the achievement of the best possible quality of life for patients and their families.

Hence high quality palliative care is person centred and based on forming a partnership among the service providers, the person with dementia and the family and carers.

Treatment focuses on palliating or relieving the symptoms experienced by a person with dementia towards the end of their life rather than on curing the condition(s) that is causing their death. For the family and carers, palliative care concentrates on providing emotional and practical support before and through the death of the person with dementia and the ensuing period of grieving. Palliative care should not be confused with euthanasia, a term which is associated with interventions aimed at hastening the death process.

Palliative care has traditionally been directed to meeting the needs of people with terminal cancer. It is now increasingly recognised as the best approach to caring for people with a range of terminal illnesses, including dementia.

Even though research has revealed some recurrent patterns in the phases of dementia and the time between diagnosis and death, the symptoms of terminal dementia do not occur in a uniform or predictable manner and variations between individuals will be quite marked. As a consequence, the emphasis of palliative care is on flexibility in order to meet individual needs, using person-centred planning. Indeed, being willing to respond flexibly to the unique needs of each individual is the cornerstone of high quality care *throughout* the dementia journey.

What is Terminal Dementia?

Some general groups of symptoms and behaviours have been identified that can signify the terminal phase for a person with dementia (Shuster 2000) (Abbey 2003):

- There is often a progressive worsening of memory resulting in increased confusion and disorientation;
- Speech and the ability to communicate often deteriorate to the point where the person may eventually become incoherent or completely mute;
- Behavioural changes may occur which can lead to a person being belligerent, sobbing or screaming, or strikingly passive and quiet, immobile and detached;
- The person's ability or desire to move independently can decline, leaving them bed/chair bound;
- The person's capacity for self-care progressively diminishes, making them totally dependent on carers;
- The person's ability to eat independently gradually disappears, often in association with a diminished ability to swallow and increased risk of aspiration. A progressive loss of appetite almost always follows; and
- Other complications can include bowel and bladder incontinence, muscle atrophy and contractures, increased susceptibility to delirium, recurrent infections, pneumonia, pain, peripheral shutdown, bed sores and general skin breakdown. Delirium can result in increased restlessness and agitation.

The appearance and prominence of these symptoms will vary between individuals because of differing disease processes, individual differences and co-existing conditions such as cardiac failure, diabetes or cancer.

Planning Palliative Care

High quality palliative care in terminal dementia is facilitated when both the person with dementia and their family have together explored issues related to treatment and management. Often the need for an enduring power of attorney for financial matters will be discussed and acted on. It is also important to clarify the person's wishes regarding their future health care, as this can provide much-needed guidance when they are no longer capable of expressing an opinion.

Each State and Territory jurisdiction has a different approach to these issues. This includes different forms of documentation for this purpose, called, for example, an Enduring Power of Attorney, Medical Power of Attorney, Advance Directive, Enduring Guardianship or Living Will. An Advance Directive (AD) is a statement by a competent person expressing their wishes in relation to their future health care, if they are not able to do so themselves at that time. Advance Directives have arisen in the context of an increasing need to respect and promote patient wishes and autonomy.

Further information about advance care planning is contained in Alzheimer's Australia's (AA) position paper on *Legal Planning and Dementia*, available on the AA website at www.alzheimers.org.au/legal.

If an adult has the capacity to make the decision him or herself, the law is clear. A competent adult may refuse treatment even if that results in his or her death. Indeed, if that adult continues to be treated against clearly stated wishes, medical staff will be committing an assault and could be liable to civil or criminal prosecution. Application of the law is far more complex when the person has impaired cognitive ability and it is often in an acute hospital setting where issues surrounding people's wishes emerge. Difficult debates can occur when decisions such as the need for major surgery, painful invasive procedures, or the possibility of artificial nutrition and hydration are discussed.

Of particular concern for service providers and family and carers is the dilemma that occurs when an AD rules out treatment which everyone believes is in the best interests of the person with dementia, or, when there is a difference of opinion about what would be in a person's 'best interest'. In spite of many efforts to improve the wording and format of ADs they are often still problematic in guiding clinical decision making. However, they remain the only way a person with dementia can leave information about their own wishes to be followed.

For some families sanctity of life may matter above all, and above what others may see as quality of life. These beliefs may mean that what service providers from one cultural background see as being evidence-based care and promoting the person's best interest may not appear in the same light to families and carers from a different background.

Satisfactory outcomes for all parties will usually be more likely if such key issues can be tackled sooner rather than later once the diagnosis of dementia is confirmed.

It is important that families have the opportunity to ensure that any documented wishes of the person with dementia, or any that can be established as having been conveyed informally, are made known to all family members, carers and service providers. Where no wishes have been recorded or made known it may fall to the families and carers to decide which care options should be adopted. Best practice guidelines for palliative care suggest that a case conference should be held, involving families and carers, the person with dementia if appropriate, and all service providers, to communicate and ensure that all wishes are met or satisfactory arrangements negotiated. Case conferences should work out clear long and short-term goals to inform service providers, family and carers about the processes which will provide comfort, the actions to be taken if emergencies arise and the purpose, type and limitations of any ongoing treatment. This process supports families and carers, assists in clarification of any issues and provides ongoing emotional support.

Care Environment

The damage in a person's brain from dementia can cause changes towards the end of life which lead to disorientation and confusion. It is increasingly recognised that a person with dementia is better cared for within a familiar environment (Hurley & Volicer 1999).

Consequently, it is better for the person to remain where they are receiving care, rather than being transferred to an acute care (eg hospital) setting, whenever that is possible.

A person with terminal dementia often will not understand the reason for their admission to an acute care system. The acute care environment is not only unfamiliar, but usually very noisy and extremely busy. These environmental factors, coupled with invasive procedures such as blood tests and x-rays, can trigger painful feelings and associated behaviours. These can include fear, anxiety, resistance, calling out, and agitation. Additionally, treatments such as intravenous therapy (drip) and catheterisation can cause discomfort and distress.

In an acute setting, the combination of behavioural changes in the person with dementia, environmental constraints and staffing issues, may result in the person being chemically and/or physically restrained. The enforced immobility reduces quality of life and can lead to further complications, such as an increased risk of infection, pressure areas, contractures and injury.

The person's quality of life may be compromised as a consequence of the characteristics of the environment in which care is provided. Therefore, the choice of care setting is important to achieve the goal of best practice dementia and palliative care that maintains the person's quality of life.

Negotiating Care with Service Providers

Making choices about care and treatment options and symptom management can be very difficult for family members and carers. There is a need for families, carers and service providers to have access to support and information on possible ways of dealing with issues that arise during this difficult time.

Alzheimer's Australia provides education services and help sheets that can assist families and carers. Additionally, the Australian Government's publication *Guidelines for a Palliative Approach in Residential Aged Care* (2004) is available from the National Palliative Care Program by calling 1800 020 787 (Freecall) or can be downloaded from <http://www.health.gov.au/palliativecare>

Care and treatment options and their ramifications should always be discussed by all those concerned, including the person with dementia, if at all possible, and at the earliest appropriate time.

Symptom Management

Approaches to symptom management will depend on the stage of the illness and any co-morbidities. The symptoms described below are not the only ones that will occur for people with terminal dementia, but are the ones that often require difficult decisions to be made.

Pain

There is strong evidence of under-recognition of pain in people with dementia. An accurate diagnosis of pain is notoriously difficult for a population where individuals cannot tell you when, where, why or how much they are hurting. A change in the person's behaviour, which may indicate pain, is often noticed by family and friends. The intimate knowledge of the person with dementia that families and carers can provide is a valuable resource in assisting service providers in the difficult task of distinguishing between physical pain and other causes for distress.

Some of the main observable indicators of pain are:

- facial expression (eg. grimacing) or body language (e.g. restlessness, agitation, guarding a part of the body, rocking, muscle tenseness);
- change in vital signs such as increase in pulse rate, breathing rate, blood pressure and sweating;
- repetitive noises or inconsolable moaning.

Any change in the person's usual behaviour may possibly denote pain and should be investigated.

Efforts are being made by researchers to address the problem of under-recognition of pain. Pain scales are available that record, in an objective manner, the signs and symptoms that are likely to indicate the existence of, and gauge the intensity of pain that a person with terminal dementia is experiencing. It is important that there is an ongoing and systematic approach to recording, assessing and managing pain. Family and carers should be able to access a record of the pain levels of the person with dementia, together with the record of the effectiveness or otherwise of any therapeutic interventions aimed at relieving pain (Australian Pain Society 2005). Further information is available in the Australian Pain Society resource, *Pain in Residential Aged Care Facilities: Management Strategies*, which is available at <http://www.apsoc.org.au/>

As with all treatment options, pain management strategies must be provided in response to an individual's assessed wishes, likes, preferences and/or needs. High touch pain management strategies are non-invasive comfort measures that, perhaps in conjunction with pain medication, can relieve physical pain and discomfort.

These strategies include: repositioning, verbal reassurance and support, soothing touch, physical exercise/movement, cold or heat therapy, massage, music, hand activity (e.g. stress balls, worry beads, play dough). However, in most cases the use of analgesic medication will be the main method chosen to relieve pain.

The core principle behind good pharmacological intervention is to use analgesics regularly, *not just as required*. The lowest dose possible that provides pain-free comfort should be prescribed and administered. If opiates, such as morphine, are required and the person with dementia has been refusing food and become malnourished they are likely to be particularly sensitive to this group of drugs. They consequently may require lower doses. The side effects of opiates (such as nausea, constipation, hallucinations, delirium and agitation) can be distressing for the person and their family and carers, while, at the same time, these could be the best drugs to provide peace and comfort. Bowel medications may be needed even if the person is eating or drinking very little to ensure that constipation does not lead to further pain (Australian Pain Society 2005).

Nutrition

A reduced desire to eat (anorexia) and difficulties with eating and swallowing are a normal part of the disease process and are often key indicators that the person is moving towards the end of their life. When the difficult questions about eating and drinking arise, the first issue to consider is whether the disease is causing the eating difficulties or if they are a symptom of something else that is treatable and judged to be worth treating, after considering any side effects.

Medications, constipation, dental problems, mouth ulcers, oral thrush, infections and even unfamiliar or disliked foods can trigger refusal of food. It is also thought that some people with terminal dementia may not recognise food as such any more. If no other triggers can be found and food and fluid intake continues to be problematic, weight loss should be monitored and specialists consulted, such as a speech pathologist to assess the swallowing mechanism and a dietician to provide advice on suitable dietary supplements.

When feeding causes choking, nutrition can be supplied by liquids manipulated with thickening agents such as gelatine. A soft or pureed diet, perhaps including protein, vitamin and mineral supplements served as yoghurt, thick shakes, custard and/or Sustagen, can be provided and spoon-feeding or adapted mugs used. Instead of three large meals per day, small frequent meals can be given.

Families and carers find issues about nutrition complex. Some of the most perplexing issues arising in end of life care are starvation and dehydration or feeling that the person with dementia may be hungry or thirsty, and the distinction between 'killing' and 'allowing to die'. They are further complicated by the way in which clinical/technical, emotional and philosophical considerations are intertwined.

These complexities cannot be avoided if the treatment option of artificial nutrition and hydration (ANH) is raised. The evidence on the use of ANH in the care of people with terminal dementia is still accumulating, but at present the body of expert opinion rejects rather than favours the use of ANH for people with terminal dementia in any but special or unusual circumstances or any choice related to cultural beliefs (Finnucane et al 1999). However, families and carers are able to make the decision more comfortably if they have enough information.

(a) Benefits of Artificial Nutrition and Hydration (ANH)

ANH is an aggressive nutritional treatment that has been demonstrated to assist in reducing septic complications post injury or surgery, if a person is unable to manage normal nutritional intake. It has been used to reduce the complications associated with burns injuries and aids wound healing. ANH in dementia care is commonly dispensed through a percutaneous endoscopic gastrostomy tube (PEG).

ANH has been promoted as improving nutrition; maintaining skin integrity by improving protein intake; preventing aspiration pneumonia; minimising suffering; improving functional levels; and extending life. There are inadequate studies however, to conclusively demonstrate these claims in respect of dementia (Milne et al 2005).

(b) Disadvantages of Artificial Nutrition and Hydration (ANH)

A number of studies have shown that tube feeding is ineffective in preventing malnutrition, preventing pressure sores or hastening wound healing, preventing aspiration, improving functional levels or extending quality of life. These studies showed that there were many adverse consequences to PEG feeding for an older person with terminal dementia. These included in the short-term: pain, peritonitis, gastro-intestinal bleeding, cellulitis, perforation, aspiration, gastro-oesophageal reflux and agitation. Long-term consequences were dislodgement of the tube and use of restraint, clogging, diarrhoea, faecal incontinence and aspiration. There is a higher incidence of pneumonia in tube fed patients in comparison to non-tube fed.

There is evidence from a recent small study, to show that there is no survival benefit for people with dementia who receive ANH (Murphy & Lipman 2003).

When considering the ANH option, it is important to remember the fundamental principle of quality palliative care is that the benefit of the intervention must be greater than the burden of the intervention for the person receiving treatment. This approach will help carers to come to decisions which are in the best interest of the person with dementia (Milne et al 2005) (Li 2002) (Byrd 2004) (Eggenberger & Nelmes 2004).

Hydration

Dehydration is the loss of normal body water and should not be confused with thirst. The effects of dehydration in the terminally ill are that pulmonary secretions decrease and there is less coughing. Shortness of breath, congestion, nausea, vomiting and abdominal pain is reduced and there is less urinary output, resulting in fewer linen changes and less disturbance for the person. When dehydration occurs, the person with terminal dementia may suffer from a dry mouth, which can be treated with mouth care and by giving ice chips to suck. Sometimes a person may suffer from an electrolyte imbalance, which can lead to muscle spasms and an altered level of consciousness. This can be treated palliatively with antispasmodics or sedation (Billings 1985). Dehydration can lead to the production of natural analgesics, specifically, the body's breakdown of fat results in ketosis and other chemical changes which provide a feeling of calm and comfort.

However, some families and carers may choose the option of fluids being delivered through artificial means, such as subcutaneous therapy. There is inconclusive evidence of any benefits to be derived from this process (Department of Health and Ageing 2004). Any decision about rehydration must focus on choices that the person would have made or what family and friends consider is in the best interests of that person. This is especially so where there are cultural and religious sensitivities. Again, families and carers need access to the most comprehensive evidence available so that they can make decisions in a case conference situation with all service providers involved.

Antibiotics

Questions may arise about the appropriateness of subsequent courses of antibiotics when a person with terminal dementia has had recurring infections.

There has been little research and debate about the use of antibiotic therapy for people with terminal dementia, partly because of the ethical difficulties in denying antibiotics to a randomly selected group of people with dementia in a research trial situation.

Researchers conclude that it is extremely difficult to arrive at safe and universally applicable answers to the question as to whether to prescribe antibiotics: decisions need to be taken in context and on an individual basis, although some work has shown that 'aggressive medical treatment of infections does not affect the progressive course of dementia and has a limited effect on mortality rates' (Hurley et al 1996).

It is possible that the other methods such as the use of sponging, use of aspirin to bring a person's temperature down, massage, analgesics and low-flow oxygen may be of more comfort during a fever, when antibiotics are unlikely to be effective, or when a person is unable to take medication by mouth.

In relation to all the circumstances described above, the focus should be on the key palliative care questions: *How useful is the treatment for the person with dementia? What choice would best promote the comfort of the person with dementia?*

Provision of Personal Care

The provision of personal care, as well as some medical procedures, may cause distress and discomfort to the person with dementia.

Invasive procedures and restraint

Invasive procedures such as having a drip, catheter, oxygen can be far more frightening and upsetting for a person with dementia than for someone who knows what is happening and why. It is often necessary to restrain an individual with dementia who is undergoing an invasive procedure, as they may want to remove the uncomfortable tubes invading their body.

The Australian Government's resource, *Decision-making tool: Responding to issues of restraint in aged care* has been developed to assist staff and management in residential aged care facilities to make informed decisions in relation to the use or non use of restraint in responding to behaviours of concern. This resource may be helpful and is available at <http://www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-decision-restraint.htm>.

Personal comfort measures

Palliative care concentrates on providing comfort in an active, not passive way, and alternatives to some invasive procedures can be found, rather than no action being taken. All involved in decision making need to be flexible, sensitive and realistic when attending to the physical comfort needs of the dying person.

The following areas are all seen as likely to need careful thought and attention:

Personal hygiene: Will the person's needs for personal hygiene be best met without using a shower or bath? Considerations in a palliative approach are privacy, pain and energy levels, as fatigue is often an issue for the dying person. Using bed baths, bag baths, hot towel baths and/or disposable cleansing wipes may be more appropriate than giving a shower or bath.

Mouth care: This is always important, but especially when the person is refusing fluids, as a dry mouth is often reported. Using swabs moistened with water, continuing cleaning of teeth, providing regular sips of water (if the person is able to tolerate this without choking), ice chips or an 'ice lolly' can relieve this symptom. Also, attention to dry lips will prevent cracked sore lips.

Difficulty in breathing: Dyspnoea is the medical word for the uncomfortable breathing that can characterise a further stage towards death. It can be frightening for everyone watching, and distressing for the person with dementia if air hunger triggers a panicky feeling. It usually helps if the person is positioned in a semi- upright position. Oxygen may be used if prescribed by the doctor and tolerated by the person with dementia. A person with dementia may pull out the nasal prongs delivering oxygen or pull off the mask, which may be distressing for families and carers to watch. However, most people do not need continual oxygen where optimal management with morphine and/or tranquilisers and a respiratory sedative is used (Department of Health and Ageing 2004).

Suctioning the upper airways if secretions are thick may be an option, but again, may be uncomfortable for the person with dementia. Medications that can reduce excess secretions may be used instead.

Skin care: Special vigilance is needed when a person's functional ability deteriorates and the person is bed/chair bound. Providing relief of pain caused by skin breakdown may be more considerate of the person with terminal dementia than many changes of dressings which could be part of any attempt to halt the breakdown process. Best practice would suggest using the person's preferred resting position where possible, particularly in the last days of life when preventing pressure sores, or healing of wounds, is no longer a priority.

Preventing skin breakdown is also considered best practice, and while this is often very difficult for people approaching death, using appropriate pressure relieving devices has been identified as a means to improve prevention of pressure ulcers (Santamaria 2005). The use of these devices may reduce the pain associated with pressure ulcers and also reduce the level of disturbance from frequent repositioning

Bowel Management: This must be maintained up until the point of a person's death. Many medications commonly used at this stage of life are capable of causing diarrhoea or constipation. The side effects and the necessity of continuing these medications need to be discussed with the person's medical practitioner.

Mobilisation: Getting people out of bed helps to prevent pneumonia, reduce contractures and prevent pressure sores. Importantly, it keeps the person positive and involved. However, a person approaching death may be more comfortable in bed rather than sitting in a chair. Time saved by not getting the person out of bed can then be spent on providing comfort care that is based on assessing and respecting the individual's needs and providing interpersonal communication if this is still possible in any sense. Alternative measures, depending on the individual involved, might include gentle massage, aromatherapy or playing special music that the person enjoyed in their earlier life.

Personal support: Even though it is difficult to communicate with a person with dementia who is approaching death, the physical presence of another person has been found to provide comfort (Department of Health and Aged Care 2000). Often a family member or friend will fulfil this role; however, if this is not possible consideration should be given to a volunteer who has appropriate and specific training to be with the person who is dying.

Spiritual Care

Attending to the spiritual needs of the person with dementia and their family and carers is an important component of palliative care. Spirituality has been defined as that quality of curiosity in people that seeks to find meaning by pondering such questions as

- Who do I belong to?
- What's the purpose of my life?
- What can I hope for? (Rumbold 2003)

Spirituality may find expression through the rituals and practices of religion, but for many it has other associations or avenues of expression. Similarly, spirituality may have God or a supreme being as its centre of focus, but need not.

Spiritual care may involve practices where the privacy of the person with dementia and their family and carers needs to be respected. Families and carers should feel free to seek opportunities for such practices to continue as needed. Spiritual counselling and support are essential to comprehensive palliative care and may help to provide rites and rituals that organise and offer symbolic meaning to individuals facing death. It is considered best practice to have a pastoral care worker who has experience and knowledge about spiritual issues as part of the service providers' team. Once again, service providers, families and carers must always remain sensitive to differences between individuals.

While ensuring that opportunities for counselling and support are readily available to those requiring them, it must be remembered that an unwanted visit from a pastoral care worker may, for some people, be seen as a presumptuous intrusion. It should be recognized that there will be no one approach that will suit all cases, given the diversity of personal belief and varying levels of comfort in confronting these great human issues. This explains the need for all planning and provision of care to remain firmly person-centred.

Cultural Issues

Consideration of cultural preferences and issues throughout the progress of the illness is also important. Families and carers need to understand the reasons for the medical and care approaches proposed and service providers need to have support in understanding cultural issues. The language used by a person with terminal dementia may revert to the one they used in childhood but this may not reflect their recent cultural practices and tastes.

Multicultural or culturally specific organisations or advisors within the health department or health care facilities can provide general information and support to care staff in understanding the needs of people with dementia who are from culturally and linguistically diverse backgrounds.

The need for service providers to understand the health and caring perspectives of different cultural groups is especially important in the context of a palliative approach. It is often at this stage that families and carers turn to culturally familiar and comforting beliefs and practices. When service providers respond sensitively to the cultural beliefs and practices of residents and families, satisfaction with end-of-life care is increased (Department of Health and Ageing 2004).

Death

As the time of death draws near it is appropriate that arrangements are made for family and friends to stay with the person with terminal dementia if they so wish. A private room is the best choice. Families and carers need to understand that the person can still hear them and may understand what they are saying. They may also need reassurance that it is acceptable to touch, hug or hold the person. It is not uncommon at this stage for there to be a moment of lucidity, where, for example, the person with dementia seems to know someone they had not recognised for months. These episodes, if they happen at all, last for a very short while. They do not indicate any change in the course of the disease and do not indicate any postponement of the person's death.

The exact moment of death itself can be difficult, not only because it signifies the final departure of the person with dementia from the lives of family, carers and service providers, but also because some of the physical signs and changes that may occur can be confronting. Gurgling sounds may be heard and the loss of the last vestiges of muscle control may be noted. Breathing will cease, but the eyes may remain open, with the pupils fixed and dilated. Other changes may occur, but there is no set pattern. In such circumstances it is important that the service provider is knowledgeable enough to help the family and others present to understand that what they are seeing is the normal change process associated with the arrival of the moment of death. Such support mechanisms are very important at this moment.

Following the death, families and carers may feel sadness, grief or guilt, relief, or any combination of these and other emotions. Service providers who may have cared for the person for a long time may also feel a sense of loss.

Memorial services help service providers deal with the grief they often have to face. Alzheimer's Australia provides access to counselling for families and carers and continues to provide support after the death of a person with dementia.

Family Carers and Decision Making

The process of a palliative approach requires families and carers to make numerous emotionally charged decisions. In spite of recent breakthroughs in the treatment and understanding of dementia, there is still no cure and no means of significantly delaying death. Acceptance of these inescapable features of dementia assists the growth of understanding among persons diagnosed and their families and carers that there may be a need for palliative care in the terminal stages of the illness.

Discussing palliative care while the person is coming to terms with a diagnosis and subsequent loss of abilities is difficult. Once the person has adjusted to the diagnosis it may be time to ask 'now what does that mean for the way ahead?' Thus the emphasis in this paper has been on preparation for all concerned, including obtaining counselling or education where needed. Pioneering work in recent decades has shown that a dignified, pain free and comfortable death for the person suffering from dementia is achievable and should be the principal imperative for the caring professions, and for family and friends of the person who is dying. Alzheimer's Australia has many experienced people committed to helping those with dementia and their families and carers through this process.

Conclusion

Palliative care approaches have a crucial role to play in the care of the person with dementia who is dying and in the support and preparation of their family and carers. This paper identifies how the person with dementia can be supported to die in comfort and with dignity. It has also identified the importance of involving and attending to the needs of the family and carers throughout this critical time.

Postscript

I hope that the paper assists Alzheimer's Australia to promote discussion by people with dementia, their families and carers about the important issues that surround dementia and palliative care.

References

- Abbey, J. 2003, 'Ageing, dementia and palliative care'. in Aranda, S. & O'Connor, M. (eds), *Palliative Care Nursing – A Guide to Practice*, 2nd edn, Ausmed, Melbourne, pp.313-326.
- Australian Pain Society 2005, *Pain in Residential Aged Care Facilities: Management Strategies*, Australian Pain Society, Sydney.
- Billings, J. 1985, 'Comfort measures for the terminally ill. Is dehydration painful?', *Journal of the American Geriatrics Society*, vol.33, no. 11, pp. 808-810.
- Byrd, L. 2004, 'The use of artificial hydration and nutrition in elders with advanced dementia', *Topics in Advanced Practice Nursing eJournal* vol.4, no.2, [Online] Available at: http://www.medscape.com/viewpublication/527_index
- Department of Health and Aged Care, 2000, *National Palliative Care Strategy A National Framework for Palliative Care Service Development*, Department of Health and Aged Care, Canberra.
- Department of Health and Ageing, 2004, *Guidelines for a Palliative Approach in Residential Aged Care*, Rural Health and Palliative Care Branch, Department of Health and Ageing, Canberra.
- Eggenberger, S. & Nelmes, T. 2004, 'Artificial hydration and nutrition in advanced Alzheimer's disease: facilitating family decision making', *Journal of Clinical Nursing*, vol.13, pp. 661-667.
- Finucane, T.E., Christmas, C. & Travis, K. 1999, 'Tube feeding in patients with advanced dementia: a review of the evidence', *JAMA*, vol. 282, no. 14, pp. 1365-70.
- Hurley, A.C. & Volicer, V. 1999, 'Caring for patients with advanced dementia: implications of innovative research for practice', *Innovations in End- of- Life-Care*, vol.1, no.4, [Online] Available at: <http://www2.edc.org/lastacts/>

Hurley, A.C., Volicer, B.J. & Volicer, L. 1996. 'Effect of fever-management strategy on the progression of dementia of the Alzheimer type', *Alzheimer Disease and Associative Disorders*, vol.10, no.1, pp. 5-10.

Li, I. 2002 'Feeding tubes in patients with severe dementia', *American Family Physician*, vol. 65, no.18, pp.1605-10, 1509-12.

Milne, A.C., Potter, J. & Avenell, A. 2005, 'Protein and energy supplementation in elderly people at risk from malnutrition'. *The Cochrane Library* ,Cochrane Review ID CD003288,[Online] Available at: <http://cochrane.org.au/library/library.htm>

Murphy, L. & Lipman, A. 2003 'Percutaneous endoscopic gastrostomy does not prolong survival in patients with dementia', *Archives of International Medicine*, vol.163, no. 11, pp. 1351-1353.

Rumbold, B. 2003 'Caring for the spirit: lessons from working with the dying', *Medical Journal of Australia*, vol.179, suppl. 6, pp. S11-S13.

Santamaria, N. 2005, *PRIME Trial* Australian Government, Canberra (Unpublished)

Shuster, J. 2000, 'Palliative care for advanced dementia', *Clinics in Geriatric Medicine*, vol 16, no 2.

GLOSSARY OF TERMS

(Note * denotes legal terms that may differ between the States and Territories.)

***Advance Directive**

An Advance Directive (AD) is a statement by a competent person expressing their wishes in relation to their future health care, if they are not able to do so themselves at that time.

Agitation

Vocal or motor behaviour (screaming, shouting, complaining, moaning, cursing, pacing, fidgeting, wandering, etc.) that is disruptive, unsafe, or interferes with the delivery of care in a particular environment.

Air hunger

Difficulty in breathing, often associated with lung or heart disease and resulting in shortness of breath. Also called dyspnoea.

Anorexia

A reduced desire to eat.

Antibiotics

Medications that kill bacteria.

Antispasmodics

Medications to help reduce spasms, stiffness and cramps.

Aromatherapy

The use of aromatic essential oils to treat many common illnesses and disorders.

Artificial nutrition and hydration (ANH)

Administration of food and fluid supplements when food and drink cannot be taken naturally.

Aspiration pneumonia

Inflammation of the lungs caused by inhaling or choking on vomitus.

Case conference

A tool for coordinating care across a multidisciplinary team where team members, family and carers, and, if possible, the client themselves, identify and discuss the care needs and goals relating to chronic or complex conditions and assign interventions to particular members of the team.

Catheter

A rubber or plastic tube used to withdraw urine from the bladder.

Catheterisation

The insertion of a catheter.

Chemical restraint

The use of sedatives or anaesthetics to control a person's activity.

Co-morbidity

A medical condition that exists simultaneously with another.

Congestion

The presence of an abnormal amount of fluid in a vessel or organ.

Contractures

An abnormal shortening of muscle or scar tissue, that results in distortion or deformity, especially of a joint of the body.

Dehydration

Excessive loss of water from the body.

Delirium

A temporary state of mental confusion resulting from high fever, intoxication, shock, or other causes, and characterized by anxiety, disorientation, memory impairment, hallucinations, trembling, and incoherent speech.

Distress

A state of physical or mental suffering.

Drip

The administration of liquid substances directly into a vein. Also called intravenous therapy.

Dyspnoea

Difficulty in breathing, often associated with lung or heart disease and resulting in shortness of breath. Also called air hunger.

Electrolyte imbalance

Lack of equality of electrolytes in the body.

***Enduring Guardianship**

A person appointed as an enduring guardian can make personal decisions on another person's behalf, such as living arrangements, medical treatment and services.

***Enduring Power of Attorney**

A person appointed under an enduring power of attorney can make financial decisions on another person's behalf, for example disposing of assets, such as a house, or operating bank accounts.

Euthanasia

The act or practice of ending the life of an individual suffering from a terminal illness or an incurable condition, as by lethal injection or the suspension of extraordinary medical treatment.

Evidence based care

The process by which health professionals make clinical decisions using the best available research evidence, their clinical expertise and patient preferences.

Functional levels

Ability to perform personal care activities necessary for everyday living, such as eating, bathing, grooming, dressing, and toileting.

Gastro-oesophageal reflux

A condition where the muscular ring at the lower end of the oesophagus is abnormally relaxed and allows the stomach's acidic contents to flow back or 'reflux' into the oesophagus.

GIT Bleeding

Loss of blood from the gastro-intestinal tract.

Hallucinations

False or distorted perception of objects or events with a compelling sense of their reality.

Hot towel baths

Soft towel bed-bathing method as an alternative to a shower or conventional bath.

Impaired cognitive ability

Impairment of mental abilities such as judgment, memory, learning, comprehension, and reasoning.

Intravenous therapy

The administration of liquid substances directly into a vein. Also called a drip.

Ketosis

A pathological increase in the production of ketone bodies.

***Living Will**

A **legal** document that expresses an individual's decision on the use of such matters as artificial life support systems.

Low-flow oxygen

Administration of oxygen at concentrations greater than room air.

Malnutrition

The cellular imbalance between supply of nutrients and energy and the body's demand for them to ensure growth, maintenance, and specific functions.

***Medical Power of Attorney**

The title given to a person who is legally appointed to make decisions relating to the medical care of another.

Mortality rates

The ratio of total deaths to total population in a specified community or area over a specified period of time.

Muscle atrophy

Muscle atrophy refers to the wasting or loss of muscle tissue resulting from disease or lack of use.

Muscle spasms

Shortness in a muscle or group of muscles that cannot be released voluntarily.

Nasal prongs

Catheter used to delivery oxygen through the nose.

Nausea

A feeling of sickness in the stomach characterized by an urge to vomit.

NESB/CALD

People of Non-English speaking backgrounds or the more recent term is people from culturally and linguistically diverse backgrounds.

Opiates

A term used to describe drugs that are derived from the juice of the opium poppy.

Pain

An unpleasant sensation occurring in varying degrees of severity as a consequence of injury, disease, or emotional disorder.

Palliative care

Palliative care is the active total care of patients where disease is not responsive to curative treatment.

Percutaneous endoscopic gastrostomy (PEG)

A surgical procedure for placing a feeding tube in the abdomen.

Perforation

An abnormal opening made by rupture or injury.

Peripheral shutdown

Decreased blood supply to the body's peripheral organs i.e. arms, legs.

Peritonitis

Inflammation of the peritoneum, the membrane that lines the abdominal cavity and surrounds the internal organs.

Person centred care

Care that focuses on the person's individual needs as paramount.

Pharmacological pain management

The administration of medication to alleviate pain.

Physical restraint

Devices used to ensure safety by restricting and controlling a person's movement.

Quality of Life

Defined as an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health and psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of the environment.

Sanctity of life

The value of life exceeds all other values. No other value overrides the value of life except possibly more life.

Starvation

A condition in which deprivation of food has forced the body to feed on itself.

Subcutaneous therapy

Fluid provided into the subcutaneous (fat) tissue.

Suctioning

To draw away or remove by the force of suction.