

Dying with and of dementia

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ABSTRACT

AIM: With an ageing population the prevalence of dementia increases. A healthcare crisis is looming.

METHOD: Dementia is a terminal condition. The latter, end-of-life phase of this disorder can be very challenging to manage. Patients, whānau and staff may struggle.

RESULTS: Clinical recognition of this phase may be difficult. Determining the appropriateness of medical interventions or palliation, likewise. The clinical load on the acute public hospital services is unbearable. The resources in the aged residential care services are limited.

CONCLUSIONS: A pragmatic and reasoned palliative approach by all professionals in the area is advocated.

Dementia is a progressive, life-limiting syndrome. The quality of life appears to slowly erode over time. Present figures reveal that 70,000 New Zealanders experience dementia/mate wareware.¹ The commendable public health endeavours to support and encourage an active and healthy older age lifestyle for those in the early and middle stages of a dementing condition, the expertise of older persons nursing and medical care and modern pharmacology may all improve the quality of remaining life, and even impede disease progression. Yet dying comfortably, peacefully and with dignity in advanced dementia is often not the eventual outcome of this, as yet, incurable disease.

Age is the major risk factor for dementia. With extra years come a deterioration of general health and an increase of disability, including neurodegenerative disorders such as dementia.² The influence of emerging parkinsonian Lewy Body-type dementias, the aged community's epidemic consumption of alcohol, and diabetic and cerebrovascular cerebral damage consequent to improved longevity because of modern management will further tax clinicians of the elderly with troublesome new challenges. If disease-modifying treatments are developed, their actions will likely be to delay neurodegenerative progression, and thereby improve the quality of life during the early and middle stages, though they will risk protracting and complicating the latter phases. The median survival time from symptom onset of dementia to death may be as little as 4–5 years, depending upon sub-type, stage of diagnosis and standard of care.³ The median survival time in the advanced stages is 1.3 years, similar to that of, for example, metastatic breast

cancer.⁴ As to when the last year of life begins is difficult, indeed impossible, to determine accurately.⁵ It is predicted that one in three people aged greater than 65 years will die with, or from, dementia.³ About half of these people will die with moderate-stage dementia from comorbid cardiovascular, oncological and other systemic diseases; a quarter will die of severe dementia.⁶ Around 70% of people with dementia have at least two comorbid chronic diseases, and the management and course of these conditions is often compromised by deteriorating cognition.⁶ Most persons with dementia will die in hospital or residential care.⁷ The usual drivers of dementia requiring institutional care are those of older age, medical frailty, severe behavioural symptoms and carer burden.⁷ The tight health budgets of the currently stretched public health system will soon become inadequate to provide an acceptable standard of care for those with advanced dementia. In addition, there is limited availability of skilled carers to provide care for the cognitively infirm. A crisis is looming.

The Myth of Tithonus

Eos lamented that she would outlive her Trojan lover, Tithonus, so she asked Zeus to make him immortal, but she forgot to ask for him to be eternally youthful. Tithonus became daily older, greyer and more shrunken, his voice grew shrill and, when Eos tired of nursing him, she locked him in her bedroom, where he turned into a cicada.⁸

The Greek myth of Tithonus advertises the suffering of persons with dementia and the burden of their care.⁸ According to various

interpreters of the myth, Eos did not abandon Tithonus despite her poor standard of care. She turned him into a cicada so no one would fault his mindless chirping and fragile body. After 3,000 years we should be doing better than Eos, but we are not.

The trajectory of dementia is unpredictable. The severity of dementia increases with age, but it can surprise. The journey may involve weeks, months, even years of humiliating revelations of cognitive disability, fading fine motor competency, loss of social skills, uncharacteristic behaviours, social “death” and an increasing dependency upon others. The psychological worries of the early stages of dementia become superseded by behavioural responses if or when confronted by overwhelming cognitive tasks. These include catastrophic reactions, cerebral panic attacks, which may result in physical reactivity—helpless paralytic immobilisation or, at other times, purposeless action including violence towards self and others. There comes a time on this journey when the damage done requires the practical help of others, as Hughlings Jackson’s *Doctrine of Dissolution* in 1873 had conceptualised.⁹ Difficult-to-manage neuropsychiatric symptoms can be eventually overwhelmed by symptoms of loss, somnolence, physical and mental inactivity (torpor) and apathy, which may paradoxically relieve some carer burden. As brain failure invariably advances the deliriant threshold falls, with recurrent deliria resulting in further brain injury. Personality change, psychoses, anxiety, depression, agitation and aggression can uncharacteristically emerge or be unmasked by the brain injury. Home care can become intolerable and dangerous. Yet glimpses of former self may still occur, such as flashes of humour and moments of reflection of past personal achievements. Tender, loving family reunions can still happen. Family and carers know this, though by the middle stages of this disease they may have had to surrender ongoing care to aged residential care facilities.

Suffering is reasonably assumed, though may be unable to be reported or objectively determined as capacity becomes compromised, then extinguished. The limited literature suggests many, if not most, suffer. One estimate is that nearly two-thirds of hospitalised end-stage dementia patients die with a “high” level of suffering.¹⁰ Yet rarely, if ever, do persons experiencing the apparent indignities of a neurodegenerative disorder comment upon the quality of their existence—it is as if survival

instincts and denial behaviours just take over as free will is lost. Witnesses also suffer: only 56% believe their relatives died peacefully of dementia.¹¹ “Dying of dementia with dignity” may be an aspiration. “*How people die remains in the memory of those who live on*” was reputedly said by Cicely Saunders, the pioneering palliative care exponent. Caring for the sick can be a positive experience but can also lead to high levels of carer burden, anxiety and depression.¹² Partners of people dying with dementia experience poorer health than those facing bereavement from other causes.¹³

Clinically determining when advanced-stage dementia becomes end-stage dementia is uncertain. Objective clinical signs are not well established. The bedside signs of those dying with dementia are conflated by comorbid disorders. If allowed, a typical dementia death involves precipitous loss of mobility, limitation of speech, physical discomfort and musculoskeletal pains, incontinence, debilitating fatigue and somnolence (Table 1). The accumulating effects of anorexia, anosmia, ageusia of ageing, loss of the fine motor skills necessary for independent feeding, dysphagia, unfitness to engage in the social aspects of dining, sarcopenia and, for some, hypermetabolic cachexia may result in irreversible inanition and malnutrition.¹⁴ Minimal energy expenditure, weakness, forgetfulness and diminished hypothalamic perception of thirst and hunger result in decreased renal function and a frail state. Attentive mouth care relieves thirst, if present, but rarely does artificial hydration improve it. Death that typically occurs on average of 10 days after the cessation of nutrition and hydration is not due to starvation or dehydration.^{5,15} There is a lack of evidence to support active interventions such as artificial hydration, enteral tube feeding and nutritional supports.^{16,17} A loss of the emotion “disgust” leads to rejection of assistance with personal cares, despite overt need. Chemical or infective aspiration pneumonia may require anticholinergic medications or even a brief trial of antibiotics to ease respiratory congestion. An intractable physiological and behavioural determination to self-destruct eventuates and a deteriorating level of consciousness progresses to respiratory and cardiovascular shut-down, likely consequent to brain stem neural death. Usually this is a peaceful process though, if compounded by agitation or delirium, tranquilising medications may be indicated. The cause of death is frequently attributed to cardiac failure and/or pneumonia rather than the primary cause of illness,

Table 1: Indicators of impending end-of-life in neurodegenerative conditions.

• Rapid deterioration of independent and safe ambulatory ability (falls, inability to sit up or hold head up unsupported, ataxia, physical rigidity, immobilisation, primitive reflexes)
• Increasing dependence for personal care (dressing, feeding, bathing, shaving)
• Loss of urinary and faecal continence
• Loss of speech (linguistic regression, limited single intelligible words only, loss of speech)
• Difficulties swallowing (choking, recurrent aspiration pneumoniae)
• Increasing fatigue and drowsiness, torpor (diurnal and nocturnal)
• Loss of appetite and weight >10% (anosmia, inability to feed self, inanition, cachexia)
• Pain (agitation, generalised musculoskeletal pains, contractures)

dementia. Acknowledging diagnostic descriptors such as vital exhaustion, inanition and *genug* (Yiddish/German for “enough”)¹⁷ as mortal signs of dementia may more accurately reflect the final stage of dementia.

What could, or should, be the management of terminal dementia? Supportive nursing care is fundamental. Modern medicine can, and often does, offer antibiotics, fluid replacement, tube feeding, resuscitation and clumsy medicinal tranquilisation. But are these interventions instituted with palliative intent or because of clinician ease and procrastination? Procedures risk adverse effects and the inability to reverse aetiology indicates a high likelihood of recurrence. Such treatments may be medically futile. To “cloak” or palliate the associated emotional and physiological distress rather than to medically battle hopelessly and ineffectively is the more appropriate management of advanced dementia states.

Specialist palliative medicine is not a viable solution to the crisis. The specialties of geriatrics, neurology and psychiatry of old age, likewise. The disease time course is long, and the disorder a complex mix of neurological, psychiatric, psychological and physical symptoms. The impending tsunami of cases and resource limitations preclude these options. The role of these specialists will be to attend to the complex cases, usually cases with comorbidities of these respective specialties, to support community practitioners and to contribute to the literature to guide clinical practice. Managing advanced illness is a core component of all medical practice. Yet it features little in training. Most attendees

of doctors, particularly the elderly, have chronic and incurable ills requiring supportive care. The fear instilled by modern medical practice is not that of death but of dying tortured by aggressive clinical interventions. Allowing a natural death requires skill and humanity. Managing pain, delirium, dyspnoea, distressed whānau, psychoses, frailties and aggressive outbursts can be challenging for all concerned but is possible and easier in the familiar environment of the person with dementia. Hospital admission for a person with dementia is often harmful, for in addition to it being confusing and disrupting, they have a higher risk of developing iatrogenic complications from polypharmacy, falls and hospital-acquired infections, these halving their survival time compared with those without dementia on admission.^{18,19} Admission to acute general hospitals, knowing full well that the best outcome may be an extra few weeks of poor quality life in a psychogeriatric aged care facility, may be a costly exercise in medical futility. Protecting acute public hospitals, allowing them to do what they best do—which is not dementia care—is vital. Aged care facilities need to function as designated and funded, where residents who take ill are treated and taken care of.

Adapting the end-of-life choices legislation is not an option. No just society can contemplate euthanasia for ill persons who are cognitively incompetent. Additionally, because of the possibility of the “disability paradox”—a change of mind when actually experiencing a previously feared condition—acting on advance care directives in neurodegenerative conditions is fraught with

practical and legal uncertainties. It is medically acceptable practice for doctors not to offer active interventions in conditions considered futile to treat. But it is a professional obligation to provide palliation in life-limiting disorders. A major tenet of palliative care is the involvement of the patient (and whānau) in decision-making. But this is not possible with those lacking capacity. Formal welfare guardians, if already appointed, can guide sensible management and need to be involved in determining management plans, though proxy decision makers are often inclined to support ongoing reasonably active treatment regimes. Family carer proxies show only mild to low agreement with stated end-of-life treatment preferences of people with dementia.¹³

Families invariably have hope and hopes may mute fear, though unrealistic hope can be psychologically damaging. Determining not-for-resuscitation status of the terminally ill should be a formality, but surrogate minds may opt for intervention if the attending doctors timidly decline to advise regarding potential harm and the extremely poor outcome of cardiopulmonary resuscitation (CPR) in this population.²⁰ Assuming some medical management assertiveness over the terminal phase of advanced dementia is necessary. A tailored palliative approach to advanced dementia is a major component of addressing the crisis in late-phase dementia care. Often the most difficult decisions of bedside doctors and proxy decision makers are to “do nothing” and not to embark upon futile treatments. Palliation is not doing nothing or clinical neglect.

The most feasible option in addressing the crisis presented by ageing and fading “baby boomers” is that of altering the culture and tasks expected of medical practice. This would need to be married to a better understanding of the natural prognosis of neurodegeneration. All doctors, nurses and aged care workers need appropriate expertise and confidence to manage all the stages of neurodegen-

erative disorders. Appropriate attention is being instilled into improving the quality of life in mild to moderately severe Alzheimer’s dementia, though not to the late stages. Dementia is a catastrophic brain failure and is no different to heart, renal or respiratory failure, disorders in which sensible withdrawal of active interventions are frequently made. Yet advanced brain failure is considered differently when shifting the goal of care from prolonging life and maintaining function to maximising comfort.²¹ Dedicated nursing and palliative care are indicated, appreciated and effective in comforting those dying with or of dementia. Prescribing effective and tolerable comfort medications for pain, anxiety, delirium, emotional distress, depression and psychosis requires a practice demanding considerable skill and a considered approach. Aged residential facilities must function as advertised and relieve emergency departments and acute medical services of their current burden. “Good” bedside decision making can avoid weeks to months of prolonged and poor-quality remaining life of the remnant cognitive shell of the unrecognisable loved one. Withdrawal of ineffective or harmful treatments is not therapeutic neglect; rather, it is core medical practice consistent with current medical knowledge. There are few more difficult tasks in the practice of medicine, and many other attractive and appealing professional roles, though few others requiring such a momentous attitude change to avert a mushrooming healthcare crisis. The public deserve end-of-life information about neurodegenerative conditions, healthcare trainees and practitioners likewise, and humane palliation and assertive clinical decision making is required, for the crisis is upon us. Sensible palliative care can improve symptom burden, prevent under-treatment and over-treatment of symptoms with unnecessary and burdensome interventions, reduce caregiver burden and enhance caregiver quality of life.⁷

COMPETING INTERESTS

Nil.

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