

Cameron Swift calls more Christians into caring for people with dementia

DEMENTIA

key points

After reviewing aspects of dementia and commenting on its impact, the author reflects on recent coverage, both negative and more positive.

While the challenges presented may appear to be ethical ones, they can often be radically reduced or eliminated by the professional competence and skill of care providers working as teams.

Because we find the prospect of euthanasia abhorrent, Christian doctors must get more involved at the intellectual, advocacy, clinical, scientific and professional levels.

The syndrome of dementia comprises a range of disorders. The most common are significantly age-associated: Alzheimer's disease, dementia with Lewy bodies (DLB), frontotemporal dementia, vascular dementia and dementias of mixed origin. The estimated prevalence is 1% in those aged 65-69, rising to 34% in those over 95.¹ Increase is predicted by 2050 in proportion to the relative numbers of the population achieving advanced age. Some important generalisations:

- Dementia is by definition progressive and irreversible, but its natural history and severity (including prognosis for life – sometimes 20 years from diagnosis) are variable and often unpredictable.
- Diagnosis may prove difficult. Both premature misdiagnosis and delayed diagnosis (sometimes because of concealment) are common.
- There has been substantial progress in the neuroscience. Responders, a subset, derive useful short-term cognitive benefit from cholinomimetic agents, but effective disease-modifying interventions are awaited.
- Levels of distress, often prolonged, are characteristically though not invariably greater amongst loved ones than amongst sufferers themselves. The social and microeconomic consequences are frequently far reaching.

Recent coverage

In September 2008 an interview given by Baroness Warnock to the Church of Scotland magazine *Life and Work* was reported:

The veteran Government adviser said pensioners in mental decline are 'wasting people's lives' because of the care they require and should be allowed to opt for euthanasia even if they are not in pain. She insisted there was 'nothing wrong' with people being helped to die for the sake of their loved ones or society. The 84-year-old added that she hoped people will soon be 'licensed to put others

*down' if they are unable to look after themselves.*²

Dame Joan Bakewell was recently appointed official 'voice of older people' and, at least by implication, later linked her new role to her support for debating assisted suicide and her advocacy of living wills.³

The Nuffield Council on Bioethics undertook a more balanced national consultation on ethical aspects, seeking to examine the experience of dementia, implications for personality and identity, decision making, aspects of care delivery, carers' needs, and research priorities and conduct.⁴ CMF responded⁵ and the final report is still awaited.

Dementia presents challenges which appear to be 'ethical' in three main areas:

- adverse prognosis and end-of-life care
- loss of capacity and its management
- resource allocation and economics

Advance directives

Carefully prepared advance directives may have a place if their real aim is to facilitate consensus between clinicians and proxies. However, meddlesome intensivism in treating dementia sufferers is rare in my experience. It would be exceptional not to factor in a known prior diagnosis of clinically significant dementia when deciding the capacity to benefit from advanced life support, and it would be a clear exclusion criterion for many major invasive procedures.

Interpreting an advance directive often becomes difficult and must ethically be set in the context and balance of other indicators of 'best interest'. For example, for a femoral fracture, hip surgery (normally with antibiotic prophylaxis) is now usually the best, kindest and most cost effective treatment, even for individuals with dementia and poor mobility, such that 'conservative' alternatives are inhumane and expensive by comparison.⁶ This might require some considerable persuasion with a nominated proxy holding a directive. Best technology is not always synonymous with disproportionate intensivism.

Sadly, Dame Joan's spectre of 'a lot of enormous machinery that can keep them pumped up'³ portrays a simplistic, populist distortion of clinical decision making that is inappropriate to her current role. Sufferers from early dementia should not be frightened or pressured into instigating such directives, either to 'defend' themselves from inappropriate medical 'interference' or because relatives, Baroness Warnock or Dame Joan Bakewell assert this is inherently a good thing.

Paradoxically, far more common and potentially far more damaging is applying a 'label' of dementia as a pretext for 'DNDA' – do not do anything (including pursue a diagnosis!) An advance directive might better stipulate that clinical rigour be sustained unless and until proven of no demonstrable benefit, and a far better solution still would be to eliminate the perhaps justifiable fear amongst older people that health care as a whole may not always guarantee their best interests.

Personhood, ethics, and expertise

However severe and distressing the case, we cannot scientifically, professionally or ethically determine whether or when dementia's manifestations might conceivably annul personhood, identity, or (importantly) relationships. A daughter responding to Dame Joan wrote:

*How does one judge that one's identity has faded away exactly? The Dad I had before his dementia diagnosis was a completely different Dad to the Dad I have today. Definitely his old identity has faded away, however he now has a new identity and it was born from his struggles to fight this damn disease. I'll be ***** if I'll put up with outsiders thinking they know what is best for him and what he wants when they will never know what his life is like unless they have lived it... Oh dear, I ranted didn't I?*

I don't think so. Our biblical understanding of *homo divinus* – man's God-given and permanent identity in his image⁸ – directly applies; but outside Christian circles the non-destructibility of personhood still squares with reality, and society erodes that concept at its peril.

The successful clinical, rehabilitative and social management of dementia sufferers challenges the best multidisciplinary skills of health and social care professionals. The frequency of 'ethical' concerns in decision making and care provision, like using restraint or 'truth telling', can be radically reduced or eliminated by the professional competence and skill of care providers working as teams in an appropriately configured environment. 'Ethics' may sometimes be invoked as absolution for poor standards or systemic neglect.

Euthanasia

The fundamental objections elaborated by CMF⁹ and elsewhere apply absolutely. Baroness Warnock's prosecution of it in this context effectively discards any prior professed commitment to its allegedly voluntary basis, and exemplifies the 'slippery slope' by arguing (?for the first time) an explicitly economic and social rationale. Thankfully, it remains an accepted human standard within 'post-Christian' Britain to strive to overcome disadvantage and care

for those disadvantaged, but can we be complacent?

Independently of the moral rationale, the 'economic tsunami' argument, though complex, is by no means established in evidence. The Royal Commission on Long Term Care¹⁰ refuted the 'demographic timebomb' concept. Informed contemporary debate is balanced,¹¹ but economic alarmism is energetically invoked by those with deeper ideological motives. Conversely, co-ordinating and delivering quality services leads to substantial cost efficiency gains.

Pursuing excellence vs doctrine of despair

Dementia services can be done magnificently. I have been privileged to witness some of the best examples, not least the skills of some outstanding nurses in old age psychiatry, both in the community and in specialist units. Significant progress has been made in understanding, organising and providing health and social care for dementia sufferers. Benchmark centres and standards have emerged although access to the best and most skilled care is still very patchy. Key is the identification, recognition and comprehensive support of the often immeasurable care delivered by families and informal carers.

Effective collaboration between the specialist old age services in psychiatry and medicine, and between primary and secondary care, is essential and effective.^{12,13} There is gradual progress, not least in recognising achievement in the delivery of 'conventional' medical/social care (as distinct from radical 'blue-skies' science). More long-term data is needed. There are promising new lines of research in basic and clinical neuroscience, but research expenditure is disproportionately low in relation to health care cost.

NICE has produced specific guidance.¹⁴ Although the pharmacological recommendations have proved controversial, much of the clinical guidance is excellent. The designation 'Cinderella service' is a contradiction in terms, a perception underpinning the current enquiry of the All-Party Parliamentary Group on Dementia into training,¹⁵ and the launch of a National Dementia Strategy.¹⁶

A Christian response

Get involved.¹⁷ As we have begun to see in good palliative care, the best response to unethical 'solutions' is to render them superfluous by advances in knowledge, good professional practice and technical expertise. This is true for dementia services. If as Christian medics we find the concept of economic euthanasia abhorrent, we all have a duty to engage directly at the intellectual, advocacy, clinical, scientific or professional levels. There are Christians in old age psychiatry but not enough.

In her little book *If it's not too much trouble* Ann Benton states 'the one thing I knew I wanted to do was to get Dad out of the hands of professional 'carers'. Bring on the Christians.'¹⁸ But we cannot endorse this dichotomy, can we?

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