End of Life in Dementia Care: Research Evidence to Support the Provincial Dementia Service Framework

Prepared by Penny MacCourt, PhD for CARMHA

Purpose of the Research
To identify research evidence to support the development of recommendations for End of Life (EOL) dementia care to be incorporated into the provincial Dementia Service Framework.

Method
A scan of the research literature for the period 1996 to present, guided by the following questions, was conducted.

1. What are the issues that differentiate end of life care for those with dementia from end of life care for the general population?
2. What are the emerging best practices to address these?
3. What is the strength of evidence that supports them?

Several data bases (i.e., AgeLine, CINAHL, PsychLit, Pubmed, Web of Science, Google Scholar), web sites (e.g., Canadian, Australian, New Zealand and British government sites; Alzheimer Societies; J.W. Crane Library; Canadian Study of Health and Aging) were searched using a combination of terms such as dementia, Alzheimer’s Disease, end of life care, palliative care, hospice, best practices, caregiving, care provider, policy, cardiopulmonary/CPR, antibiotics, interventions, tube feeding, hospital transfer, advanced directives, prognosis, environments, and experience. These searches resulted in 285 publications (see attached bibliography), which were examined for relevance to the topic and inclusion of research data. Most of the studies are observational studies and only a few included evaluation of interventions. Almost none of the studies are randomized control trials. Some expert opinion publications (Canadian Consensus on Dementia Care, Best Practices in Long Term Care and Guide to End of Life Care for Seniors) and reference sections of pertinent unpublished papers were also searched.

Analysis
The Strength of Recommendation Taxonomy (Ebell, Siwek, Weiss, Woolf, Susman et al., 2004) SORT, was used to rate (1) the quality of individual studies, and then (2) the strength of the resulting body of evidence that could support potential recommendations in a given area.

The quality of individual quantitative studies is assessed on two criteria: quality of patient oriented outcomes and study design.

- Patient oriented outcomes (i.e., outcomes that matter to patients such as reduction in morbidity and mortality, symptom improvement, quality of life and lower cost); are rated as good quality, limited, or none.
- The design of each study is rated using Levels of Evidence 1, 2 or 3.
  - A rating of 1 is given to SR/meta-analysis of high quality studies with consistent findings; high quality randomized control trials (RCT); high quality cohort studies for prognosis; validated clinical decision rule in a relevant population and high quality diagnostic cohort studies.
A rating of 2 is given to lower quality SR/meta-analysis, clinical trials or cohort studies; and to retrospective cohort studies, case control studies, and case series.

A rating of 3 is given to: consensus guidelines; extrapolations from bench research; usual practice; opinion; disease-oriented evidence or case series for studies of diagnosis, treatment, prevention or screening.

The SORT tool does not have a schema for assessing qualitative studies and nothing similar could be found. In keeping with the practice of Interior Health Phased Pathway the criteria of credibility, applicability (or fittingness), auditability and confirmability are used to assess the quality of individual qualitative studies. If all four criteria are met the study is included in the body of knowledge and given a Level of Evidence rating of 2.

The strength of evidence for recommendations (based on the SORT methodology) is determined by assessing groups of related studies (i.e. the bodies of evidence for particular topics) in terms of consistency of conclusions between studies and the degree to which they have patient oriented outcomes.

**A** = recommendations are based on consistent good quality patient oriented evidence.

**B** = recommendations are based on inconsistent or limited patient oriented evidence.

**C** = recommendations are based on consensus, usual practice, opinion, disease oriented evidence or case series for studies of diagnosis, treatment, prevention, or screening.

**Results**

The results from literature reviewed were combined into statements to describe the body of evidence, as follows, and then developed into potential recommendations for the Dementia Service Framework.

- **Sensory stimulation activity** in advanced dementia can increase psychological well being (Witucki & Twibell, 1997).

- **Intercurrent infections** are a highly likely consequence of advanced stage dementia (Volicer, 2005).
  - Risk of intercurrent infections can be reduced by annually vaccinating individuals with dementia, care givers and care providers for influenza (Brandels et al, 1998).
  - Oral care program reduces occurrence of pneumonia at EOL in LTC facility settings (Yoneyama et al).

- **Aggressive medical treatment** for individuals with advanced dementia is often inappropriate for medical reasons, has low rates of success and can have negative outcomes that hasten functional decline and health (Volicer, 2005).
  - CPR is unlikely to be successful (Dull et al, 1994; Benkendorf et al, 1997; Ebell et al, 1998) and where it is most survivors go to intensive care but die within 24 hours (Zweig, 1997).
  - Antibiotic therapy does not seem to prolong survival in advanced dementia and is not necessary for comfort which can be maintained through other means without antibiotics (Volicer et al, 1998). Where used the diagnostic procedures may be uncomfortable and the treatment cause adverse side
effects. (Fabiszewski et al, 1990; Volicer et al 1998; Luchins et al 1997; Hanrahan et al 1999). Irregardless of whether or not pneumonia is treated with antibiotics it cause suffering and symptomatic treatment is required (van der Steen et al, 2002).

- **Tube feeding** at EOL should be discouraged on clinical grounds (Finucane et al, 1999). Tube feeding does not increase survival of those with advanced dementia (Murphy & Lipman, 2003; Meier et al, 2001; Finucane et al, 1999), reduce the risk of infection (Gilllick, 2000) prevent aspiration or improve functional status or comfort of the individual with dementia (Gilllick, 2004; Sanders et al 2000; Abuksis et al 2000). There is considerable discord between physician opinion, reported practice and literature in regard to tube feeding at end of life (Shega et al, 2003).
  - Incidence of tube feeding can be reduced through protocol to consult palliative care team prior to doing so, and through educational program (Monteleoni & Clark 2004).
  - Education for physicians and other health care professionals needed about PEG placement for those with dementia at EOL.

- **Pain** in advanced dementia is difficult to assess and requires a combination of patient report, caregiver report and direct observations (AGS Panel on Persistent in Older Adults, 2002). Pain is often undetected (Cook et al, 1999) and under treated for those with dementia compared to those without, (Morrison et al, 2000; Kaasalainen et al, 1998).

- **Hospitalization** at EOL frequently results in functional decline that does not improve significantly at discharge (Volicer et al 2001). Aggressive medical treatment (with its’ own risks) is often used to manage confusion, anorexia, incontinence and falls that often follow hospital transfer (Ahronheim et al1996). Pneumonia can be equally well managed in facility, with better outcomes, compared to hospital treatment. (Fried et al, 1997; Mylotte et al 1998).
  - Transfer from facility to hospital is influenced by non-medical factors: nursing homes with special care units, greater physician to patient ratios and physician extenders (Evercare and PACE programs in US: Kane et al 2005; Wieland et al 2000) are less likely to hospitalize their residents (Intrator et al, 1998, 2004); Fried et al, 1997; Barker et al; Thompson et al, 1999).
  - Hospital and intensive care unit stay can be decreased by early assistance to unit staff by a palliative care team (Campbell et al 2004).
  - EOL experience for caregivers in Assisted Living (or similar) settings compared to Nursing Home settings is similar in process and outcome (Sloane et al, 2003).

- **Caregivers at EOL experience burden**, have limited understanding of disease progression, and are ambivalent about anticipated death of family member (Forbes et al, 2000; Gessert et al, 2000). The negative impact of caregiving on those caring for someone with dementia vs those caring for a cognitively intact person, is greater,
Caregivers who are strained have increased mortality rate in comparison to their non caregiving relatives (Shulz & Beach, 1999). Caregivers experience high levels of depression prior to death of family member (Schulz et al, 2003).

- Caregivers require support through the grief process (Canadian Study of Health and Aging Work Group, 2002; Meuser & Marwit, 2001).
- Respite and psychoeducational support groups have demonstrated efficacy in supporting caregivers’ psychological well being; (Brodaty & Green, 2001).
- Caregivers report satisfaction for family members with AD where the PEACE (Palliative Excellence in Alzheimer Care Effort) program is in place (Shega et al, 2003)

- **Caregivers are not well prepared for decision making roles** (Mitchell & Lawson, 1999). Spouses of individuals with advanced dementia generally select CPR, respirator, antibiotics and feeding tubes in face of critical illness( Potkins et al 2000).
  - Where education about pros and cons CPR (O’Brien et al, 1995) use of antibiotics and other treatment options in advanced dementia is provided, cognitively intact individuals would limit their treatment (Schonwetter et al, 1996; Gjerdingen et al 1999).
  - Positive relationship with health care professional is vital to support caregivers who must make treatment decisions for end of life care (Caron et al, 2005)
  - Those caregivers who forgo treatment require most emotional support (Mezey et al 1996).

- **Discussion about EOL care** should be guided by patient’s prior wishes, agreed upon goals of therapy, and knowledge of potential benefits and burdens of treatment options (Sachs, 2004).
  - What matters most in EOL care from perception of seriously ill persons and caregivers is: trust in treating physician; avoidance of unwanted life support; effective communication; continuity of care; life completion (life review, resolving conflict, saying goodbye). Individualized approach to EOL care needed as priority given to each factor differs (Heyland et al 2006).

- Scenario based evidence suggests that surrogates can not accurately predict their elderly family members preference for life-sustaining treatments, even when the family member had completed a **health care directive or a valued activities directive** and discussed it with the surrogate (Coppola, Ditto, Danks and Smucker (2001) and Ditto, Danks, Smucker, Bookwala, Coppola et al (2001). A **protocol for proxy decision making** re EOL in dementia care, but has not been evaluated (Volicer, Cantor, Derse, Edwards, Prudhomme, et al. (2002: R3).

- Individuals dying with dementia have **symptoms and health care needs comparable to those dying of cancer** (McCarthy et al, 1997).

- **Good palliative care** calls for interdisciplinary care, attendance to advance care planning, psychosocial issues and management of symptoms (Gillick, 2005).
• **Multidisciplinary guidelines for EOL care**, collaboratively developed, can have positive impact on palliative care for EOL dementia (e.g., decreased antibiotic use, improved pain management (Lloyd-Williams & Payne, 2000/1).

• **Prognostic markers of advanced dementia incorporated into National Hospice Organization (USA) do not accurately predict 6 month life expectancy** except when at 7C or greater (Hanrahan et al, 1999; Schonwetter et al 2003).

• **Access to hospice care supports caregivers** and provides bereavement services (Murphy et al, 1997).

• Provider education, provider feedback and reminders are associated with significant improvements to **providers’ adherence to disease management programmes** for patients with wide variety of chronic diseases (Weingarten et al 2002).

**Expert Consultations**
The bodies of evidence derived from the research literature (above) were shared in a telephone discussion with Dr Ladislav Volicer at the School of Aging Studies, University of Florida, a researcher and expert in the field of EOL dementia care. He validated the results and confirmed that there is a lack of research evidence to guide practice in the following areas:

- How to make an accurate prognosis about when individuals with dementia will die.
- Whether or not hospice care is a “better” place than nursing homes for individuals with dementia who have palliative care needs.
- Prevention and management of contractures.
- Development of nutritional guidelines for end of life.

Dr. Volicer made the point that lack of research evidence does not mean that current approaches are either adequate or inadequate, only that they have not been evaluated. He stated that expert opinion derived from patients, care givers and care providers should guide practice until such research occurs.

Dr. Kiran Rabheru, a Geriatric Psychiatrist in Vancouver Coastal Health Authority and associated with the Alzheimer Society of B.C., was also interviewed. He did not see any gaps in the results of the literature review and felt that this underlines a pressing need for research about EOL dementia care. He suggested that the recommendations for which there are supporting evidence should be very strongly worded in order that they lead practice. Dr. Rabheru felt that the gaps revealed should drive future research, e.g.:

- How should families be involved in decision making?
- How should conflict amongst family members regarding EOL decisions, be managed?
- How should information about EOL and treatment (e.g., antibiotics, CPR) be communicated to families?
- When should treatment be ended?

Dr. Jean Kozak, a psychologist and epidemiologist in Vancouver Coastal Health Authority, also validated the research recommendations in an interview. He too highlighted gaps in research to date, for example:

- Are advanced care plans effective (for the client, for the care providers)?
• No reliable appropriate pain assessment when the individual can not communicate verbally.
• What is “best practice” in palliative care for those with dementia?
• Need to understand what we do that supports caregivers.
• What are the needs of caregivers at EOL?
• Would providing appropriate support during the EOL and following bereavement have positive impacts on caregivers’ health and mortality?
• Lack of research into role of spirituality at EOL for those with dementia and their caregivers.
• What kind of policy changes would facilitate access to palliative care in the home? To hospice care?

Louise Stern, a Doctoral candidate at the School of Social Work at the University of British Columbia was consulted about her work related to EOL dementia care and culture. No research studies that could support specific recommendations were identified. She suggested that attention to cultural values at EOL is however an important principle that could be incorporated into the Dementia Service Framework as expert opinion. Areas for research that she identified are:
  • How do individuals and their families experience dementia and dying?
  • What is the role of cultural values in how individuals and their families experience dementia and dying?
  • What are the implications of cultural values for EOL decision making?

A meeting was held to review all of the EOL Recommendations in the Dementia Service Framework with members of the Provincial End of Life Working Group (Laurianne Jodouin, Manager, Home and Community Care, Ministry of Health; Donna Lommer, Executive Director, OHSA Residential and Palliative Services, IHA; Marianne McLennan, Director, Seniors’ Health, Spiritual Care and End of Life Care, VIHA; Judy Lett, Palliative Care Coordinator, NH); Dr. Romaine Gallagher, Division of Palliative Care Department of Family Practice, UBC; and, Dr. Brian Plain, Medical Consultant, VIHA. In regard to the research recommendations made in this document, participants did not identify additional research literature. They did however reiterate a need for research in areas identified by other consultants, as follows:
  • There is an urgent need for research into advance care planning (e.g., how and when should it should be discussed with clients; family members role; communicating advanced care directives to care providers; are they followed?)
  • How can sensitivity and adaptation of EOL services for ethnic and cultural differences be assured?
  • Could a system for ethics reviews and consults support clients and care providers in making EOL decisions.
  • How can clients and caregivers be informed (sensitively, accurately and effectively) of the physical and functional realities of the end stages of dementia, to support decision making.

Additional areas of research identified by participants are:
  • How can pain be managed effectively for those with dementia at EOL when there are existing co-morbid conditions?
  • How can care providers elicit clients’ values regarding EOL?
  • What are the spiritual needs of individuals with dementia at EOL and how can these be met?
Recommendations for Dementia Service Framework

The bodies of evidence were “translated” into potential recommendations for incorporation into the Dementia Service Framework. The strength of the potential recommendations is noted, along with key supporting evidence. See Table 1.

### TABLE I

**POTENTIAL RECOMMENDATIONS FOR THE DEMENTIA SERVICE FRAMEWORK**

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<th>RECOMMENDATION</th>
<th>SUPPORTING EVIDENCE</th>
<th>STRENGTH</th>
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<tr>
<td><strong>Individual</strong></td>
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<tr>
<td>Individuals with dementia should expect and receive appropriate pain assessment and adequate pain management</td>
<td>Pain in advanced dementia is difficult to assess and requires a combination of patient report, caregiver report and direct observations (AGS Panel on Persistent in Older Adults, 2002: R2). Pain is often undetected (Cook et al, 1999: R3) and under treated for those with dementia compared to those without, (Morrison et al, 2000: R1; Kaasalainen et al, 1998: R2). There are a variety of pain assessment tools but none that are definitive for non communicative individuals with dementia (Stollee et al 2005: R1). Irregardless of whether or not pneumonia is treated with antibiotics it cause suffering and symptomatic treatment is required (van der Steen et al, 2002: R1).</td>
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<td>Individuals with dementia should expect to receive good oral care</td>
<td>Oral care program reduces occurrence of pneumonia at EOL in LTC facility settings Yoneyama et al; R1</td>
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<td>Individuals with dementia should expect to receive an annual vaccination for influenza</td>
<td>Intercurrent infections are highly likely consequence of advanced stage dementia (Volcer, 2005) Risk of intercurrent infections can be reduced by annually</td>
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<td>Vaccinating individuals with dementia, care givers and care providers for influenza (Brandels et al 1998: R2).</td>
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<td>• Individuals with dementia can expect to have their psychosocial needs met.</td>
<td>Sensory stimulation activity in advanced dementia can increase psychological well being (Witucki &amp; Twibell, 1997: R2).</td>
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<td>• Caregivers should expect to be informed about risks and benefits of interventions at end of life prior to their being considered for their family member.</td>
<td>Spouses of individuals with advanced dementia generally select CPR, respirator, antibiotics and feeding tubes in face of critical illness(Potkins et al 2000; R2) Caregivers are not well prepared for decision making roles (Mitchell &amp; Lawson, 1999); and experience burden, have limited understanding of disease progression, ambivalent about anticipated death of family member (Forbes et al, 2000: R2; Gessert et al, 2000: R2).</td>
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<td>• Caregivers should expect to receive emotional support from health care providers when needing to make decisions about levels of care to be provided at end of life.</td>
<td>• Positive relationship with health care professional is vital support to caregiver decision making (Caron et al, 2005: R2) • Those caregiver who forgo treatment require emotional support (Mezey et al 1996: R2).</td>
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<td>• Family members of those with dementia should expect emotional support from health care providers through their family members’ dying and after their death, to be available.</td>
<td>• The negative impact of caregiving on those caring for someone with dementia vs those caring for a cognitively intact person, is greater, (Ory et al, 1999: R1) • Caregivers require support through the grief process (Canadian Study of Health and Aging Work Group, 2002: R3; Meuser &amp; Marwit, 2001). High levels of depression prior to death of family member—need support (Schulz et al, 2003: R1). • Caregivers who are strained</td>
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have increased mortality rate in comparison to their non caregiving relatives (Shulz & Beach, 1999: R1).
- Respite and psychoeducational support groups have demonstrated efficacy in supporting caregivers’ psychological well being (Brodaty & Green, 2001: R2).

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<th>Care Provider</th>
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<tr>
<td><strong>Physicians and other healthcare providers</strong> are expected to increase their knowledge around advance care planning, including skills in providing end-of-life discussions and information about interventions, by participating in continuing education.</td>
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<td><strong>Healthcare providers</strong> should inform individuals with dementia and their caregivers that advance care planning for end-of-life care may improve their quality of life, and encourage and support this process.</td>
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<td><strong>All physicians who care for individuals with dementia</strong> should be expected to possess the required skills to conduct end-of-life discussions with their patients and their significant others. This would include a skill set to:</td>
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<td>- Be able to convey difficult news.</td>
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<td>- Possess interpersonal skills to facilitate engaging and listening to patients, their families and other healthcare providers.</td>
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<td>- Encourage shared decision-making around planning and</td>
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<td><strong>Where education about pros and cons CPR (O’Brien et al, 1995: R2) use of antibiotics and other treatment options in advanced dementia is provided, cognitively intact individuals would limit their treatment (Schonwetter et al, 1996; Gjerdingen et al 1999: R2).</strong></td>
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<tr>
<td><strong>Primary physician should guide discussion about EOL care in light of patient’s prior wishes, agreed upon goals of therapy, and potential benefits and burdens of treatment options (Sachs, 2004: R3).</strong></td>
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- Choosing appropriate interventions.
  - Knowledge of best practice palliative care interventions for dementia (von Gunten et al, 2000, R3)

- Healthcare providers should engage individuals with dementia and their family members in advance care planning by providing Information:
  - about the disease course in advanced stage/end of life such as,
    - Likelihood of recurrent and intercurrent infections
    - Co-morbidities such as depression
  - about risks vs benefits of various treatments/medical practices related to advanced dementia/end of life such as,
    - Antibiotic therapy
    - Enteral tube feeding.
    - CPR
    - Artificial hydration
    - Transfer to hospital

- Aggressive medical treatment for individuals with advanced dementia is often inappropriate for medical reasons, has low rates of success and can have negative outcomes that hasten functional decline and health (Volicer, 2005)
- Antibiotic therapy does not seem to prolong survival in advanced dementia and is not necessary for comfort which can be maintained through other means without antibiotics. Where used the diagnostic procedures may be uncomfortable and the treatment cause adverse side effects. (Fabiszewski et al, 1990; Volicer et al 1998; Luchins et al 1997; Hanrahan et al 1999)
- Tube feeding does not increase survival of those with advanced dementia (Murphy & Lipman, 2003: R1; Meier et al, 2001: R1; Finucane et al, 1999; R1) reduce the risk of infection (Gillick, 2000) prevent aspiration or improve functional status or comfort of the individual with dementia (Gillick, 2004; Sanders et al 2000, R1; Abuksis et al 2000). Tube feeding at EOL should be discouraged on clinical grounds (Finucane et al, 1999: R1).
- CPR is unlikely to be successful (Dull et al, 1994; Benkendorf et al, 1997; Ebell et al 1998:R1) and where it is most survivors go to intensive care but die within 24
hours (Zweig 1997).
- Transfer from facility to acute care frequently results in functional decline that does not improve significantly at discharge (Volicer et al 2001). Aggressive medical treatment (with its' own risks) is often used to manage confusion, anorexia, incontinence and falls that often follow hospital transfer (Ahronheim et al1996).

### Support Systems

- Individuals with advanced dementia and their caregivers may expect access to palliative care expertise and staff at all times, across care settings.

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- Caregivers report satisfaction for family members with AD where PEACE (Palliative Excellence in Alzheimer Care Effort) program in place (Shega et al, 2003: R3)
- Individuals dying with dementia have symptoms and health care needs comparable to those dying of cancer (McCarthy et al, 1997: R2).
- EOL experience for caregivers in Assisted Living (or similar) compared to Nursing Home settings is similar in process and outcome (Sloane et al, 2003: R2).
- Good palliative care calls for interdisciplinary care, attendance to advance care planning, psychosocial issues and management of symptoms (Gillick, 2005: R3).

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- What matters most in EOL care from perception of seriously ill persons and caregivers is: trust in treating physician; avoidance of unwanted life support; effective communication; continuity of care; life completion (i.e., life review, resolving conflict, saying goodbye); support services for remaining at home; symptom relief. An Individualized

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- Individuals with dementia and their families should expect system change to better align what matters most to them at end-of-life to the care provided within the health authorities.
approach to EOL care needed as priority given to each factor differs (Heyland et al 2006: R2).

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<thead>
<tr>
<th>Individuals with dementia can expect that care providers are vaccinated against influenza.</th>
<th>• Risk of intercurrent infections can be reduced by annually vaccinating individuals with dementia, care givers and care providers for influenza (Brandels et al 1998).</th>
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### Health Care Environments

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<th>• Training/education related to provision of end of life care should be provided/supported across all care settings by the Health Authorities and partners for individuals with dementia, caregivers; care aids/home support workers; health professionals and physicians across settings</th>
<th>• Considerable discord between physician opinion, reported practice and literature (Shega et al, 2003: R2). Incidence of tube feeding can be reduced through protocol to consult palliative care team prior to doing so, and through educational program (Monteleoni &amp; Clark 2004: R2). • Provider education, provider feedback and reminders are associated with significant improvements to providers’ adherence to disease management programmes for patients with wide variety of chronic diseases (Weingarten et al 2002: R1-not specific to dementia).</th>
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<tr>
<th>• Each Health Authority should develop a protocol for making end of life treatment decisions/care where the individual lacks decisional capacity, and that involves significant others when available</th>
<th>• Primary physician should guide discussion about EOL care in light of patient’s prior wishes, agreed upon goals of therapy, and potential benefits and burdens of treatment options (Sachs, 2004: R3). • Multidisciplinary guidelines, collaboratively developed, can have positive impact on palliative care for EOL dementia (decreased antibiotic, improved pain management (Lloyd-Williams &amp; Payne, 2000/1: R2).</th>
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<td>• Primary physician should guide discussion about EOL care in light of patient’s prior wishes, agreed upon goals of therapy, and potential benefits and burdens of treatment options (Sachs, 2004: R3). • Multidisciplinary guidelines, collaboratively developed, can have positive impact on palliative care for EOL dementia (decreased antibiotic, improved pain management (Lloyd-Williams &amp; Payne, 2000/1: R2).</td>
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<td>Government policy should ensure equitable access to appropriate services and supports in the home for those who plan to die there at equivalent cost to those individuals who are institutionalized (e.g., for incontinence and similar care products; home support; respite; palliative care consultation/team).</td>
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<td>Access to hospice care supports caregivers and provides bereavement services (Murphy et al, 1997)</td>
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<td>Criteria for designating end of life to enable designation as “palliative” and therefore access to appropriate services/supports needs to be established and should consider longer time frame than 6 months.</td>
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<td>Prognostic markers of advanced dementia incorporated into National Hospice Organization do not accurately predict 6 month life expectancy except when at 7C or greater (Hanrahan et al, 1999: R1; Schonwetter et al 2003).</td>
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