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Dr Ian Holland
Committee Secretary
Senate Standing Committees on Community Affairs
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By email: community.affairs.sen@aph.gov.au

Dear Dr Holland,

Senate Community Affairs Committees Inquiry into Palliative Care in Australia
Additional Material from Alzheimer's Australia

During our appearance before the Committee on 24 April, Alzheimer's Australia undertook to provide additional information on aspects of the current palliative care guidelines in need of revision, and on palliative care services for people with dementia in the states and territories of Australia.

We have consulted with Alzheimer's Australia organisations and with other stakeholders around Australia, and are pleased to provide our response and recommendations.

I would like to acknowledge Professor Jenny Abbey in particular for her assistance in developing the response to the question on guidelines.

We trust that this information is useful, and please feel free to contact us again if we can be of any other assistance.

Regards,

Glenn Rees
CEO, Alzheimer's Australia

30 May, 2012

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FOLLOW UP SUBMISSION TO THE COMMUNITY AFFAIRS COMMITTEE ON PALLIATIVE CARE

ALZHEIMER'S AUSTRALIA

30 May, 2012

Contents

1 Background

During our appearance before the Committee on 24 April, 2012, Alzheimer's Australia was asked to provide further information in response to two questions:

1. How should the existing guidelines in respect of palliative care be reviewed and revised to provide better outcomes for people with dementia?
2. What view does Alzheimer's Australia have at the State and Territory level of the existing provision of palliative care services?

As well as responding to these two questions, Alzheimer's Australia would like to take the time to comment on the utility of the Aged Care Standards in delivering palliative care to people living with dementia in nursing homes.

2 Summary and Recommendations

2.1 Guidelines

Both the community and residential palliative care guidelines fall short of the mark with respect to dementia, particularly in the difficult areas of force feeding, terminal dehydration, and patient's wanting to die. In part, this is because the recommendations contained in the guidelines require a relatively high level of scientific evidence for endorsement by the NHMRC, and in many of these difficult areas, despite lots of practical knowledge and anecdotal evidence, the more rigorous research has simply not been undertaken.

The more recent community palliative care guidelines are better than the older guidelines for a palliative approach in residential care, particularly when considered alongside the associated practice guides for care workers and for family carers. The residential care guidelines are in urgent need of review, with attention to the specific needs of people with dementia.

> **Recommendation 1.** That the guidelines for a palliative approach in residential care are urgently reviewed, with a particular focus on the needs of people with dementia, and a section on the difficult issues of force feeding, terminal dehydration and 'wanting to die', despite limited evidence in these areas.
>
> **Recommendation 2**. That practice guides for care workers and residential care managers are produced alongside updated guidelines for a palliative approach in residential care, as per the practice guides associated with the community palliative care guidelines.

Most of the end-of-life care delivered to people with dementia is provided by general health or aged care workers, with assistance and support from palliative care professionals only as needed. As palliative care guidelines are unlikely to be used or adopted by generalists, there is a need to develop a more general set of guidelines for the care of people with dementia that deal with the same end-of-life issues in a way that is more appropriate for non-specialist health and aged care professionals. These guidelines should reference the palliative care guidelines (both residential and community care), and emphasise the need for consultation with palliative care specialists from the point of diagnosis on.

> **Recommendation 3**. That new guidelines for the care of people with dementia for non-specialist care workers and healthcare professionals be developed in consultation with consumers, researchers and other key stakeholders.

2.2 Australian palliative care services for people with dementia

Consultation with Alzheimer's Australia state and territory organisations and other key stakeholders revealed that palliative care services, on the whole, are difficult to access and are not meeting the needs of the majority of people with dementia.

There are, however, isolated examples of good practice. These include:

- **Models of care**. The Liverpool Care Pathway and the Gold Standards Framework are general palliative care models that work reasonably well for people with dementia, and have been adopted by a number of jurisdictions. There are also models developed specifically for end-of-life dementia care such as the Integrated Care Framework for Advanced Dementia developed by HammondCare
- **Community Palliative Care Services in Residential Aged Care**. The most effective services for people with dementia are community palliative care services that provide outreach into residential aged care facilities (where the majority of people with advanced dementia live) in either clinical or advisory capacities. The biggest problem with such services is that they are inconsistently available and funded through a variety of internal, local, state or Commonwealth funding.

The ***Living Longer Living Better*** aged care reform package has set aside funding to improve palliative care services by:

- increasing specialist palliative care and advance care planning advisory services in residential and primary care;
- expanding the Program of Excellence in the Palliative Approach (PEPA) training program; and
- reducing hospitalisation.

It is vital that this new funding and the resulting programs build on what we know, and ensure increased consistency in palliative care funding and service availability for people with dementia across Australia.

> **Recommendation 4**. That the Commonwealth and the States work together with stakeholders to implement the palliative care measures in the aged care reform package in a way that increases consistency around best practice models of palliative care for people with dementia, and makes available greater funding for specialist community palliative care services to provide clinical and advisory services to residential and community aged care.

Finally, the legislation, requirements and terminology for advance care planning (a vital element of palliative care for people with dementia) are inconsistent between jurisdictions in Australia, and this inconsistency poses a significant barrier to greater uptake of advance care planning. With the rollout of the Personally

Controlled Electronic Health Record providing a prime opportunity to promote advance care planning, it is vital that this inconsistency be addressed.

> **Recommendation 5.** That the national framework for Advance Care Directives[1] be implemented in full by all Australian governments

2.3 Aged Care Standards and Palliative Care

One of the 44 aged care standards relates specifically to palliative care provision in residential aged care. However, this is difficult to assess, and is considered in the context of all of the other outcomes. Consequently, the current standards fall short of what is required to ensure quality palliative care in residential aged care facilities, particularly for people with dementia.

Living Longer, Living Better priorities greater transparency in respect of monitoring quality and outcomes, and this is a priority that Alzheimer's Australia strongly supports. The development of In the context of palliative care for people with dementia, it will be important to work with academics, clinicians, service providers and consumers to design outcomes that are meaningful, transparent and measurable.

> **Recommendation 6.** That priority is given to developing transparent outcomes for end of life care in the process of developing relevant and transparent national aged care quality indicators and a rating system.

3 Palliative Care Guidelines

The palliative care guidelines currently approved by the National Health and Medical Research Council are:

1. Guidelines for a palliative approach in residential Care (May 2006)
2. The guidelines for a palliative approach for aged care in the community setting (2011).
    a. Associated booklets for community care workers entitled: “How a palliative approach can help older people receiving care at home: A booklet for Care Workers”, and “How a palliative approach can help older people receiving care at home: A booklet for older adults and their family carers”

Alzheimer’s Australia believes that if end-of-life care does not take into account the specific needs of people with dementia, it is highly likely to fail them, resulting in reduced autonomy for the person with dementia, and avoidable physical and emotional distress for both the person and their family members.

Consequently, there is a need to ensure the very particular needs of people with dementia are recognised at end-of-life in ways that ensure palliative care delivers the same benefits to people dying with dementia as people dying with cancer or other terminal conditions.

Guidelines are only one element of the necessary comprehensive approach that includes increasing awareness and understanding of dementia, delivering better training to medical practitioners and care workers to allow them to provide necessary information, support and care to people with dementia from first presentation of symptoms until death, and increasing the flexibility of services available to people with dementia and their carers. Guidelines are, never-the-less, very important.

The following section examines the community care guidelines and the residential care guidelines in turn, highlighting the positives in each, and suggesting necessary changes. We also suggest the development of a set of dementia specific end-of-life care guidelines that can be used and promoted in conjunction with the palliative care guidelines or separately by those who are caring for people living with dementia, but would not consider themselves to be involved in or responsible for the delivery of palliative care.

3.1 Community Care Guidelines

The guidelines for a palliative aged care in the community setting go further than the residential care guidelines by providing specific guidance on caring for people with dementia across seven main areas:

1. a palliative approach in the community;
2. family carers;

3. advance care planning;
4. symptom management;
5. psychosocial care;
6. spiritual support
7. specific sections about older people with particular cultural needs or perspectives

3.1.1 What works well?

The booklet for care workers associated with the community care guidelines is helpful in outlining clear strategies which do assist in good end-of-life care for people with dementia For example the "practical tips" in relation to symptoms[2] are as follows

Practical tip

It will help health care professionals to manage symptoms if you make detailed notes on:

1. what the symptom was and how it felt (Example: Dull ache in the back)
2. when the symptom occurred (Example: Woken by this in the night)
3. what was done to ease (Example: My carer rubbed my knee and gave me a hot pack)
4. the effect of what was done (Example: The pain went away in about 10 minutes)
5. how long it took to work (Example: The pain went away in about 10 minutes) Family and friends can help you to keep these records.

And in relation to dehydration:[3] "It is sometimes not appropriate to try to get an older person to drink when they are extremely frail or unwell — such as when death is approaching."

Practical tip: When an older person becomes so frail or unwell that they have difficulty drinking, ice chips may make them feel more comfortable. Ask your supervising health care professional if this would be appropriate.

3.1.2 What needs to change?

As is usually the case, the guidelines stop short in discussing unsafe or force feeding. For example this is what is included in relation to feeding in the care booklet;[4]

The following strategies are generally useful when a care worker is helping an older person with swallowing difficulties:

- providing meals in a quiet place with no distractions
- making sure that the older person takes small mouthfuls and eats slowly
- making sure that the older person avoids talking while eating
- making sure that each mouthful has been swallowed before another is taken
- positioning the older person sitting upright with the head forward (i.e. not leaning back) when meals or drinks are taken and for at least 30 minutes afterwards

However, the following information is **not** included, and this is where the ethical and the "not allowed" aspects enter care – even people putting out guidelines feel uncomfortable including the following kind of statement and this is where many nurses and care workers face ethical dilemmas.[5] [6]

Force feeding, which is uncomfortable for the person receiving the force, can be very dangerous due to the strong possibility of fluid getting into the lungs causing a probable aspiration (fluid in the lungs) pneumonia.

Force/unsafe feeding is characterised by such actions as:

- Using devices such as syringes to dribble water into the mouth;
- Pouring fluid from a spouted cup;
- Putting food into the mouth before the last mouthful has been swallowed;
- Persisting with feeding when the person with dementia is rejecting the action by turning their head away, rejecting the food;
- Giving food or water to a person with advanced dysphagia.[7]

Including practical instances such as these, and discussing issues such as terminal dehydration are examples of the steps that go further than the present guidelines

3.2 Residential Care Guidelines

3.2.1 What needs to change?

The guidelines in respect of residential care are out of date, and in many cases, do not contain adequate information. There are inadequate references to dementia particularly in respect of:

- **Advance care planning for residents with dementia**; limited to very general and nonspecific information (Chapter 4 page 57 Section 4.2)
- **Advanced dementia**; limited to very general nonspecific information (Chapter 5, pages 61-67)
- **Psychological support**; some useful specific recommendations, but limited information overall (Chapter 7 pages 126 and 127 Section 7.5)

The Guidelines for a Palliative Approach in residential care are due to be updated, according to NH&MRC guidelines. However, if the same approach is taken by the NH&MRC as was taken with the Community Guidelines, where only evidence in published papers is used, there will still be many limits to their usefulness.

Alzheimer's Australia recommends that the residential aged care guidelines like the community guidelines should address key issues in respect of dementia.

3.2.2 Dementia specific end-of-life care guidelines

We believe that it would also be helpful to prepare self contained guidelines on the palliative approach to dementia that would provide a better focus for training and best practice in the aged care sector. The “Planning for Palliative Dementia Care, Resource Guide” prepared by ACH Group in South Australia provides a good starting point. These guidelines are written in clear, plain English and are “practice based” rather than “evidence based”, although they are supported by evidence where it is available. These guidelines do, albeit briefly, raise the issues of ‘wanting to die’ and ‘terminal dehydration’.

We believe that the opportunity in preparing dementia guidelines should be taken as an opportunity to discuss a number of key issues around:

- Terminal dehydration
- Pain relief specifically for people with advanced dementia
- Not wanting to be kept alive

These issues are sensitive and there is inadequate academic evidence on which to base best practice. It is for example, a matter of difficult judgement when to stop feeding. Many nurses would stop feeding but feel that “they are not allowed” to exercise their judgement and allow the individual to peacefully start on their end of life journey. These things are difficult to capture in guidelines and are more a question of staff having the confidence to exercise their judgement in the knowledge that their senior management will support them. The end result of staff not being confident is that individual lives are prolonged often in very difficult circumstances and frequently against the wishes of the family.

It will be important that the revision of the existing residential guidelines and the dementia specific product that we believe is necessary are accompanied by an active education and training strategy. Arguably end of life care of people with dementia should be a compulsory part of Certificate III and IV.

4 Palliative Care Services in Australian states and territories.

In response to the Committee's question, Alzheimer's Australia National Office has consulted with Alzheimer's Australia organisations in each state and territory, as well as a number of other stakeholders.

The general consensus is that access to palliative care services for people with dementia is poor throughout Australia.

At the same time, there are instances of innovative and high-quality palliative care services and programs for people with dementia. Although these are generally not state-specific, they are described according to the state or territory in which they operate in the following.

In addition, there is significant variation between states and territories in legislation and arrangements for advance care planning; a critical element of palliative care for people with dementia that does vary substantially between states and territories. These have been described in detail by Professor Colleen Cartwright in the publication *Planning for the End of Life for People with Dementia, Part 1*[8], and are included here for the Committee's reference in Tables 1 and 2.

Table 1: Terminology used in each state/territory for Advance Care Planning for health-related matters

	Written Instructional Directive	**Patient-Appointed Agent/Proxy**	**If No-one Appointed by Patient**
ACT	Health Direction	Medical Agent; or Attorney for Medical Treatment under Enduring Power of Attorney	Health Attorney: in priority order - domestic partner; care; close relative or friend
NSW	Common Law Advance Directives	Enduring Guardian	Person Responsible: in priority order – spouse (includes de facto and same-sex); carer; close relative or friend
NT	Advance Directive	No provision	No provision
QLD	Advance Health Directive	Enduring Power of Attorney for Personal/Health matters	Statutory Health Attorney: priority order same as NSW
SA	Advance Directive or Living Will	Medical Agent appointed under a Medical Power of Attorney; or Enduring Guardian	Contact the SA Office of the Public Advocate for directions
TAS	Common Law Advance Directive	Guardian	Person Responsible: in priority order – spouse; carer; close relative or friend
VIC	Refusal of Treatment Certificate	Medical Agent – appointed under EPoA Enduring Guardian with health care powers Person appointed in writing to make decisions about medical/dental treatment including the proposed treatment	Person Responsible (apart from patient or VCAT- appointed person) in priority order – domestic partner, primary carer, nearest relative over 18
WA	Advance Health Directive	Enduring Power of Guardianship	Contact the Office of the Public Advocate WA for directions

Table 2: Summary of National Law Relating to Advance Care Planning, June 2010

	Written Directive	**Patient-Appointed Agent/Proxy**	**Comments**
ACT	**YES**	**YES**	*Powers of Attorney Act 2006* allows an adult to give a direction about the refusal or withdrawal of medical treatment. There is no requirement for the condition to be current or terminal. It also provides for appointing an Enduring Power of Attorney/agent for medical decisions.
NSW	**YES**	**YES**	The NSW Health document *Using Advance Care Directives* (2004) encourages the use of common law advance directives; *NSW Supreme Court case 2009* confirmed that they are legally binding. The *Guardianship Act 1987* allows a person 18 years or over to appoint Enduring Guardians as substitute decision-makers.
NT	**YES**	**NO**	*Natural Death Act 1988* allows a person 18 years or over to make an advance directive to refuse extraordinary treatment in the event of a terminal illness.
QLD	**YES**	**YES**	*Powers of Attorney Act 1998* and *Guardianship & Administration Act 2000* allow a person 18 years or over to make an advance directive to consent to or refuse treatment and to appoint an Enduring Power of Attorney for health matters to consent to or refuse medical or dental treatment.
SA	**YES**	**YES**	*Consent to Medical Treatment and Palliative Care Act 1995* allows a person 18 years or over to write an advance directive that refuses consent to medical treatment for the terminal phase of a terminal illness and appoint an agent/ medical power of attorney as a substitute decision maker.
TAS	**NO**	**YES**	*Guardianship and Administration Act 1995* allows a person 18 years or over to appoint Enduring Guardians as substitute decision makers.
VIC	**YES**	**YES**	*Medical Treatment Act 1988* allows a patient to write a “refusal of treatment” certificate, but only for a current illness, which does not have to be terminal. The legislation also allows appointment of an agent/substitute decision maker who can refuse treatment.
WA	**YES**	**YES**	*The Acts Amendment (Consent to Medical Treatment) Act 2008* allows an adult to write an advance directive to consent to or refuse treatment for a current condition or terminal illness and to appoint an Enduring Power of Guardianship as a substitute decision maker.

4.1 Queensland

4.1.1 Queensland Health Metro South Health Service District

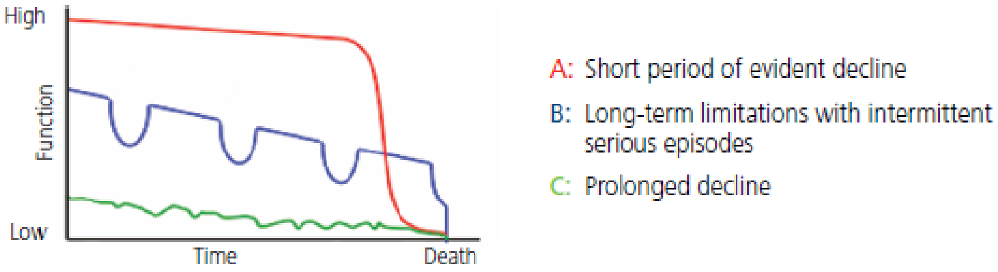
This Health Service provides palliative care across community, hospital and residential aged care services. The residential care component includes the only dedicated team in Queensland providing services in residential care facilities and many of the residents seen by the service have dementia. This team was developed in the mid-2000s with a Qld Health grant for Pilot Nurse Practitioner Candidate Positions, and has been established as an ongoing service within the Health Service District over the past seven years. The team includes a palliative care physician, a specialist palliative care Nurse Practitioner, and palliative care nurses.

This team works with the treating GP to develop an initial care plan, and to manage complex care, with implementation of the plan left to the GP and staff. It has developed an end-of-life care pathway for residential aged care based on the UK Liverpool Care Pathway model that has been taken up across the whole of Qld Health.[9] This team provides services across all of the 80 residential care facilities in the Health Service District, and has developed good networks and referral pathways amongst local primary and acute care providers.

4.2 South Australia

4.2.1 SA Health Palliative Care Services Plan 2009-2016

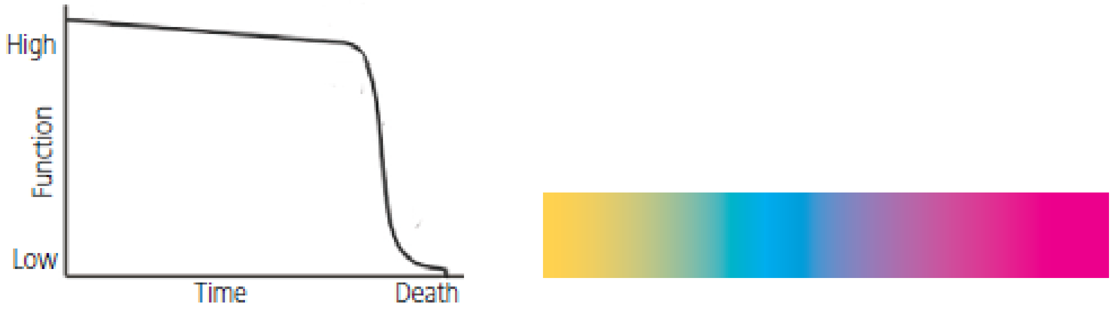
This plan sets out a framework and structure for the development of palliative care services within SA Health. This plan emphasises the need to enhance opportunities for home-based palliative care and the need to build capacity, and includes plans to increase the widespread uptake of advance care planning. It also discusses the need to deliver care services according to end-of-life trajectories, using a model adapted from Lynn and Adamson[10], and shown in the figures below (pp 5-6).



Taken from Lynn & Adamson (2003)

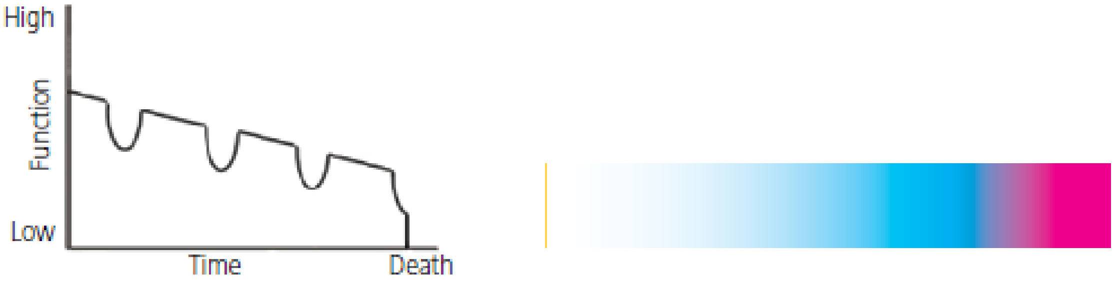
Trajectory A: Short period of evident decline

Mostly cancer



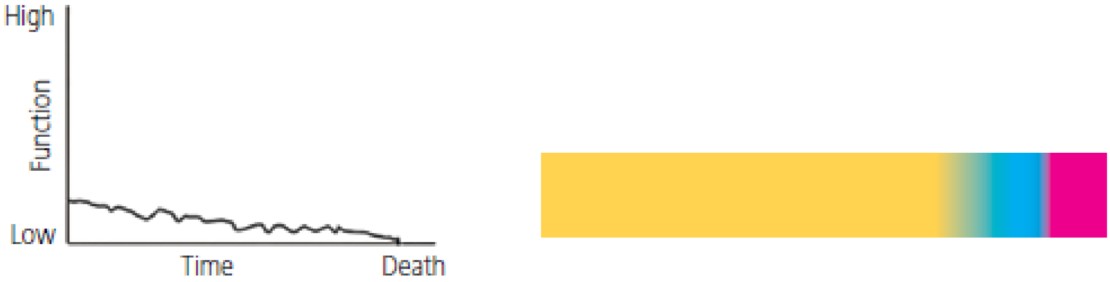
Trajectory B: Long-term limitations with intermittent serious episodes

Mostly heart and lung failure



Trajectory C:: Prolonged decline

Mostly frailty & dementia



🟨	End of life care provided by generalist providers without assistance from specialist providers of palliative care.
🟦	End of life care led by generalist providers with some level of continuing or occasional direct input from specialist providers of palliative care.
🟪	End of life care led by generalist providers with some level of continuing or occasional direct input from specialist providers of palliative care.

While useful, and perhaps reflective of optimal palliative care provision at present, this framework falls short of Alzheimer's Australia's recommendations by envisaging specialist palliative care services for people with dementia as limited to the final stages of the condition, rather than being available as needed throughout the journey. This is too late for advice or implementation of palliative issues such as end-of-life care planning and medical decision making.

4.2.2 ACH Group

ACH Group is a leading provider of housing, community and residential aged care services in SA and Victoria. The organisation has a track record of innovation and leadership in dementia care, and the organisation maintains a dementia learning and development unit to ensure skills and capacity amongst their workforce.

Key resources for people with dementia developed by ACH Group are the *Planning for Palliative Dementia Care Resource Guide* and the associated *Planning Ahead: An Information Guide for People with Dementia and their Families.* These resources were developed with funding from the Commonwealth through the local palliative care funding program, and were based on previous work by ACH Group and others, as well as a comprehensive review of available evidence. In addition, ACH Group has developed a DVD for Aboriginal Elders in SA providing information and promoting the benefits of advance directives to assist them to plan for end of life care. These resources are targeted at family carers, nurses, care managers and care workers rather than general or specialist medical practitioners. However, they provide a very useful tool that has been used with a large number of ACH Group staff and family carers. The result has been a modest increase in provision of quality palliative care for people with dementia across ACH Group's community and residential aged care clients. It has also strengthened the relationship with community palliative care agencies who provide advice to ACH Group staff in managing palliative care and access to palliative care specialists when needed. A recent program of funding through the SA Palliative Care Council allocated Commonwealth palliative care equipment funds to replace Graseby syringe drivers for pain relief in our community nursing services. However, significant barriers remain; for example, convincing GPs to do home visits or palliative care case conferencing for people with dementia in the community; obtaining necessary GP referrals to specialist palliative care services, particularly for people receiving community care; or obtaining a community palliative care package at all with a primary diagnosis of dementia (if dementia is a secondary diagnosis, alongside a diagnosis of cancer, for example, this is somewhat easier).

Following the development of these resources, ACH Group undertook training with international expert Joyce Simard to trial the *End-of-life Namaste comfort care model for people with dementia*[i] (Namaste is a Hindi greeting meaning 'honouring the spirit within') for people with dementia in residential and community care. The program allowed staff to take people with advanced dementia (in the last 6-12 months; those who were bed-bound at least 50% of the time) in small groups in sensory rooms on a daily basis, to provide sensory care, facial, foot and hand massage etc, warm blankets, soft things to hold – aimed at giving people a real sense of comfort. The result was better sleep and less agitation. The program is offered now at two time points: during the last 6 months if there is distress, and in the last few days (calming terminal restlessness) and providing families and staff with techniques of comfort care for the person. While successful, this model was very intensive – requiring training for staff and families and one to one staffing overnight. These approaches in combination with good pain control medication and repositioning are similar to what is found in hospices. However, most people with dementia do not die in hospices. Adequate funding this kind of intensive work would be through a palliative care allowance for people with dementia in addition to their regular support service, or a combination of EACH-D and Community Palliative Care package. Elements of this approach have been incorporated into residential and community services provided by ACH Group.

Finally, in cooperation with a project by Resthaven, ACH Group offered expertise and training for care workers on the use of Montessori based interventions for people with advanced dementia at home to provide some stimulation and distraction from agitation . A gap in services however is the availability of multidisciplinary support and counselling for staff and families during the long and unpredictable end of life phase. Existing pastoral care services within church based services such as Resthaven provide this support at present and would be worth expanding to allow those services not religiously affiliated to provide this needed service.

4.3 Victoria

4.3.1 Palliative Care Consortia

Victoria has a well-developed palliative care system that operates through palliative care consortia linked to each of the states eight health regions (3 metro, 5 regional). These collectives are funded by the State Government, were established in 2004, and are led by a mix of health regions, community palliative care providers, GP networks (transitioning to Medicare Locals), and community organisations.

These consortia comprise all funded palliative care services in each region as well as other stakeholders from health and community services. They:

- undertake regional planning in line with departmental directions
- coordinate palliative care service provision in each region
- advise the department about regional priorities for future service development and funding
- in conjunction with the Palliative Care Clinical Network implement the Victorian palliative care service delivery framework and undertake communication, capacity building and clinical service improvement initiatives.[11] This framework recommends the use of the Liverpool Care Pathway that has been found to work well in the context of cancer[12]. However, concerns have been raised as to its suitability in the context of dementia.[13]

Specialised palliative care services are available through health professional or self/carer referral through community based providers, e.g. Eastern Palliative Care Services. However, as with other palliative care services around Australia, the majority of clients are those with cancer, and while the services have the skills to provide appropriate care to people with dementia, a range of systemic factors limit access to these benefits.

4.3.2 Aged Care Link Nurses

A new initiative of the Victorian State Government is the establishment of an aged care link worker program. This program will provide recurrent funding for eight aged care link nurse positions (one in each of the palliative care consortia). These positions will not be involved in clinical aspects of palliative care. Rather, they will work with local residential aged care providers to:

- build capacity and understanding of palliative care amongst staff and management in areas such as advance care planning, pain management, nutrition and hydration
- connect aged care providers with local palliative care services, and
- act as a resource to help facilitate better palliative care outcomes for people dying in residential aged care facilities, the majority of whom will have dementia.

This program will be limited to residential aged care providers and will not extend to community aged care providers at this stage.

4.4 NSW

4.4.1 HammondCare

HammondCare is a large community and residential aged care provider and hospital operator with specialist dementia and palliative care teams. The organisation has collaborated with a number of key stakeholders to develop and pilot an evidence-based dementia-specific *Integrated Care Framework for Advanced Dementia* (ICF-D) under the Department of Health and Ageing’s Local Area Palliative Care Grants program round 5. The ICF-D is a framework for incorporating guidance on specific care for palliative issues in advanced dementia and communication needs of family, comprehensive learning modules for staff, resources for continuous practice quality improvement and brochures and facts sheets for caregivers. The ICF-D is developed with stakeholders, consumers, families, care staff, GPs, and specialists, and informed by national and international guidelines, policies, and high-quality published evidence. Further work to develop and extend this project and make it available to aged care providers across Australia is commencing in mid-2012 with funding from the Alzheimer’s Australia National Quality Dementia Care Initiative.

4.4.2 Palliative Care NSW

Palliative Care NSW has developed a suite of information resources on Advance Care Planning for people with dementia living in NSW. These materials were developed in partnership with Alzheimer’s Australia (NSW) as part of the Local Palliative Care Grants Round 5 funded by the Department of Health and Ageing, and have been well received.

4.5 Tasmania

Tasmania's Cradle Coast council is working in partnership with the North West Area Health Service and the University of Tasmania on a government funded pilot the adoption of the Gold Standards Framework across local residential aged care facilities. The Gold Standards Framework was developed in the UK as a multidimensional training program to teach and support aged care workers and other healthcare professionals to recognise, assess and respond in a structured way to the needs of residents in the last year of life, and to promote multidisciplinary communication and care. The Gold Standards Framework was not developed specifically for dementia, however UK evaluation has shown that it can halve rates of hospitalisation and hospital deaths from residential care.[14]

4.6 Western Australia

Silver Chain, the largest community health and aged care provider in Western Australia, has an innovative model of community-based palliative care that multidisciplinary and specialist palliative care services to people living in their own homes throughout the Perth metropolitan area. This service is available through GP referral and while the majority of referrals are still related to cancer, the program is sufficiently flexible to cater for and provide intermittent services to people with dementia relatively early in the disease process (i.e., before the advanced stages of the condition). The service is funded primarily through the WA Department of Health and the Department of Veterans affairs, and admits over 3000 people per annum.

4.7 Northern Territory and ACT

Consultation with Alzheimer's Australia organisations and other stakeholders in ACT and the Northern Territory revealed that residents with dementia have significant problems in accessing appropriate palliative care in these Territories (as in many other places in Australia), and that to the best knowledge of those consulted, there are no innovative services or programs specifically designed to assist them.

5 Aged Care Standards and Palliative Care

5.1 Overview

Achieving greater transparency in respect of monitoring quality and outcomes is set as a priority in ***Living Longer, Living Better*** and one Alzheimer's Australia strongly supports. Designing outcomes that are measurable is a complex task not least in the context of dementia and end of life but it is one to which Alzheimer's Australia recommends priority should be given in the reform of aged care.

5.2 Palliative Care-Related Standards

There are four main Aged Care Standards related to the accreditation of residential aged care facilities:

- Management systems, staffing and organisational development
- Health and personal care
- Resident lifestyle
- Physical environment and safe systems.

Each Standard is broken up into various outcomes (44 in total) that inter-relate and are rated as part of a matrix. This makes it difficult to look at particular outcomes in isolation. Assessors consider the impact on residents and also the strengths of each facility's systems and processes related to the individual outcomes and ultimately the standard.

For example, nurses complain that they are often asked about resident's 'weights' when Assessors are checking nutritional standards – if Assessors find, for example , that 50% of the residents have not been 'weighed' every month, or that residents' have lost weight , they do not appear to cross check to see if these residents are in the late stages of a dementing illness, or , indeed , receiving palliative care , where weight loss would be expected. Instead the facility might be criticised over this Standard.

In considering Palliative Care the outcome is 2.9 which states:
"The comfort and dignity of terminally ill residents is maintained".

The focus of this expected outcome is *results for residents*.

5.3 Results for Outcome 2.9

- That management can demonstrate that the practices of the home maintain the comfort and dignity of terminally ill residents.
- That residents or their representatives confirm the home's practices maintain terminally-ill residents' comfort and dignity

5.4 Processes contributing to Outcome 2.9

Assessors consider:

- How the home ensures palliative care assessments are conducted and communicated as part of an ongoing documented assessment of the resident's health status. Assessors consider whether this includes:
  - consultation with residents/representatives and others (medical officers and health professionals) about palliative care needs and preferences including the resident's specific physical, emotional, cultural, and spiritual needs
  - consultation with family and friends regarding the care environment and their role in the resident's care
  - residents/representatives' terminal wishes are recorded and respected (this may include a living will).
- How palliative care plans are developed and communicated to the relevant staff as part of the general care process? This should include:
  - development of a multidisciplinary approach, including complementary therapies as appropriate with effective referral mechanisms ensuring continuity of care
  - provision of emotional and spiritual support to residents
  - specialised equipment, supplies and materials to aid the resident in the terminal stages of life.
- How the home ensures palliative care delivery is consistent with planning?
- If the home has access to:
  - a specialist palliative care provider
  - an interdisciplinary team
  - an out-of-hours service in case of death?
- How the home regularly evaluates and reviews the palliative care system to determine its effectiveness in meeting the needs of residents. For example, are:
  - staff educated about the principles, objectives and practices of palliative care?
  - staff practices monitored including in relation to the use of assessment tools, equipment, and methods of facilitating the comfort and dignity of terminally ill residents?
  - individual residents/representatives and others (medical officers and health professionals) consulted about the resident's individual ongoing needs and how effectively they are being met?
  - assessment tools monitored for effectiveness and appropriateness?

These questions and factors are all considered during a full accreditation assessment, however, this one outcome is considered along with 43 other outcomes. Anecdotal reports indicate that many assessors look at the palliative care outcomes relatively superficially (concentrating more on other issues such as pain management or medication management (outcomes 2.8. , 2,7) – as these are easier to discuss with residents and their representatives, and are also easier to assess in terms of tangible indicators.

What is often found is that documentation about a person's end of life wishes is limited to the name of the preferred funeral parlour.

In terms of processes, anecdotal reports again indicate that assessors conclude that if a home has things such as a ‘palliative care box’ (with CD’s, soft blankets, aromatherapy oils etc) then the home ‘does’ palliative care quite well, especially if they link in to either the local hospital or community palliative care service.

5.5 Assessment outcomes related to palliative care

Expected outcome 1.7 Inventory and equipment. It is expected that all appropriate equipment and supplies are accessible as and when required to aid the resident in the terminal stage of care.

Expected outcome 2.5 Specialised nursing care needs. Some aspects of palliative care may be considered specialised nursing care needs.

Expected outcome 2.8 Pain management. Pain management would be expected to play a large part in the provision of care for most terminally ill residents.

Other expected outcomes of Standard Two. Various expected outcomes relating to health and personal care are involved in the palliative care of a terminally ill resident. The focus of care for residents who are terminally ill may also change, for instance, oral and skin care may have a different focus, and processes or techniques may be employed by staff at the home to ensure this new focus is effective in maintaining the comfort and dignity of the resident.

Expected outcomes 3.4 Emotional support and 3.8 Cultural and spiritual life. Additional emotional support and cultural and spiritual care may be required for some terminally ill residents.

Expected outcome 3.6 Privacy and Dignity. This expected outcome requires that “each resident’s right to privacy, dignity and confidentiality is recognised and respected”.

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