

Dementia: A Challenge to the Church

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The Challenge to the Church



Vince O'Rourke's *I Wish I Were a **Leper**: the diary of one couple's struggle with fear, faith and Alzheimer's*

- When Vince's wife Margaret developed early dementia, she said, "I wish I were a **leper**.' Startled, [Vince] asked why a **leper**. She said, 'If I were a **leper**, He would cure me.'" (p. 14)
- Vince developed the image: "I have likened the stigma society places on those who suffer from Alzheimer's to that of the **leper** in Biblical times... Our experience was that many friends and even extended family members could not deal with the outward expressions seen in the one having the disease. We felt abandoned, outcasts like the **lepers** of old." (p. 6)
- We cannot cure dementia. **But if we try, the Church can help to cure the **leprosy** of dementia.**



Overview

1. The Dementia Epidemic
2. What is Dementia?
3. The *Report* of the (UK) Nuffield Council on Bioethics
4. Catholic Teaching about Tube Feeding
5. Catholic Health Australia's *Guide*
6. Questions for Discussion

Resources



1. *I Wish I Were a Leper: the diary of one couple's struggle with fear, faith and Alzheimer's*, by Vince O'Rourke
 - available for \$29.95 (plus \$5 postage) from:
<http://orourke.pbworks.com/w/page/6735197/FrontPage>
2. *Dementia: Ethical Issues*, by the Nuffield Council on Bioethics
 - *Report* (about 200 pages), *Executive Summary* (17 pages), and *Guide* (20 pages)
 - Download or order print copy from www.nuffieldbioethics.org/dementia
3. *Ministering to people with dementia: a pastoral guide*
 - available for \$37.50 from *Catholic Health Australia*:
<http://www.cha.org.au/publications.html> or (02) 6203-2777.



1. The Dementia Epidemic

World Alzheimer Report 2015: The Global Impact of Dementia, from Alzheimer's Disease International

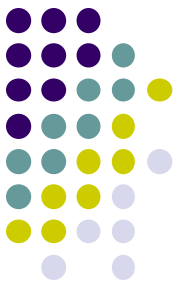
- issued on 25 August 2015
- 90 pages, written in English
- download from <http://www.alz.co.uk/research/world-report-2015>
- In 2015, 46.8 million people worldwide are living with dementia.
 - 58% are living in low- and middle-income countries.
- By 2030, 74.7 million will live with dementia.
 - 63% will live in low- and middle-income countries.
- By 2050, 131.5 million will live with dementia.
 - 68% will live in low- and middle-income countries.



1. The Dementia Epidemic (cont'd)

Dementia in Australia, by Australian Institute of Health and Welfare

- 252 pages, issued on 27 September 2012
- download from <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737422943>
- In 2011, about 298,000 Australians were living with dementia.
- In 2015, about 342,800 Australians are living with dementia.
- By 2030, about 550,200 Australians will be living with dementia.
- By 2050, about 891,400 Australians will be living with dementia. This is almost TRIPLE the 2011 figure.



2. What is Dementia?

Nuffield Council *Report*, page 4:

- “a collection of signs and symptoms such as memory problems, communication difficulties, difficulties with organising and planning one’s day-to-day life, changes in mood and behaviour, and the gradual loss of control of physical functions”
- these symptoms are “an indication of physical damage to the brain as a result of chronic progressive degeneration of nerve cells”

2. What is Dementia? (cont'd)



- caused by a variety of diseases
 - Alzheimer's disease is the most common and best known
 - There are almost 40 other diseases which also cause dementia, including vascular dementia, dementia with Lewy bodies, Parkinson's disease dementia, and frontotemporal dementia.
 - Different forms of dementia may initially affect people in different ways. They may also progress in different ways. For this reason, it can be useful to know what form of dementia a person has, what effect it is currently having, and what effect it may have in the future.

2. What is Dementia? (cont'd)



- Current drug treatments cannot reverse the underlying degeneration of brain cells. For a while, they may improve or at least delay decline in cognitive function.
 - Different types of dementia require different treatments. There are no effective medicines for some types of dementia.
- Information and advice, psychological therapies to improve confidence, practical help in the home, and assistive technologies may improve the quality of life and independence of people with dementia.

2. What is Dementia? (cont'd)



- Alzheimer's disease usually progresses through mild, moderate and severe stages.
- People with dementia can have good and bad days.
- They may be better at certain times of the day, e.g. better mid-morning, then 'sundowning' late afternoon.
- There can be early onset dementia.
- Dementia is a terminal condition.
- **ASK QUESTIONS!** One of the best ways to understand a person with dementia is to ask those who care for them.

Stories about Dementia



DVD *The Notebook*

DVD *Still Alice*

Vince O'Rourke's *I Wish I Were a Leper*

- Vince was Director of Catholic Education in Brisbane 1983–1998.
- Margaret's early onset Alzheimer's disease was diagnosed when she was 59. There were signs of deterioration 12 or 18 months before this.
- Vince cared for Margaret at home for 7½ years.
- Margaret was in a nursing home for the last 15 months of her life. Vince visited her 3–4 hours every day.
- Margaret died on 10 October 2006. She was 67½. She and Vince had been married for just under 41 years.
- Vince kept a diary or journal. He has reworked this into a 230-page record of the **struggles** and **joys** of this journey.

Stories about Dementia



Vince O'Rourke's *I Wish I Were a Leper*

- Margaret's attempts at conversation were almost impossible to follow.
- Margaret had no memory of their life together.
- Margaret did not recognise Vince or know that he was her husband.
- sleep deprivation, urinary and faecal incontinence
- Margaret found a new friend in her reflection in the mirror.
- many unexpected surprises, e.g. even after she lost the ability to speak, Margaret's beaming smile of recognition
- Margaret's kind hairdresser Mary who was not distressed when Margaret had an animated conversation with the people in the mirror.
- the kind people at Mass who were not distressed when Margaret spoke loud nonsense to Vince during the service.

3A The Nuffield Council *Report:* Ethical Framework



The Council's ethical framework has 6 components:

1. A case-based approach to ethical decisions
 - = focus on the facts and values in each situation, and compare them with other cases in which we have worked out what to do
 - Ethical dilemmas arise frequently in the day-to-day care of people with dementia, e.g. use of monitoring and tracking devices, use of restraint, balancing freedom of action with the need to protect the person, issues related to sexual relationships and sexual disinhibition, if and when it is acceptable not to tell the truth, cases of abuse by family and friends, etc.
 - These dilemmas are often problematic and stressful for carers.
 - Can we support carers by asking about the ethical dilemmas that they face?

3A The Nuffield Council *Report*: Ethical Framework



2. A belief about the nature of dementia

- = Dementia arises because of a brain disorder. It is harmful to the individual. We must seek to provide good quality care which minimises this harm.

3. A belief about the quality of life with dementia

- = with good care and support, people with dementia can expect to have a good quality of life throughout the course of their illness.
- We should therefore challenge negative views about dementia, eg among those who say, “If I get like *that*, shoot me!”
- Our faith also challenges these negative view of dementia. We believe that the Creator of Life can bring new life out of every human experience, including dementia.

3A The Nuffield Council *Report*: Ethical Framework



- 4) Promoting the interests of both the person with dementia and those who care for them
 - = these interests include autonomy (the freedom to make our own choices) and well-being (which includes the experience of pleasure).
 - Promoting autonomy involves enabling and fostering relationships that are important to the person, and supporting them in maintaining their sense of self and expressing their values.
 - At times, the separate interests of carers must be recognised and promoted, even if these conflict with the interests of the person with dementia.

- 5) Acting in solidarity
 - = we recognise our responsibility to support people with dementia and those who care for them.

3A The Nuffield Council *Report:* Ethical Framework



6) Recognising personhood, identity and value

- = the person with dementia remains the same, equally valued person throughout the course of their illness, regardless of the extent of the changes in their mental abilities and other functions.
- We should therefore challenge views which deny the personhood of the person with dementia, e.g. “Really, my mother died two years ago. All that’s left is a shell,” “The lights are on but nobody’s home,” “Dementia is a ‘living death’ or ‘death that leaves the body behind’.”
- The spirit or soul of the person with dementia is still there. They may struggle to express who they are because of often profound disability.
- Our task is (as much as possible) to help the person with dementia to hold on to who they are. We often have to remind them who they are. We may have to research their lives so we know who they are.
- Especially for people who have been religious, religion and spirituality are very important in this task of reminding people who they are.

3B The Nuffield Council *Report:* Dementia and Society

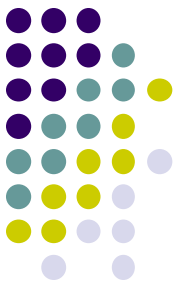


- Despite the fact that many people with dementia enjoy a good quality of life, the general perception both of dementia and of people with dementia is overwhelmingly negative.
- Dementia carries a stigma today that cancer no longer does.
- People with dementia often internalise societal attitudes, and therefore feel deeply ashamed, inadequate and stupid. As a result, they may withdraw from mainstream society and become very isolated.
- This marginalisation is harmful for people with dementia.

3B The Nuffield Council *Report:* Dementia and Society



- We must challenge this societal attitude towards dementia.
- The Catholic Church has an important role in this:
 - Around Australia, large numbers of people gather for Sunday Mass. If we can educate them about dementia, we can bring about significant societal change.
 - To do so is part of our mission of ushering in the Kingdom of God.
- What reasonable adjustments can we all make so that people with dementia are able to participate more fully in mainstream society?
- “For dementia to be truly normalised, it needs to be an accepted, visible part of society in the same way that physical disability is increasingly recognised as part of the norm.” (p. 67)



Some more resources

- “Caring for People with Dementia” (a summary of the Nuffield Council Report), *Chisholm Health Ethics Bulletin* 15, no. 3 (Autumn 2010): 6-9.
- “Catholic Teaching about Tube Feeding,” *Chisholm Health Ethics Bulletin* 16, no. 2 (Summer 2010): 8-12.
 - Download them for free from <http://www.chisholmhealthethics.org.au/publications>
- Alzheimer’s Australia *National Dementia Helpline*
1-800-100-500

4. Catholic Teaching about Tube Feeding



- Catholic teaching holds that tube feeding is “in principle, *ordinary* and *proportionate*, and as such morally obligatory” for cases of post-coma unresponsiveness (vegetative state).
- Even in these cases, tube feeding is usually stopped when death is imminent. It is then futile and overly burdensome (‘extraordinary’ or ‘disproportionate’ means).

4. Catholic Teaching about Tube Feeding (cont'd)



- In advanced dementia, people lose the capacity to feed themselves.
- The alternatives are hand feeding or tube feeding through a PEG (percutaneous endoscopic gastrostomy).
- In most cases, tube feeding offers no benefits over hand feeding. It does not improve nutritional status, reduce the risk of aspiration pneumonia, or prolong life.
- It may impose significant burdens such as restraint. It also deprives the person of the human contact of hand feeding.
- Decide on a case-by-case basis, but tube feeding is rarely a good idea.

Catholic Health Australia's *Guide*



- Issued in 2008, it is just over 50 pages.

Foreword by then-President of ACBC Archbishop Wilson: “I commend all priests and parishes in Australia to make constant reference to this timely publication.”

1. Why a publication on dementia for parishes?

- “Increasingly, parish priests and parish workers are being called upon to minister to people with varying stages of dementia and their families.”
- “In producing this guide, CHA is responding to a call from priests, religious and lay people in parishes.”

Catholic Health Australia's *Guide* (cont'd)



2. What is happening when a person has dementia?

- “[I]t is completely normal to feel vulnerable, lacking in skills and often confronted by one’s own fear of having dementia... If you wait until you feel you have the necessary skills and confidence, perhaps you will never begin.”

3. Supporting the spiritual journey of the person with dementia

- “Even when all other memories have been stripped away, people with dementia will remember prayers and hymns and can be visibly moved and touched by a spiritual encounter such as receiving Communion or sitting with a priest or someone from their Church.”
- “Some people may need assistance in coming to terms with a diagnosis which is frightening.”
- “Simple prayers can be reassuring” e.g. praying the Rosary

4. Communicating with the person with dementia



What works best

- Allow plenty of time for a response.
- Talk in a gentle way. Keep sentences short and simple.
- Use orienting names, such as ‘your son Jack.’
- Use the person’s own name regularly.

What to avoid

- Avoid competing noises such as TV or radio.
- Avoid pronouns as much as possible.
- Don’t change from one topic to another.
- Don’t ask a lot of direct questions.

4. Communicating with the person with dementia



What works best

- Use hand gestures and facial expressions.
- Stay still while talking.
- Wear traditional clerical attire.
- To call to prayer, use gestures such as the Sign of the Cross or joining one's hands in prayer.

What to avoid

- Don't talk about people in front of them as if they are not in the room.
- Don't be uncomfortable with silence.
- Don't argue. It will only make a difficult situation worse.

Catholic Health Australia's *Guide* (cont'd)



5. Ministering to the person with dementia

- “Actively encourage family members to take their loved one to Mass.... it may be more appropriate for them to come to quieter weekday Masses.... Ensure the church is accessible as possible and minimise the possibility of tripping. The toilets should be very clearly labelled and accessible.”
- “For many people living with dementia, there can be strong issues of guilt and unresolved conflict.... The Sacrament of Reconciliation can bring peace of mind and healing.”
- A person with dementia may forget that they’ve been to Confession and ask for it repeatedly. Family members should remind them that they have made a good Confession and that God has forgiven them. If they remain agitated, one tip is to get them to repeat their ‘penance’ e.g. “Fr Joe asked you to say three Hail Mary’s, let’s say them together now.”

Catholic Health Australia's *Guide* (cont'd)



5. Ministering to the person with dementia

- “A person in danger of death, who is sick or who has dementia may receive” the Anointing of the Sick. “A request from [the people who love and care for the person with dementia] or the person with dementia for Anointing of the Sick should be respected.... [T]he use of oil and the sensate nature of the Sacrament can touch their spirit where words alone would not reach.”
- At a funeral, “it is important to resist the temptation to state that the person actually died some time ago, or that they have simply been a shell during the years they had dementia. This undermines their human dignity and the value of their whole of life experience.”

Catholic Health Australia's *Guide* (cont'd)



6. Ministering amidst the challenges

- If they become upset, don't be distressed. Consider what happened to make the person act this way. Try distraction or change the topic of conversation. Seek advice from the person's caregivers.

7. Ministering to carers

- Carers “need a place where they can be honest, where they can cry, be angry or silent...”
- “Carers welcome the question, ‘What do *you* need?’”

Conclusion and References

- “For many people with dementia it is often the spiritual experiences of human encounters, prayer and the Sacraments that bring peace and solace in a part of their life journey which can sometimes be frightening and lonely.”

6. Questions for Discussion



- What experiences have I had of people with dementia?
- What have I learnt? What has 'worked' for me in ministering to them?
- What stood out to me as important in this presentation?
- How can I/we continue to educate ourselves and the others who minister in the diocese about dementia?
- How can I/we educate the people who attend Mass in the diocese about dementia?
- How can I/we reach out to people with dementia?
- Are there people or places who can help us?
- Are there people or places that I/we should particularly reach out to?

Presenter



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