

WRESTLING WITH DEMENTIA AND DEATH

A REPORT FOR ALZHEIMER'S AUSTRALIA

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**TALKING ABOUT ALZHEIMER'S
ACROSS AUSTRALIA**
FIGHTDEMENTIA.ORG.AU

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FOREWORD

It is never easy to have discussions about death and dying or to face the reality that you or someone you love has a terminal illness. People put off discussing preferences about end of life care for as long as possible. Research from Palliative Care Australia in 2011 found that only about a third of Australians have discussed preferences for end of life care with their family. Even amongst older people, only about half had discussed their preferences with their family.

For people with dementia and their carers, talking about death and dying is complicated by the progressive nature of the disease and the eventual loss of capacity of the person with dementia to be involved in decisions about their care. People with dementia are encouraged to document their wishes for end of life care early on in the dementia journey, but discussions about the realities of death and dying are often avoided for as long as possible.

For consumers there are two main strategies to ensure that individuals with dementia receive end of life care that meets their wishes.

First, there is a need to demystify concepts and experiences of end of life care. This paper, *Wrestling with Dementia and Death*, attempts to do this by providing an overview of some very challenging practical issues faced by individuals with dementia and their families at the end of life. This paper may be difficult and confronting for some people as it covers difficult issues such as nutrition and hydration at end of life. But it will be a valuable resource for many who are seeking more information about what to expect towards the end of life and how to develop an appropriate care plan. This paper should be read in conjunction with Alzheimer's Australia's *Planning for the End of Life for People with Dementia* by Professor Colleen Cartwright which provides detailed information about options for advance care planning and legal issues around capacity.

Second, there is a need for systems change to encourage people to think about end of life care and to document their wishes. For example, aged care providers should be required to discuss advance care plans with any new clients entering the community or residential aged care system. Arguably it should be a basic requirement for good care for the service provider to know the wishes of the client. It should of course be the choice of the individual as to whether they complete an advance care plan, but the topic should at least be discussed. Discussions about planning for end of life care could also be incorporated into the 75+ health check.

I am hopeful that this publication, and its companion *Models of Dementia Care: Person Centred, Palliative and Supportive* will spark discussion and interest in these issues.

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Lucille Bloch
Chair, Alzheimer's Australia's National Consumer
Advisory Committee

SUMMARY

This paper discusses practical issues faced by individuals with dementia and their families^a as the illness progresses towards death. It provides information to assist people with dementia to die in a peaceful and dignified way, according to their wishes. When thinking about their own death, most people would prefer to die in a peaceful, dignified and pain-free way, close to family. Sadly however, this is not the reality for many, particularly for people with dementia.

Instead, the usual end-of-life care for a large number of people with dementia involves the removal from home to emergency hospitalisation, which may include unnecessary medical tests while pain and other symptoms are unrecognised and under-treated. In some cases medical decisions are made by health professionals with little regard for the person's wishes and values, or those of their families.

This paper has been developed with the goal of supporting people with dementia and their families to have discussions about death and end of life care and to understand some of the practical issues that must be dealt with towards the end of life. With good communication and documentation of wishes, people with dementia can receive appropriate care at the end of life and experience a peaceful, dignified death.

Alzheimer's Australia has previously published a two-volume guide to planning for end-of-life for people with dementia, covering advance care planning in volume one, and in volume two, exploring end-of-life options, including assisted voluntary euthanasia. Alzheimer's Australia has also released a paper by Professor Julian Hughes, *Models of Dementia Care* which aims to stimulate debate about models of end of life care and set out an approach for supportive care for people with dementia. This paper compliments and should be read in conjunction with these other papers.

The content of this paper is set out in two parts.

Part 1 covers some of the most complex issues that are likely to be encountered by those with dementia, their families and friends, including communication, capacity, the need for control, and legal and ethical concerns.

Part 2 looks at specific elements of end of life care and how they are applied in the context of dementia, including symptom control, food and water, medications, hospitalisation, home and residential care, and recognising signs of imminent death.

^a In this paper the term family is used throughout to mean any person who is close to or has an attachment to or an involvement with the person who has dementia.

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Advance Health Directive

A document prepared by a person while they have capacity, identifying their wishes with respect to future health care.

Anorexia

Loss of desire to eat.

Behavioural and Psychological Symptoms of Dementia¹ (BPSD)

People with dementia may experience behavioural and psychological symptoms during the course of their illness. These may include:

- Behavioural symptoms; screaming, restlessness, physical aggression, agitation, wandering, culturally inappropriate behaviours, sexual disinhibition, hoarding, cursing and shadowing.
- Psychological symptoms; anxiety, depressive mood, hallucinations, delusions and psychosis.

Culturally and Linguistically Diverse (CALD)

People who identify themselves as having a specific cultural or linguistic identity in relation to their place of birth, ancestry, ethnic origin, religion, preferred language, or language(s) spoken at home.

Cheyne-Stokes breathing

Cheyne-Stokes breathing is an abnormal pattern of breathing that occurs when death is imminent and is characterised by progressively deeper and sometimes faster breathing, followed by a gradual decrease that results in a temporary halt in breathing called an apnoea (loss of breathing). The pattern repeats, with each cycle usually taking 30 seconds to 2 minutes.

Dementia

Dementia is the umbrella term for a group of illnesses affecting the brain that cause memory loss, changes in emotions, social interactions and behaviour, reduced problem solving abilities, and a progressive decline in functioning. Alzheimer's Disease is the most common form of dementia, but there are over 100 other types.

Dysphagia

Difficulty in swallowing.

Family

Family incorporates all individuals who are close to the person who has dementia including people such as relatives, friends, neighbours or carers.

GP

General practitioner.

Health Professional

Workers from the health and community care sectors such as nurses, doctors, social workers, case managers, and other qualified allied health workers.

Hospice care

The concept of hospice has been evolving since the 11th century. Then, and for centuries thereafter, hospices were places of hospitality for the sick, wounded, or dying, as well as those for travellers and pilgrims. Modern hospices are usually attached to acute hospitals and provide end-of-life care for people with a prognosis of, usually, less than three months to death. They also often supply outreach palliative care services.

Incontinence

Incontinence is the loss of control of bladder and/or bowel function.

Palliative approach

A focus on comfort and care of an individual and their family who are dealing with a life-limiting illness. This positive approach focuses on comfort, care and the reduction of symptoms and distress.

Palliative Care

Palliative care is an approach that aims to improve the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.²

Pulmonary Aspiration

The entry of secretions or foreign material into the trachea and lungs.

Residential Aged Care Facility (RACF)

Formerly called Nursing Homes.

Vascular dementia (also called multi-infarct dementia)

The term refers to a group of syndromes caused by different mechanisms all resulting in vascular lesions in the brain.

WHO

World Health Organisation.

INTRODUCTION

Learning that oneself or a family member or friend has a terminal illness can be shocking and stressful. When people are dying with dementia, the issues around death are often even more sensitive and complicated. Unlike other terminal diseases such as cancer, a person dying with dementia will typically have lost most of their physical and mental abilities by the time they reach the last weeks and days of their lives. This means that family members and carers may have to make decisions about the care provided at the end of life.

The purpose of this paper is to outline some of the issues that need to be considered for end of life care including communication, capacity and decision making. It also outlines specific aspects of end of life care that can contribute to a more comfortable end of life experience.

A dignified death rarely happens as a matter of course. It requires planning and decisions about end of life care. In many cases people with dementia have a sub-optimal experience of death, with unnecessary suffering or distress for the person with dementia, and unnecessary confusion, uncertainty and distress for families. This can be avoided, however, with appropriate care, support and documentation of wishes.

Some of the factors that complicate end of life care for people with dementia include:

- poor general understanding of dementia in the community and amongst many in the medical profession;
- the medical culture of fighting disease and protecting life at any cost;
- a lack of planning for or communication about death between the person with dementia, their family members, health and care professionals; and
- the loss of capacity of the person with dementia with the near inevitability that medical decisions will have to be made at a time when the person with dementia often no longer has the capacity to provide input.

Added to this are more general complications not constrained to dementia, including legal and financial arrangements.

While all of these issues are difficult to confront and deal with, many can be addressed and planned for well in advance of death in a way that minimises their impact and allows the person with dementia to express their wishes and preferences regarding the end of their life while still able. Confronting some of the issues around death and dying in dementia in advance can also help families, medical and care staff to communicate and agree on measures to be taken in a way that increases understanding, decreases uncertainty, and helps to reduce distress. This, in turn, can help the family to focus on the person with dementia and the grieving and mourning that comes with their passing, rather than on the logistics, decisions and uncertainty that too often dominate the final days of life, and the days thereafter.

PART 1: DEALING WITH DEATH AND DYING

Advance Care Planning and good end of life care empower people to have a say over the care they receive and the type of death they may have. This section provides information on specific issues that arise in implementing a supportive approach to end of life care, which includes facing the realities of approaching death with a person who has dementia.

Communication

Dementia is a progressive disease and at some stage in the disease's trajectory the person with dementia will begin to lose the capacity to communicate; and eventually, if dementia runs its full course, that capacity will, sooner or later, be lost altogether. There is information available to families^b about creative ways to enhance communication while extending the period in which it remains possible.

What is rarely discussed, however, is how to talk about death and end of life issues. Many families find it difficult to face the reality that dementia is a terminal illness that will eventually lead to death. A lack of discussion about death and dying means that the wishes of the person with dementia are often unknown. The Alzheimer's Australia end-of-life publications^c emphasise the importance of a person with dementia making an advance directive while their communication is still clear and competent. Communication about end of life issues needs to be a continuous process. Individuals may change their views about the care they would like to receive as their disease progresses and their circumstances change.

The regular use of a diary to document communication with the person with dementia, after an advance directive has been made, assists family and health professionals to document ongoing communication with the person. This documentation will give some indication of the individuals care preferences, for example whether the person with dementia wants or does not want invasive and life prolonging treatment as they approach death; and it may also reveal that, whatever they wanted earlier, they have now come to want something different.

People with dementia from diverse backgrounds face additional challenges in planning for end of life care. There are often different cultural and religious beliefs which impact on preferences for end of life care and communication can become more difficult as individuals, for whom English is not a first language, may revert to only speaking in their native language as the illness progresses. This may make it difficult for health professionals who have to rely on family or interpreters to understand the person's needs.³ The Cultural and Indigenous Research Centre Australia (CIRCA) have produced a Strategic Model for people with dementia⁴ which may be a useful resource.

Discussions about death and dying can bring up views about suicide or euthanasia. In some cases individuals consider suicide because they fear losing control and have concerns about a lack of quality of life at the end of their lives. The person with dementia may speak about wanting to commit suicide or just discuss wanting to die. Studies have shown that suicide is more prevalent after people have received a diagnosis of dementia than in the general population⁵.

For family and health professionals, preventing a person taking their own life is a painful and difficult process. If there is talk about not wanting to live with the disease the first approach is to listen and not ignore these statements. Alzheimer's Australia provides opportunities for counselling at all stages throughout the illness. Carers who have concerns about an individual wanting to take their own life should contact a health professional. They may also want to contact LifeLine for support on 13 11 14.

^b Alzheimer's Society (2013). Communicating. http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=130

^c Alzheimer's Australia (2011). Planning for the End of Life for People with Dementia. Part 1 & 2. <http://www.fightdementia.org.au/research-publications/alzheimers-australia-numbered-publications.aspx>

Capacity

Capacity is the ability to make an informed decision. For some decisions there is a specific legal test for capacity. The focus in this paper is on how to support the person with dementia to enable them to have the capacity to speak for themselves for as long as possible.

It is easy to think that capacity only matters when there are legal issues to decide, such as making a will or an advance directive, at all points from diagnosis onwards. In fact capacity is at the heart of communication for the person with dementia.

Generally, when a person has capacity to make a particular decision they can:

- 1 understand the facts and the choices involved;
- 2 weigh up the consequences; and
- 3 communicate the decision.

It is possible to extend a person's capacity, partly by encouraging the person with dementia to continue to have control over their own lives. Every day decisions about when the person should get up, what to wear or what to eat, can sometimes be overtaken by health professionals or family members, even when the person still has the capacity to make their own decisions.

An additional difficulty in coming up with definitive answers is the fact that capacity can fluctuate as this case study from the Capacity Tool Kit⁶ illustrates.

Decision specific capacity

I have a grandfather with dementia. Sometimes he seems to know that I'm his grandson and other times he thinks I'm his son. He has good days and bad days.

At one stage he needed an operation on both eyes because he had cataracts. When the doctor did the first operation, my grandfather didn't know what was going on. He was having one of those bad days and seemed to be stressed out about the hospital. He thought he was at the hospital campsite in the war. He couldn't understand the cataract surgery and the doctor ended up asking my dad to sign the forms to say he could have the operation.

It's funny, really, because when he went back to have the other eye operated on he seemed much better, and when the doctor talked with him he knew what was going on. I think the doctor realised this because he got my grandfather to sign his own forms that time. I don't know why my grandfather understood the second time. Maybe it was because he had done it before or maybe he was just having one of his better days.'

**Lachlan, grandson
Capacity Tool Kit (p. 21),
State of New South Wales
through the Attorney General's
Department of NSW 2008**

The level of capacity a person has at a particular time can depend on the following factors:

- the type of decision being made: Is it a financial decision, a health decision, or some other kind of decision?
- the timing of the decision: Is the person tired? Is the person more able to make decisions in the morning, for instance?
- is the decision simple or complicated? e.g. life or death?
- how much information has the person been given, and what is their level of understanding about the information?
- is an interpreter required?
- how will the physical environment in which the decision is being made affect the person? For example, while in an acute medical unit, decisions might be fraught with emotions and tensions of the moment.
- the trust in the person assisting with the decision.
- has the person a minor, temporary illness? For example, a cold, urinary tract infection or asthma that may be unsettling them?

Once again, regular use of a diary can assist by documenting the fact that the person's capacity fluctuates, or, perhaps, that they are really set and determined on a certain way forward.

Presumption versus protection

What should our starting assumption be in regards to the capacity of a person with dementia? This paper strongly advocates beginning by presuming that the person has capacity and working out approaches and protocols from there in line with the actual evidence. This pragmatic but principled approach should last until death, with limitations on autonomy and free choice being made only as they become necessary in practical terms.

Even with a presumption of capacity, it is still important to think about the balance between a person's right to make a decision and the extent to which that person's health or safety might be in danger in a particular matter if they are allowed to act according to their preferences of the moment. Weighing the possible benefits against the possible risks may be difficult. Will the psychological loss incurred by having the right to decide taken from them be more or less than the emotional and tangible damage likely to result from being allowed to make a choice that always looked to be the wrong one and proved to be just that? A 'risk benefit assessment'⁷ is recommended as an appropriate way to assist with these types of dilemmas.

Every person has the right to make their own choices and their own mistakes, up to a point. Judging where that point lies at the time is difficult but necessary. If we instead start with a positive presumption of lack of capacity we potentially violate the basic rights of an individual with dementia to autonomy.

If a person with dementia makes an unwise decision, or one that you disagree with this does not mean that a person lacks capacity; it may not even mean that their choice is wrong. For example, the person may indicate that they no longer want to eat or drink. In a recent legal decision called the Brightwater case, a decision was made that supported such a choice by a resident.⁸

Martin CJ concluded that Brightwater (the aged care facility) would not be criminally responsible for any consequences to the life or health of Mr Rossiter caused by ceasing to administer nutrition and hydration to him, if this was done in accordance with his expressed wishes and informed consent. His Honour expressed some concern as to whether Mr Rossiter had been given sufficient information to appreciate fully all the consequences of his decision to refuse nutrition and hydration, and therefore directed that he be given further advice by an appropriately qualified medical practitioner about these consequences. It was held that if Mr Rossiter then maintained his wish to refuse nutrition and hydration and this wish was complied with, no issue of liability would arise for Brightwater or the treating medical practitioners.

This judgment makes it clear that the duty of care of the residential aged care facility was to comply with the wishes of Mr Rossiter.⁹

If a person with dementia tries to refuse nutrition or hydration they are presumed not to have capacity – and will often have a person sit in front of them putting a spoon in their mouth saying things like ‘*just a spoonful*’, or ‘*try it for me*’. If there is a clear advance directive from the person with dementia and the family feel that the pushing food away, or spitting it out, is the desire of the person with dementia, then it is not the right of the nursing staff to insist that the person be fed.

Family members sometimes disagree about the capacity of a person with dementia as is shown in this second case study from the Capacity Tool Kit. One way to solve such a difference of opinion is to seek an independent person to make the decision about the capacity of the person with dementia. This usually involves contacting the State Public Advocate and/or Guardianship Board. The individual seeking the decision is required to have evidence about the presence or absence of capacity and any ‘mental illness’. This will include making sure that the person with dementia has been assessed by one or more health professionals before any hearing can be held.

Assuming capacity

'I don't like arguing with my sister Eugina, but she thinks that because my brother has been told that he has Alzheimer's, it means he can't make any decisions for himself. I tried to explain to Eugina that you have to have reasons, evidence if you like, to show that someone can't make a decision about something for themselves.

I know that she is just being protective, but she doesn't have to worry. When Eugina actually sees him I think she will understand. (She doesn't live near us).

He might have been told that he has Alzheimer's, but the idea is not to strip him of his right to live his life like he wants. Eugina and I should monitor the things he can and can't do before taking over any decisions.

***Nicias, brother
Capacity Tool Kit (p. 32),
State of New South Wales
through the Attorney General's
Department of NSW 2008***

Of particular concern for health professionals and families about "capacity" is the dilemma that occurs when an Advance Directive 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'. Here is a story where the nursing staff decided that their 'duty of care' outweighed the Advance Directive that had been clearly made and supported by the family.

This story is from a carer whose wife had been diagnosed with younger onset dementia in her middle age. She saw her mother die of the same condition and had therefore made her own wishes about end-of-life very clear, even to the point of wearing a medic-alert bracelet with those wishes inscribed on it. Her family were all in agreement with those wishes. During her stay in the Residential Aged Care Facility (RACF), after she had long lost capacity, these wishes were formally documented into her care plan during a meeting with staff, the family and her GP.

This is a brief excerpt of the last part of Diana's life as described by her husband.

One night, I arrived a little late to give her her evening meal and found a carer had already started feeding her. The carer was trying very hard to get her to eat but the food kept dribbling out because she was not swallowing. It was obvious to me that Diana did not want to eat so I stopped the carer from trying to feed her.

Next morning I received a call from the home informing me that Diana had suffered a serious seizure in the early hours of the morning and had not recovered as yet.

She did regain consciousness the next day. I asked the Director of Nursing (DON) what he thought about her condition and he said that she was not doing well and not fighting back like she always had done before. I agreed, and said I really thought that even before this event, her quality of life was so poor that there was no reasonable state for her now to recover. I reminded him about our document and said that we, Diana's family, still wanted it respected.

By the fifth day after her seizure, Diana had not taken any food (as far as we knew) and had only taken a small amount of fluid. I tried to make it well known amongst the carers that we did not want them pushing Diana to eat or drink.

By this stage I felt certain that she was not going to improve and I was worried about what quality of life would she have if she did improve. We had a sense that despite her condition and the existence of our written wishes for her palliative care, some carers were obviously not supportive of our approach and on several occasions during that week, there was evidence that someone had tried to feed and hydrate her. On each occasion I complained to the DON but that did not solve the problem.

I obtained information about the comfort of dying from terminal dehydration. I made copies of the information for the DON and for several carers who were very interested as they claimed they had no training or information about best practice palliative care.

The next morning when I arrived at the home, I found one of the Registered Nurses (RNs) trying to re-hydrate Diana. I expressed my surprise that she was not following the palliative care program and I tried to explain why we had taken this approach. She stated that she could not accept or support it and that she would have to be directly instructed by the DON before she would desist with her efforts. I immediately contacted the DON who said that he considered her condition to be 'stable' and would review her situation with a view to trying to re-hydrate and feed her in a day or two. I was very upset and challenged this course of action but he again claimed that he had a duty of care to her. I questioned that duty of care and asked him what level of quality of life he thought he could help her regain. We ended the conversation with him agreeing to our wishes in the short-term (including instructing the RN) but he stated he would review her condition with the GP and ourselves in a few days.

On the eighth day after the seizure, I could see that Diana was looking distressed and I asked the RN to give her something for pain relief. Every time I asked,

they gave her a Panadol suppository but I would have to ask. I kept saying to them that I knew that the GP had written orders for pain relief PRN including morphine if needed. After a couple of days on Panadol, I finally persuaded them to start Diana on morphine. By the next day, I had to ask them to increase the dose. She was also accumulating fluid at the back of her mouth for which they gave her atropine but once again, I always had to ask for it to be given. This was the pattern right up to the time she died - that is, they would not administer more of either drug unless we asked them to do so.

On the afternoon of Diana's last day, once again, I had to ask for atropine to be administered. At around 11.30 pm, she was again showing signs of pain and distress and again we had to ask for more morphine. At midnight, the staff turned her as they had not done so since 5.00 pm. The turning seemed to move fluid in her lungs, her breathing became more laboured and she died quietly at about 12.30 am.¹⁰

This story raises questions about how staff should respond to Advance Care Plans which seem to conflict with their perceived duty of care. In this case 'duty of care' was used to justify what the staff wanted to do. With better training and understanding how to manage a dignified and peaceful death, the concept of duty of care may be able to be clarified for staff. This should be a responsibility of management of RACFs.

There are many examples from carers of people with dementia of Advance Directives not being honoured. In spite of efforts to improve the wording and format of Advance Directives they are often still problematic in guiding clinical decision making. However, they remain the only way a person with dementia can set out a legal document which provides information about their own wishes to be followed. Different individuals place greater weight on quality of life and 'sanctity of life'. As a result, what service providers from one cultural background see as being evidence-based care and person-centered care and promoting the person's best interest, may not appear in the same light to families and health professionals from a different background.

PART 2: ELEMENTS OF END OF LIFE CARE FOR PEOPLE WITH DEMENTIA

As has been made clear in the earlier sections of this document, end of life care for dementia may involve a broad range of different considerations, and elements, depending on the person's situation, preferences, and the physical, social, medical and care context in which they are living. Information about end of life care should be made available to the person with dementia soon after diagnosis in order to ensure that the person can be involved in planning for their care. This section discusses different components of care for people with dementia at end of life.

Components of Care

Symptom control at end of life

This section will discuss palliative approaches to specific symptoms which are commonly experienced by people with dementia towards the end of life. In relation to all the circumstances described below, the focus on treating symptoms should be on the key palliative care questions:

- 1 How useful is this treatment for the person with dementia? and
- 2 What choice would best promote the comfort of the person with dementia?

Pain

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

Some of the main observable indicators of pain are:

- facial expression (e.g. grimacing, flushing of skin) 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.

There should be an ongoing and systematic approach to recording, assessing and managing pain. Pain scales¹¹ 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 dementia is experiencing. It is important to consider causes of pain common in older people (e.g., history of arthritis, low back pain, neuropathies). Musculoskeletal and neurological disorders are the most common causes of pain and should be given priority in the assessment process. A recent fall or other acute medical problem (e.g., urinary tract infection, pneumonia, skin tear) is also likely to cause pain, and should be investigated as a possible cause.

Families and health professionals, especially visiting GPs, should be able to access a record of the pain levels of the person with dementia, together with the record of the effectiveness of any therapeutic interventions aimed at relieving pain.¹² 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; or
- 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 pain management is to use analgesics regularly, not just as required. The lowest dose possible that provides pain-free comfort should be prescribed and administered according to a prescribed schedule. 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. Although the side effects of opiates (such as nausea, constipation, hallucinations, delirium and agitation) can be distressing for the person and their family the drugs should not be discounted as they could still be the best medications to provide peace and comfort. Even if the person is not eating or drinking, bowel medications may also be needed to ensure that constipation does not lead to further pain.

The difference between excellent pain management, terminal sedation and euthanasia is discussed in the Alzheimer's Australia's end-of-life papers that can found on that Alzheimer's Australia website.^d

Incontinence

The loss of control of bladder and bowel functions will probably occur by the time an individual reaches the late stages of the disease. As people get close to death, and take less food and fluid, incontinence of urine will lessen and this adds to a person's comfort, as there are less 'wet beds' to change that cause discomfort to the person. However, constipation may be a side effect of opiates given to assist with pain. When pain relief with morphine is considered, dealing with constipation must be planned. A doctor must prescribe the best medication for constipation in each individual case. The aim here is to relieve pain and provide comfort.

Antibiotics

It has been known for years that antibiotics are of limited benefit to most people with end-stage dementia. An academic review paper published in 2002 reported that: *'the use of systemic antibiotics is prevalent in the treatment of patients with end-stage dementia, despite the limited utility and discomfort associated with the use of these agents'*.¹³

Despite this, the treatment of people with dementia with many courses of antibiotics over the course of the trajectory of the disease still continues. Research has shown that:

Aggressive treatment of infection does not improve survival rates among persons with severe dementia³² and has been associated with accelerated progression of the severity of dementia³³. Antibiotics and other aggressive measures, although they probably do not improve survival, are associated with numerous adverse outcomes, including renal failure, allergic or drug reactions, rash, diarrhoea, antibiotic resistance, use of intravenous lines and mechanical restraints, and prolonged time till death.

Other methods to relieve the discomfort of an infection, such as the use of tepid sponging or 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.

^d Alzheimer's Australia (2011). Euthanasia is only one part of the end-of-life debate. <http://www.alzheimers.org.au/research-publications/euthanasia-is-only-one-part-of-the-end-of-life-debate.aspx>

PART 2: ELEMENTS OF END OF LIFE CARE FOR PEOPLE WITH DEMENTIA continued

Food and water

Decisions surrounding nutrition and hydration are some of the most difficult and emotionally charged issues that must be faced by families of people with end-stage dementia. Families need to make these decisions based on the individual circumstances and the known preferences of the individual with dementia. The loss of thirst and appetite, and a slow shut-down of the body's digestive system is a normal part of death that often has benefits to the dying person. However, seeing the person you care about looking as though they are being starved can be highly distressing, and as a result, artificial nutrition and hydration of people with advanced dementia may occur. This section will outline the key issues that need to be considered.

Terminal dehydration

When a person with dementia begins to lose their appetite and/or choke on food and water, is often one of the most difficult times for families. Families often express their concern through sentiments such as 'We can't let mum (dad/aunt/friend) starve to death' when staff explain that the family member has stopped eating or drinking. There may be reversible reasons for difficulty with feeding and hydration, for example, a urinary tract infection, pain or not liking particular foods, and if a person is still able to swallow safely encouragement to eat can take these forms:

- Finger food offered;
- Attractive soft food – the sense of smell and taste may be lost – so the only encouragement to eat may be how attractive the food looks;
- Positioning;
- Good dental and mouth care;
- Check medications;
- Stroking the throat (if tolerated);

- Placing food on tongue before asking the person to swallow; and
- Telling the person what the food is.

When a person begins to refuse food and fluids it is often a sign that the death process has begun, and anorexia is very common in people with late-stage dementia. Lack of energy, dysphagia or nausea can all lead to the lack of desire for nutrition and hydration. This absence of nutrition leads to isotonic dehydration: the loss of salt and water from the body. Whilst potentially distressing for the families and health professionals, the evidence indicates that death by terminal dehydration is not painful and that attendant physical discomfort can be adequately alleviated.

It has been found that '*...approximately half of all patients with dementia will be unable to feed themselves within eight years of their diagnosis. Moreover, 85 percent of patients with dementia have demonstrated refusal to eat.*'¹⁵

At the point in the dementia journey where the assisted feeding is being considered, a supportive end of life approach to dementia care would call for consideration of whether a decision to stop offering food or fluids to the person at the end of their life may instead be in their best interests. This decision is a very personal and individual one which must be based on both the documented wishes of the individual as well as an understanding of the medical circumstances.

Ceasing food and fluids at this point in the disease will lead to dehydration which in turn will lead to death, it is very unlikely at this stage that the person would have any appetite or any sensation of feeling hungry or thirsty.¹⁵ Instead of discomfort, dehydration can lead to the production of natural analgesics, when the body's breakdown of fat results in ketosis and other chemical changes which provide a feeling of calm and comfort.¹⁷

A paper written by palliative care nurses indicates that: *'death from dehydration is typically a pain-free and peaceful process ...terminal dehydration is relatively quick and painless occurring in less than 2 weeks, it is believed dehydration actually minimises suffering through altered sensations or the production of an analgesic effect'*.¹⁸

In some circumstances there may be a case for putting up fluid in a drip. This approach is considered palliative if dehydration precipitates an electrolyte imbalance (electrolytes are substances such as sodium and potassium) which can cause symptoms such as headaches, confusion, restlessness, irritability, nausea and vomiting.¹⁹ Therefore putting up a drip with an infusion of substances such as saline (or fluids with a particular electrolyte component) may bring comfort. However, studies have also found that people who are treated with subcutaneous fluids can become 'waterlogged' and have to be treated with medications to remove fluid from the body when limbs become swollen²⁰.

Dysphagia

The other important issue relating to terminal dehydration is the loss of the ability to swallow in the late stage of dementia. This is called dysphagia. When a person with dementia begins to choke it is usually because the illness has made swallowing food difficult or even impossible. Again, this is a typical sign of late stage dementia, and excluding other medical complications, often a sign of approaching death. Dysphagia is common in nursing home residents, with up to 60% of residents having clinical evidence of this swallowing disorder. It is recommended that making an order for *'nil by mouth'* for people with dementia with suspected dysphagia is the strongest measure that can be taken to prevent choking and pulmonary aspiration.²¹ Again, this is hard for families to cope with, but a much more comfortable death will be achieved through dehydration than through death by fluid in the lungs which results in choking. Throughout this period mouth care is the most important comfort measure that can be supplied.

PEG feeding (also called Artificial Nutrition and Hydration (ANH))

The last issue to deal with in this section is the question of giving food and water by artificial means which is known as PEG (Percutaneous Endoscopic Gastrostomy) feeding. The procedure involves a small operation and nutrition is then provided directly into the stomach.

There are illnesses or injuries that require PEG feeding, such as an acute head injury with prolonged loss of consciousness, but for people with dementia, PEG feeding has been found to be of virtually no benefit, and can cause pain and suffering. For example, evidence shows that long term complications rate range from 32% to 70%, and that there is:

- no improvement in nutritional markers;²²
- increased risk for pressure ulcer formation;
- no prevention of oral secretion aspiration.

Also that:

- terminal diseases are not reversed by placement of PEG. There is no survival benefit for people with dementia who receive ANH²³; and
- PEG feeding may increase suffering and discomfort.

The decision about PEG feeding/ANH is often complicated by issues of ethics and cultural beliefs. The views of the person with dementia must be taken into consideration if there is an advance directive present, and discussion with palliative care service personnel may be the best way to achieve a satisfactory solution for all parties.

PART 2: ELEMENTS OF END OF LIFE CARE FOR PEOPLE WITH DEMENTIA continued

The doctor who inserts a PEG should outline the circumstances and criteria in which it is to be removed. An example of this is when a person has a major stroke and in the moment, all may agree that a PEG tube is appropriate as the person is unable to eat. Five years later, when the person has a stroke related dementia, and has not significantly recovered, the issue of removing the PEG tube may then be far more difficult. Once the PEG is in place it may simply be left in when the person is moved to an RACF and then 'taken for granted' that it will be continued.

Location

Hospital

The possibility of transfer to hospital must be discussed as part of planning for end of life care and decisions should be made about reasons which would necessitate a transfer. This information needs to be documented and clearly communicated to relevant aged care staff. This planning is important in order to reduce unnecessary hospitalisations.

Hospitals can pose greater risks for people with dementia than for other patients. The unfamiliar environment of the hospital can cause confusion and distress and may lead to an increase in cognitive and behavioural symptoms. Individuals with dementia may have difficulty communicating their needs and staff may not have the training required to communicate with the individual. These difficulties can lead to increased lengths of stays and an increased risk for complications. Estimates from NSW hospitals suggest that people with dementia stay in hospital almost twice as long as those without dementia.²⁴ Family and health professionals should ensure, when hospitalisation is essential, that the person receives appropriate support and care and does not stay in hospital longer than necessary.

One of the most common reasons for hospitalisations for a person with dementia is a fall. Falls are very common as the disease progresses and can lead to serious fractures that require hospitalisation or even surgery to alleviate discomfort and pain. If the person is hospitalised, care must be taken to ensure that they receive appropriate dementia care. In many cases it is better for the person with dementia to be treated outside hospital. This may be possible if there is a system of portable X-Rays available so that the person can be X-rayed and treated at home or in the RACF in which they are living. Unfortunately, this system only operates in some states in Australia and is not widely available.

Hospitalisation is common at the end of life of a person with dementia. It is important that family and health professionals are prepared for symptoms associated with impending death so that an ambulance is not called due to concerns over symptoms experienced by the person with dementia. Once an ambulance has been called, then ambulance officers are obliged to commence resuscitation and the person will be given further 'curative' treatment in the acute setting, often in spite of advance wishes being documented. In a RACF casual staff may not know the person with dementia and may call an ambulance to ensure they 'don't get into trouble' for the person dying. Well documented information and a thorough hand-over process is the only way to avoid these situations.

Home versus residential aged care

Most people want to die at home, surrounded by familiar things and people who care and have cared for them deeply over a long period. Many individuals with dementia utilise home care packages to enable them to live at home for longer. Access to home care packages will increase over the next five years as a result of the **Living Longer. Living Better.** Aged Care reforms. However, realistically, community care is only possible as the disease progresses if there is an informal carer who is able to assist the person with dementia in addition to formal services. Even when an informal carer is available it may become too difficult for them to continue to support the person at home. Caring for someone with dementia in the later stages of the disease is challenging.

Regardless of whether an individual is in residential care or living at home they should have access to good end of life care. The family can assist by informing staff about the wishes of the person and being clear and straightforward in talking about death. This is not to negate the difficulties, as one relative expressed them when telling her mother's story:

*'It is now three years that my mother has lived in the nursing home. At the beginning of these three years my emotions were running riot. I would go from guilt to relief, sadness to sorrow, anger to sheer frustration'*²⁵

As her mother settled into the nursing home and became frailer, this daughter became part of the nursing home family, visiting every day and helping staff in all sorts of ways which helped her feelings of guilt and sorrow. She was able to assist in her mother's peaceful and dignified death when the time came.

²⁵ NSW Government (2011) At home with dementia: a manual for people with dementia and their carers. http://www.adhc.nsw.gov.au/__data/assets/file/0011/228746/at_home_with_dementia_web.pdf

[†] [http://www.health.gov.au/internet/main/publishing.nsf/Content/400BE269B92A6D73CA2578BF00010BB0/\\$File/COMPAC-30Jun11.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/400BE269B92A6D73CA2578BF00010BB0/$File/COMPAC-30Jun11.pdf)

PART 2: ELEMENTS OF END OF LIFE CARE FOR PEOPLE WITH DEMENTIA continued

Particular issues for end of life care at home

There are many publications that can assist with information about providing end of life care in the community. For example a useful recent research report, 'Bringing Our Dying Home: Creating Community at End of Life' discusses best practice in end-of-life care in the community. However, although this deals comprehensively with end-of-life care in the community, as so often happens, the particular needs of people with dementia are not discussed²⁶. A NSW manual^e discusses many practical aspects of care; and the 'Guidelines for a Palliative Approach for Aged Care in the Community Setting: Best practice guidelines for the Australian context' are available online.^f

Research shows that, as in residential care, Behavioural and Psychological Symptoms of Dementia²⁷ (BPSD) are the most common cause of strain for the family and health professionals caring for the person with dementia. It is a difficult task for a family to keep a person with dementia home until death. In some circumstances it can be done, with planning, organisation and realistic goals, such as respite for carers, support from palliative care services and the right equipment. Planning for end of life care at home should include a case conference involving the GP, all family members, community services who are assisting and anyone representing the spiritual or religious needs of the person, if appropriate. The agreements from this conference should be recorded and available for anyone to see. Most of all, the death itself and any deterioration preceding this must be planned carefully, so that the person is kept comfortable and pain free and not rushed to hospital at the last minute. It is important that people know the signs of imminent death and are supported with this.

Particular issues for end of life care in residential care

Inexperienced staff, new staff or staff from different cultures may struggle with coping with a palliative/ supportive approach to end of life care. The only solution to this is a case conference with close family involvement, with results clearly written in the case notes. Education is also necessary so that staff understand the need to adhere to the wishes of the individual with regards to their end of life care. If family and staff have good communication they may feel more comfortable with supporting a person towards a peaceful and pain free death instead of persisting with a curative regime.

Signs of imminent death:

- The skin is likely to have a grey tinge or pallor. Extremities, such as lips and the nail beds may become bluish;
- The person is likely to start feeling cold, with their temperature dropping;
- Blood pressure will fall;
- Pulse is likely to become irregular until it slows and eventually stops;
- Breathing is likely to become shallow, with Cheyne-Stokes breathing (shallow and laboured);
- A death rattle may be present.

These signs may be difficult for family members, but if they are anticipated, and the person receives adequate pain relief and support, then that is a good death, for the person, and the people sharing that with them.

The death rattle, one of the signs of impending death, is a noisy, chesty rattling breathing that can occur close to a person's death. There appear to be two reasons for the death rattle, "*type I is caused by an accumulation of salivary secretions when swallowing reflexes are inhibited and type II is caused by an accumulation of bronchial secretions in patients too weak to cough effectively*".²⁸

This symptom can be very distressing for families and many ask questions such as, "*Is my mother going to drown to death?*" and also ask for the person to be 'suctioned'. Far better treatment, and much more comfortable for the dying person, is the administration of appropriate medications and the reduction of any fluids. Drugs that dry up a person's secretions (e.g., hyoscine hydrobromide) are useful²⁹ but choices will depend on the doctor or palliative care nurse attending to the person with dementia. It appears that the death rattle is not uncomfortable for the person if adequate pain relief and reduction of mucus occurs.

Wrestling with death and dementia is a challenge for the individual with dementia, the family as well as care providers. It is crucial that there is good communication about issues relating to end of life care early in the disease when the individual with dementia can be supported to document their care wishes. As the disease progresses it is critical that families are aware of the various components of end of life care in order to advocate for the best possible end of life care for their family member. Communication and open discussions about death, dying and a supportive approach to end of life care are critical.

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