

‘Calling it quits’ – Dying with dementia

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Abstract

Dementia is a prevalent terminal condition. Many people with dementia are admitted to hospital where they may receive life saving interventions, the benefits of which should be questioned. This paper argues for advanced care planning and the timely deployment of a palliative approach to the care of people with dementia.

Key words: Dementia, palliative care, social death, care planning

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Introduction

As the population ages, dementia becomes more prevalent. Below the age of 65 years, less than 1% of the population is affected. By the age of 85 years, at least 25% of people manifest the syndrome (Blennow et al., 2006), and 50% of nursing home residents have dementia. By 2010, an estimated 240,000 Australians will have dementia (Alzheimer’s Australia, 2007). In contemporary Australian society, caring for people with dementia is providing many challenges.

This paper questions why elderly people with dementia are admitted to hospital for life saving treatments that do not appear to improve their quality of life. It also explores appropriate care for these people. After introducing dementia from a medical perspective, social issues including identity, roles, and personhood are discussed, together with the variable attribution of social death. Clarification of “when is a person with dementia dying?” is attempted before looking at how people can be allowed to die. Accepting a palliative approach as an appropriate clinical course, the question of how this may be facilitated is raised. This includes discussion of consensus decision making in the clinical setting, and the application of a health promotion approach at community level. Both professional experience and a review of the literature inform this position.

Dementia—Clinical perspectives

Dementia evolves insidiously and there are progressive impairments in cognitive and language abilities (Blennow, de Leon, & Zetterberg, 2006). Impaired learning and retention results in short term memory deficits. There are also deficiencies in orientation, reasoning abilities and judgment, ability to manage complex tasks, spatial and constructional abilities, and the ability to recognise previously familiar situations and objects. Participation in social activities (including work), relationships, and self care abilities is affected. In people with early or mild

dementia, insight or awareness of the cognitive changes is not uniformly absent (Aalten, Van Valen, Clare, Kenny, & Verhey, 2005). A person may be aware of some gaps, but not others. However, deterioration in the ability to perform activities of daily living and greater global dementia severity are associated with lower levels of awareness (Aalten et al., 2005).

The commonest pathological process associated with dementia is Alzheimer's disease (65%) (Franchi, 2007). Other types include vascular dementia (15%), dementia with Lewy bodies (10%), fronto-temporal dementia (5%), and dementia of Parkinson's disease (<5%) (Franchi). An etiological, anatomical, or pathological diagnosis provides limited guidance in determining prognosis. All types are progressive neurodegenerative conditions (Franchi). People with advanced or end stage dementia are typically unable to name or recognise family members; have severely limited language abilities; limited or no self care abilities such that they require assistance with bathing, dressing, feeding and toileting or continence management; and they are unable to participate in decision making (Casarett, Takesaka, Karlawish, Hirschman, & Clark, 2002; Morrison & Sui, 2000). Dysphagia (inability to swallow) also occurs and general mobility becomes impaired (Sachs, Shega, & Cox-Hayley, 2004). These people are predisposed to malnutrition, infections, pressure areas, falls and fractures (Sachs et al.).

Following clinical recognition of dementia, the median survival is between 3 and 6 years (Mitchell, Kiely, Hamel, Park, Morris, & Fries, 2004a). For people with dementia, the trajectory towards death is punctuated by inter-current medical conditions. Because the final medical episode may be similar to previous acute episodes, prospectively identifying the terminal illness can be difficult (Sachs et al., 2004). Pneumonia due to aspiration is a common terminal event (Chen, Lamberg, Chen, Kiely, Page, Person, & Mitchell, 2006).

Dementia—Social perspectives

Identity, the sense of who one is, includes components of consciousness, self awareness, a sense of agency, differentiation—being distinguished from others, and continuity—a sameness or consistency across time (Gillies & Johnston, 2004). Chronic conditions challenge the continuity of self (Gillies & Johnston). Through changes in memory, judgment, thinking, orientation, language, behaviour and personality, this uncertainty about self is compounded for people with dementia.

Identity is closely linked to the social roles that are fulfilled throughout life. There is a reflexively reinforcing creation of self, and role fulfillment provides evidence to support concepts of self (Gillies & Johnston, 2004). When opportunities for role fulfillment are limited, sources of validation of self are attenuated.

The person with dementia loses cognitive skills, and this is accompanied by loss of control and loss of personal independence. Apparently helpful social manipulations often occur, as family members and others intervene to care for and protect the person with dementia. Opportunities for participation and meaningful activities are restricted (Gillies & Johnston, 2004). Additionally, the person is undermined as opportunities for decision making are removed, or the person is deemed "incompetent." Roles such as matriarch, father or brother are surrendered. Loss of certainty regarding self is reinforced and self esteem is diminished. This occurs simultaneously with role erosion.

Kontos (2005) and Bond (1992) challenge the biological determinism that a diagnosis of dementia inflicts. This labelling is accompanied by stigmatisation. People are depersonalised, invalidated, regarded as dysfunctional and devalued as their ability to contribute to society is minimised (Blauner, 1966). Kitwood (1997, cited in Kontos, p.) refers to the “malignant social psychology.” Alternatively stated, socio-psychological and cultural factors, in addition to the neurological factors, contribute to loss of identity and roles. The social environment ceases to be life giving. Accepting the determinism of the biomedical model promotes infantilisation, and isolation of people with dementia from social life (Bond). Not only do they disconnect from economic and community life, but they also become disengaged from their families (Blauner). The person’s social identity is lost indirectly as the result of the disease, through the way the person is viewed and treated by society and its members (Poveda, 2003). Countering the depersonalising forces, though operating at a personal rather than social level, are approaches to care that enable individuals with dementia to use their abilities, exercise choice, express feelings, and develop and maintain relationships (Kontos). It has been proposed that wellbeing can be maintained, regardless of cognitive status, by meeting these psychological needs (Kontos).

As dementia progresses, changes in personality and behaviour occur, rendering the person altered, or even unrecognisable to family and others (Gillies & Johnston, 2004). This raises the issue of personhood. What does it mean to be a person? Or, what does human life mean? It involves not just having a life, but leading a life. This includes agency, and the ability to choose between plans. It embraces capacity for interpersonal relationships and the ability to enjoy life. Absence of these attributes may be construed as loss of personhood, and the individual with dementia may be subjected to “non-person” treatment. This is social death, that Sudnow (1967, cited in Timmermans, 1999, p.) defined as “that point at which socially relevant attributes of the patient begin permanently to cease to be operative as conditions for treating him, and when he is essentially regarded as already dead.” This is how a person with advanced dementia may be perceived by others (Sweeting & Gilhooly, 1997). While expressed “self perceived” social death is possible in other clinical conditions, the cognitive and language deficits that a person with advanced dementia experiences impairs any such communication.

Sweeting and Gilhooly (1997) studied a sample of 100 relatives of people with a primary diagnosis of dementia, to assess social death on a scale from belief to described behaviours. Over one-third of carers believed and behaved as if the person was socially dead. Such behaviours included not acknowledging the person, not correcting mistakes, not bothering to make the person look his or her best, not expending the effort to encourage participation, and generally treating the relative as a task rather than a person. About one-fifth of respondents believed the person with dementia was socially dead, but the behaviours of these respondents were discordant. They considered that their actions should not hurt the affected person’s feelings, dignity should be maintained, and participation should be encouraged to prevent further decline. Social death was predicated on a lack of reciprocity in the relationship, with comments such as “he’s absolutely nil for company” and “it’s like living with the living dead” (Sweeting & Gilhooly). Over one-third did not believe or behave as if the relative was socially dead. Some intervened to prevent it; for example, by providing strong encouragement for ongoing participation, and ensuring maintenance of dress standards. There was expression of the relatives’ ongoing feelings and love. These relatives created and perceived an ongoing relationship and social life, acknowledging the person as deserving of treatment as an individual human being. This study clearly demonstrated a range in the concept

of social death as described by relatives who did not correlate with clinical dementia severity. The suffering experienced by relatives was also apparent.

In the clinical situation, ascertainment of social viability or its obverse, social death, is not uncommon though these terms are not generally used. Rather social aspects are incorporated in the term, quality of life. This focus on quality of life has contributed to raising the threshold of personhood (Sweeting & Gilhooly, 1997). In clinical practice, informal, discretionary and value laden judgments are made. For example, if there is not a 'do not resuscitate' (DNR) order, the default position in hospital practice is resuscitation in accordance with clinical protocols. However, if a person is perceived as socially dead by the leader of this clinical team, the resuscitation effort may be ritualistic, minimalist, and lacking in commitment (Timmermans, 1999). Similarly, recommendations by clinicians regarding other treatments for people with dementia may reflect the clinician's perspective on the social value and attributes of the person.

Is the person with dementia dying?

The previous section discussed social death and it is noted that in an era of evidence based clinical practice, there is no validated objective test for social death. Social viability and social death are enmeshed with quality of life decisions, and relatives' perceptions regarding the social life of people with dementia span the spectrum through living, viability and death, regardless of dementia severity.

In discussing social death, the uncoupling from biological death is apparent. Many medical practitioners do not recognise dementia as a terminal condition (Hertogh, 2006). Mitchell, Kiely, and Hamel (2004b) reported that while 71% of people admitted to nursing homes with advanced dementia died within 6 months, clinicians only anticipated this short a life expectancy in 1%. Dementia severity assessments in current clinical use focus on cognitive and functional deficits and are not designed to determine life expectancy. Terms such as 'severe', 'advanced' or 'late' do not mean that death is imminent. Conversely, people die with less severe dementia. In one Dutch study (Koopmans et al., cited in Hertogh, 2006), of people with dementia in nursing homes, only 14% survived to late stage.

To be eligible for palliative care or hospice services in the United States (US), a prediction that death will occur within 6 months is required. Mitchell et al. (2004a) devised a Mortality Risk Index Score (MRIS) (Table 1) to enable newly admitted nursing home residents with advanced dementia to be screened for risk of mortality within 6 months. Poorer survival is associated with older age, greater functional impairment, male sex, cardiovascular disease, diabetes mellitus, and poor nutrition. These factors also predict poorer survival in people with less advanced dementia, and other nursing home residents without dementia. The MRIS is an imperfect instrument. Using 6 as a cut point, the sensitivity is 61%. The MRIS detected only 61% of people who died within 6 months. It did not identify 39% who also died. As a predictive tool, at the cut point of 6, the risk estimate of death is only 40%. There is no information regarding the use or validation of this tool in Australia.

Morrison and Sui (2000) compared the 6 month mortality of elderly cognitively intact adults with that of people with end stage dementia, for pneumonia (13% vs 53%) and hip fracture (12% vs 55%). They demonstrated limited life expectancy for people with end stage dementia following these conditions. Tuch (2003) described the situation in the Netherlands where 80% of people with severe dementia do not receive antibiotics for pneumonia. The 30-day mortality is 90%.

This compares with a 30% 30-day mortality for the antibiotic treated group. A retrospective study in long term residents in Boston, who were dying with advanced dementia found 64% had suspected pneumonia within the 6 months prior to death (Chen et al., 2006). Fifty-three (53) per cent had suspected pneumonia within 30 days of death. There is a rising incidence of pneumonia towards the end of life. It is the harbinger of death.

Dying—Interventions and goals of care

Table 1: Mortality Risk Score for Stratification of Residents into Levels of Risk for 6 Month Mortality

Risk factor	Points	Score
Activities of daily living score=28*	1.9	
Male sex	1.9	
Cancer	1.7	
Congestive Heart Failure	1.6	
Oxygen therapy needed in prior 14 days	1.6	
Shortness of breath	1.5	
<25% of food eaten at most meals	1.5	
Unstable medical condition	1.5	
Bowel incontinence	1.5	
Bedfast	1.5	
Age >83 years	1.4	
Not awake most of the day	1.4	

Total risk score, rounded to nearest integer. Possible range, 0-19

*The Activities of Daily Living Scale is obtained by summing the resident's self-performance ratings for the following 7 functional activities: bed mobility, dressing, toileting, transfer, eating, grooming, and locomotion. ...[F]unctional ability is rated on a 5 point scale for each activity(0, independent; 1, supervision; 2, limited assistance; 3, extensive assistance; 4, total dependence). A total score of 28 represents complete functional dependence.

If total risk score is...	Risk estimate of death within 6 months %
0	8.9
1 or 2	10.8
3,4, or 5	23.2
6,7, or 8	40.4
9, 10 or 11	57.0
12 or greater	70.0

There are considerable difficulties determining when the person with dementia is dying. However, the disjunction between social and biological death creates the opportunity for “discretionary death.” This has been described as “death by deed” (Machado, 2005, p. ?). A reduction in the temporal gap between social and biological death, to approach the typology of the modern death where social and

biological death occurs concomitantly (Walters, 1994), can be effected by a medical deed of omission or inactivity.

End of life care for people with dementia may invoke discussion of medical futility. Futility is the relationship between an action and the desired goal, and “medical futility” refers to “a clinical action serving no useful purpose in attaining a specified goal for a given patient” (Kasman, 2004, p.). Goals of treatment and care need to be specified. In the clinical situation of a person with dementia, benefit-centred futility, where treatments would not benefit the person may be argued. Preventing medical treatments from prolonging dying can be a challenge. Medical futility can convey unilateral, unequivocal and negative judgment about a person’s quality of life (Karlavish et al., 1999). It can convey that nothing more can be done, and implies that a person’s life is of no value. Those who argue against the concept of futility recommend reliance on standards of care—with implications of social and clinical norms, and patient’s best interests—with accompanying moral and value judgments, to resolve end-of-life issues (Kasman).

Mitchell et al. (2004b) described non palliative interventions within 120 days prior to death in Boston nursing home residents dying with advanced dementia. Twenty-five (25) per cent had a feeding tube inserted, 49% had laboratory tests performed within 30 days prior to death, 11% had trunk or limb restraints, and 10% had intravenous fluids or medications. Compared with people with terminal cancer, they were 2.2 times more likely to receive a feeding tube, 2.5 times more likely to have laboratory tests performed, and 1.79 times more likely to be restrained. In comparison to people with terminal cancer, people with advanced dementia received more medical interventions, implying a lack of recognition of the terminal phase.

Up to 44% of nursing home residents with dementia die with feeding tubes in place in some US states (Sachs et al., 2004). One of the indications of impending death is loss of ability to eat (Panke & Volicer, 2002). There is empirical data and expert opinion that the use of feeding tubes provides little or no benefit and does not prolong life (Mitchell et al., 2004b). It does not reduce the risk of aspiration pneumonia, and there are studies suggesting that it increases the risk (Karlavish et al., 1999). Enteral feeding does not prevent weight loss nor pressure areas, and it is associated with an increased 12-month mortality. There is little or no discomfort with a gradual process of decreasing intake of food or fluids. Accompanying electrolyte disturbances and changes in endogenous opioids may alleviate discomfort during the dying process (Hinkka, Kosunen, Metsanoja, Lammi, & Kellokumpu-Lehtinen, 2002; Panke & Volicer). Tube feeding often requires restraint and can cause discomfort. However, there are deep values regarding feeding and what is meant by care for people with dementia (Karlavish et al.). Families may be concerned that the person is being ‘starved to death’ (Panke & Volicer).

People with dementia experience acute medical problems in their final phase. These acute conditions may be related to the dementia, for example—aspiration pneumonia; or due to chronic conditions that are common in elderly people, for example—myocardial infarction (Lamberg, Person, Kiely, & Mitchell, 2005). When these people are admitted to hospital, life prolonging treatments are often instituted. In addition to relocation to an unfamiliar environment, these people may be subjected to diagnostic studies including blood tests and diagnostic imaging, causing pain and discomfort, as well as frequent dislocating transport about the facility. While challenging for sick cognitively intact patients, it can be confusing and anxiety provoking for those patients whose cognition is defective (Panke &

Volicer, 2002). Patients with dementia may be unable to tolerate treatments such as intravenous therapy or urinary catheterisation, and there may be the need for restraint to prevent the removal of appliances or wandering. Complications including constipation and pressure areas may occur and patients commonly receive inappropriate care for their functional and cognitive deficits (Hertogh, 2006). Hurley, Volicer, and Blasi (2000) recommend that when people with dementia have to be hospitalised, a familiar caregiver should be present during the treatment process, and the special needs of this population should be supported. Hospitalisation for acute illness is accompanied by a decrement in function, and any recovery of function is usually incomplete (Panke & Volicer; Sachs et al., 2004).

Luchins and Hanrahan (1993) ascertained the type of health care that family caregivers regarded as appropriate for their relative with end stage dementia. Comfort and control of pain was chosen by 70.6% (Table 2). Less aggressive care was preferred when there was already an advanced care plan. Also, older family members were more likely to choose less aggressive care. Of the 92% of study participants who nominated that they would speak with the doctor regarding care choices, only 42% has previously discussed terminal care preferences with the affected person. Thirty-five (35) per cent thought that the person would defer the care choice to them. This deferment of choice is one of the reasons elderly people cite for not completing advanced health directives (Luchins & Hanrahan).

Table 2: Distribution of preferred level of health care for end-stage dementia patients: Family members of dementia patients

Preferred levels of health care for end-stage dementia	%
Do everything to prolong life	4.1
Do everything but electric shock to restart the heart	3.7
No respirator, no electric shock to restart the heart	15.1
No respirator or electric shock to restart the heart; also exclude medications for acute illness	5.8
Also exclude tube feeding; focus on comfort and control of pain	70.6

Previously mentioned interventions including hospitalisations are of limited benefit and incur physical and ‘dignatory’ harms for people dying with dementia. There has been recent promotion of a palliative approach to care for these people (Hertogh, 2006; Hughes, Robinson, & Volicer, 2005; Mitchell et al., 2004a).

Palliative Care:

- affirms life and regards dying as a normal process;
- neither hastens nor postpones death;
- provides relief from pain and distressing symptoms;
- integrates the physical, psychological, social, emotional and spiritual aspects of care, with coordinated assessment and management of each person’s needs;
- offers a support system to help people live as actively as possible until death; and
- offers a support system to help the family cope during the person’s illness and in their bereavement.

(National Palliative Care Strategy, 2000)

This is person-centred dementia care. It is not about disqualification from legitimate health care. Palliative care is holistic and focuses on quality of life. It also includes adequate pain relief. In people with dementia, pain is under recognised, but it may manifest as behavioural changes or agitation. A palliative approach appropriately limits medical interventions including cardiopulmonary resuscitation, tube feedings, antibiotics and hospitalisations, and it can be pursued in both institutional and community based settings. Although there are dementia hospice units, Hughes et al. (2005) suggested that residential aged care facilities that provide care for people with dementia could continue the care as a specialist palliative care unit.

Letting it happen

The terminal care preferences for people with advanced dementia are often unknown (Hughes et al., 2005; Luchins & Hanrahan, 1993). To overcome this problem, advanced care planning is recommended. This includes written statements, advanced care directives that outline people's future care choices in accordance with their views on quality of life (Timmermans, 1999). These are supported by legislation in Queensland, South Australia and the Northern Territory, but all medical practitioners are encouraged to respect the expressed wishes. This is consistent with the dominant Western ethical principle of autonomy. Discussions regarding the documentation of future care preferences should occur as soon as possible after dementia is diagnosed, and while the person may still be competent to participate in decision making. A test score of 16 or less (out of 30) on the Standardized Mini-Mental State Examination, a common clinical assessment tool, is associated with an 89% probability that the person lacks capacity (Etchells, et al., 1999). This score reflects moderate dementia. A test score of 17 to 23 is associated with a 27% probability, while a score of 24 to 30, is associated with a 3% probability of lack of capacity. Templates are available that encourage people to be specific regarding care preferences by attending to issues such as DNR orders, hospitalisation, antibiotics, and artificial hydration and nutrition. Ambiguous or inaccurate directives may not prevent inappropriate medical interventions (Timmermans). Most residents who have dementia in Australian nursing homes have lost capacity by the time they are dying (Brown, Grbich, Maddocks, Parker, Roe, & Willis, 2005). Mitchell, Teno, Intrator, Feng, and Mor (2007) found that only 18.8% of nursing home residents with advanced dementia had advanced health directives ("living will"). The prevalence of advanced care directives in Australian residential aged facilities is not known.

In the absence of expressed wishes regarding care, surrogate decision makers are required. In Queensland, this may be the Health Attorney appointed under an Enduring Power of Attorney; or the Statutory Health Attorney, usually the person's spouse, primary carer, close relative or close friend. At the time of nursing home admission, advanced care planning may be discussed. The surrogate may be dealing with issues of separation, and relinquishment of care roles, when he/she is confronted by these moral decisions regarding care. The surrogate should support the affected person's values and act in the person's best interests (Kasman, 2004). However, Luchins and Hanrahan (1993) found only 42% had previously shared this information. Although dementia is a progressive condition, advanced care planning that limits aggressive interventions is often not effected until late in the disease course (Mitchell et al., 2007). This contrasts with the findings of Luchin and Hanrahan (1993) who found that majority of families desire the least aggressive care for their relative with late stage dementia. This discrepancy may

reflect the difficulty in accepting that the person is dying. Nursing home patients dying with dementia were only one-third as likely as people with cancer to have ‘do not hospitalize’ (DNH) orders. In the context of uncertainty in disease trajectory, and possibly new relationships between the doctor and patient and family, proxies may insist on hospital admission. Children are less likely to support DNH orders than older surrogate decision makers (Lamberg et al., 2005). The establishment of DNH orders promotes a palliative approach to care, and invoking DNH orders only when death is imminent, effectively delays palliation (Lamberg et al.).

The doctor has an important and powerful role in the dying process. As previously mentioned, advanced care planning is an integral component of the medical management plan when dementia is diagnosed. Also, at this time health maintenance and preventive health practices should be interrogated and probably discontinued (Forbat & Service, 2005). Legally and ethically, doctors are required to adhere to advance care directives. However, doctors may be unwilling to withhold treatment (Farber, Simpson, Salam, Collier, Weiner, & Boyer, 2006). They may seek to avoid the psychological responsibility for death, or they may view many technological and medical interventions as routine. Allowing patients to die from treatable conditions may be unacceptable to some doctors (Tuch, 2003). Withholding or withdrawing fluids and nutrition raises legal and ethical concerns, but this has been clarified in Australian case law (Ashby & Mendelson, 2004). While medical treatment to palliate pain and discomfort is not optional, administering fluids and nutrition other than by mouth is regarded as a life saving medical intervention that patients or their surrogates can refuse. Further, the law does not impose a rigid obligation to administer fluids and nutrition to a dying patient, even if his/her wishes are known (Ashby & Mendelson, 2004). The decision incorporates not only consideration of the person’s (or family’s) wishes, but also ‘best interests.’ In other medical situations, there is evidence that doctors do not always comply with advanced health directives (Timmermans, 1999). It should be appreciated that when advanced health directives are prepared, there may be incomplete knowledge of the circumstances under which they will be used. The medical practitioner may have little idea of the person’s values regarding quality of life (Johnson, 1998, cited in McDonald, 2004) and may even project preferences reflecting personal, familial and socio-cultural environments, onto the patient (McDonald).

These decisions occur in a complex social nexus and a “new normative equilibrium” is being established. Patient or surrogate autonomy is supplanting medical autonomy, and this is supported by changes in the broader culture that encompass personal empowerment and self determination (Machado, 2005). Other agents including ethicists, government agencies, courts, public discussion and the media have become institutionalised. Norm formation and norm regulation is occurring, not only in the medical profession, but also between the profession and other social agents representing the general public, mass media, political leadership, the law and courts.

Making it happen

An emerging theme is the palliative approach to care for people dying with dementia and the need for advanced care directives to be completed earlier. Because of the time involved and inherent difficulties in assessing competence, few general practitioners are involved in assisting elderly people with advanced directives (Brown et al., 2005). In residential care facilities in South Australia,

while advanced directives were recommended, only a small number of facilities required them (Brown et al.). Not surprisingly, advanced directives were uncommon, but there was often less formal documentation of patients' wishes. The Canadian "let me decide" advance directive program, was associated with fewer hospitalisations, and less resource use. The program consisted of education for staff of hospitals and nursing homes, residents and families; and direct support to achieve an advanced health directive (Molloy, et al., 2000). Satisfaction with care was not affected by the initiative. Of note, only 50% of residents in the intervention nursing homes had a completed advanced health directive. In a Boston study reviewing DNH orders in nursing homes, Mitchell et al. (2007) found that not only were individual resident characteristics associated with directives to forgo hospitalisation, but organisational and health service factors were also important.

Karlawish et al. (1999) have promoted an approach to planning palliative care for people who lack decision making capacity that is based on consensus. Key areas for clarification include diagnosis and prognosis, benefits and burdens of different clinical interventions, and the meaning of terms such as "starvation", "suffering", "quality of life", "feeding" and "dying." Not only should decisions be based on the person's preferences but also a balance of the benefits and burdens of the available options in terms of ability to relieve suffering, and maximise dignity and quality of life. Key steps include the identification of key decision makers, allowing them to narrate how the person has arrived at this stage of the illness, teaching the surrogate about the course of dementia, advocating for the person's quality of life and dignity, and providing guidance based on clinical evidence and experience. Surrogates may pursue decision making incrementally, with a definite hierarchy of non interventions. For example, CPR may be denied, while antibiotic treatment may still be acceptable. In these circumstances, advanced care planning is an iterative process.

While much of the focus of care planning has been on cessation of active medical interventions, it is important to appreciate that dementia is a chronic condition and that a care pathway or chronic disease management plan needs to be developed. Under Medicare, doctors can receive payment for developing such management plans, as well as participation in team care. Recent Medicare changes have reduced 'red tape' to encourage general practitioners to use these enhanced primary care items.

Models of health promotion, while seemingly contradictory, can be applied to palliative care (Kellehear, 1999). The *Ottawa Charter for Health Promotion* (1986, p.) builds on the World Health Organization's definition of health as "a state of complete physical, mental and social wellbeing ..." Promoting health means building healthy public policy, creating supportive environments, strengthening community action, developing personal skills, and reorienting health services. Health is more than an individual responsibility. It is embedded with the social and physical environments. In the context of palliative care, health promotion means enhancing the sense of control and support for people with terminal illnesses (Kellehear). Focusing on dementia, healthy public policy should include not only the incorporation of dementia within national palliative care policies, but also the legislative frameworks for advanced care planning, and financing structures for residential aged care facilities, and complex care under Medicare. Supportive environments also include the professionals' and organisations' cultural environments that support people's decisions, as well as the physical and team environments to enable palliative approaches in community dwellings, nursing homes and hospitals. Promoting these changes will require the support of the general community. This will be a challenge given the stigmatisation and

marginalisation of elderly people, and people with dementia (Sweeting & Gilhooly, 1997), and a general reluctance to engage in meaningful social discourse on death (Kellehear, 1984). Promoting personal skills for the person with severe dementia to achieve self determination is an absurdity but for people with early dementia and families and carers, education and skills development to enable meaningful participation in and advocacy for care planning is required. Reorienting health services includes not only accepting the palliative approach for dementia care, but building a comprehensive public health approach that embraces community education and community development. To effect these goals, substantial consideration will need to be given to devising strategies. There will also need to be political, community, organisational and professional support for the implementation.

What can be done for the person with dementia now?

General practitioners who provide care for older people need to be prepared to diagnose dementia, and develop patient-centred care plans that incorporate the patient's wishes if possible. When surrogate decision makers are involved, an iterative consensus based process may be required to ensure that care plans are appropriate to the care needs. Recognising dementia as a chronic disease to be managed in a chronic disease framework with pathways, care plans and recall systems should be within the scope of all general practices. A possible approach to promote change in attitudes and clinical practice that includes an appropriate palliative approach to care for people with dementia is the identification of GP peer leaders who may lead diffusion of this innovation in clinical practice.

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