

‘Understanding Dementia’ (What it is to be human)

by

Professor Rodger Charlton MD FRCGP

Today's Talk

- **Aim** – This is not a heavily academic referenced talk and nor should it be, but,
- It is about Dementia, the common problem of dementia, what is to be human both as a person with dementia and their carers
- It is very much from a medical perspective as the spiritual side will be discussed later

Introductions







Hampton
Surgery





George Davies Centre



George Davies Centre





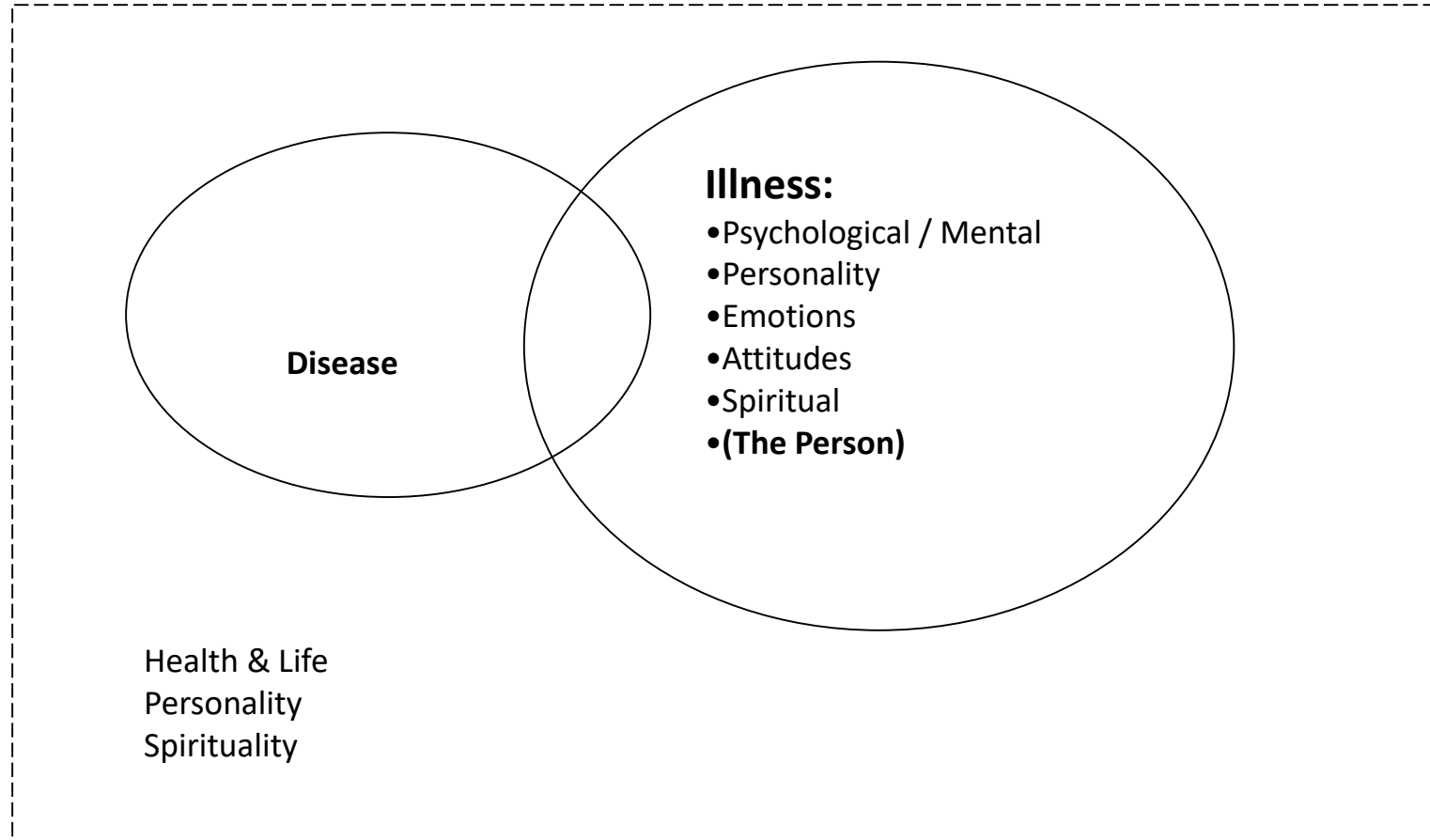
Knowle United Reformed Church

Patient Expectations of You

- future of GP/Medicine hasn't changed

- In any Illness eg Dementia, - **To be their doctor**
- Accompany them on the journey
- To follow them up, even when cure is not possible
- Availability
- **Be there for them**
- Communication, communication, communication
- Not Sympathy or Empathy but **Compassion**

- First, some Theory
- Remember there is a difference between Illness and Disease
- Dementia is a disease process but manifests itself as an illness which will be different and unique to each individual



What is General Practice?

- And what of the many factors today - social, psychological, physical and spiritual that influence a disease and so course of an illness such as dementia?
- For patients and their carers it is the GP and their multi-disciplinary team who have the role of advocates navigating the hugely complex system of the NHS and how to get care for someone with dementia

Medicine is not an Exact Science

- For me as a GP, medicine is both an art and a science – important now as in 1930
- ***“Medicine is not, and probably never will be, an exact science; it is an art aided by the application of several sciences, in which philosophy, religion, and sometimes commercialism also play a part.”***
- (H Rolleston 1930 - lecture on medicine as a career BMJ 1930 ii 699-702)



Photo by J. Pang



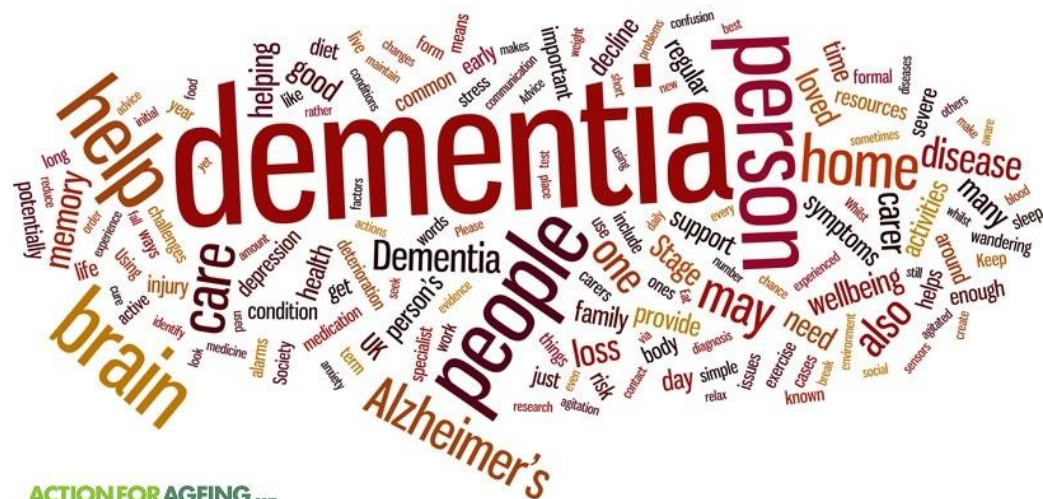


In the Future

- The UK population is projected to increase by 9.6 million over the next 25 years from an estimated 63.7 million in mid-2012 to 73.3 million in mid-2037 [Office for National Statistics)
- The number of people aged 80 and over in the UK is projected to more than double to 6 million by mid-2037
- Frail elderly population (transition to 90-110)
 - Current life expectancy in UK; male 79, female 83

The Future

- Dementia in UK; **1 in 79 people** in 2014 (Alzheimer's Society estimate to increase by 156% in 2051)



Statistics

- According to the Alzheimer's Society there are around 850,000 people in the UK with dementia.
- 1 in 14 people > 65 will develop dementia
- 1 in 6 people > 80



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- Communication, communication, communication
- Not Sympathy or Empathy but Compassion
- The same can apply to you as a Minister



Cum Scientia Caritas

- "Scientific skill with loving-kindness"
- McCulloch, G.L. The James Dundas Simpson Address: Cum Scientia Caritas. *J.Roy.Coll.Gen.Practit.* 1969; **18**: 315-20.



www.nhs.uk

- If you are becoming increasingly forgetful, particularly if you are over the age of 65, it may be a good idea to talk to your GP about the early signs of dementia.
- As you get older, you may find that memory loss becomes a problem.
- **It is normal for your memory to be affected by stress, tiredness, or certain illnesses and medications -
It does not mean you have dementia!**

Dementia as a Disease

- Dementia isn't just about memory loss. It can also affect the way you speak, think, feel and behave.
- It's also important to remember that dementia is not a natural part of ageing
- Forgetfulness yes, this can be annoying if it happens occasionally, **but if it's affecting your daily life or is worrying you or someone you know, one should seek help**

What is dementia?

- Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning/cognition. This may include problems with:
- memory loss
- thinking speed
- mental sharpness and quickness
- language
- understanding
- judgement
- mood
- movement
- difficulties carrying out daily activities

Causes / Types of Dementia

- There are many different causes of dementia. People often get confused about the difference between Alzheimer's disease and dementia.
- [Alzheimer's disease](#) is a type of dementia and, together with [vascular dementia](#), makes up the vast majority of cases of Dementia
- In my experience Alzheimer's is rapid and affects physical function
- Vascular – gradual onset, mainly memory, physically the person tends not to deteriorate – (Stepwise Decline)

Change in the Person

- People with dementia can become apathetic or uninterested in their usual activities, or may have problems [controlling their emotions](#).
- They may also find social situations challenging and lose interest in [socialising](#)
- ***Aspects of their personality may change***
- A person with dementia may lose empathy (understanding and compassion), they may see or hear things that other people do not ([hallucinations](#)) (Consider suicide risk-Rob Williams with Lewy body dementia)



People with Dementia need a lot of help, understanding and love

- Because people with dementia may lose the ability to remember events or fully understand their environment or situations, it can seem as if they're not telling the truth, or are wilfully ignoring problems.
- As dementia affects a person's mental abilities, they may find planning and organising difficult
- ***Maintaining their independence may become a problem***
- A person with dementia will therefore usually need help from friends or relatives, including help with decision making

Why is it important to get a diagnosis?

- Although there is no cure for dementia at present, if it's diagnosed in the early stages, there are ways you can slow it down and maintain mental function.(Medication)
- A diagnosis can help people with dementia get the right treatment and support, **and help those close to them to prepare and plan for the future.** (eg living will, LPA)

Continuing to lead an active life

- With treatment and support, many people are able to lead active, fulfilled lives
- The symptoms of dementia tend to worsen with time.
- **In the much later stages of dementia, people will be able to do far less for themselves and may lose much of their ability to communicate.**

How is the Diagnosis made?

Six Item Cognitive Impairment Test (6CIT)

(6CIT - Kingshill Version 2000, Dementia screening tool)

Patient's Details:	Date:
	Name of Assessor:

Question	Score Range	Score
1. What year is it?	0 – 4 Correct - 0 points Incorrect – 4 points	
2. What month is it?	0 – 3 Correct – 0 points Incorrect – 3 points	
3. Give the patient an address phrase to remember with 5 components, eg John, Smith, 42, High St, Bedford		
4. About what time is it (within 1 hour)	0 – 3 Correct – 0 points Incorrect – 3 points	
5. Count backwards from 20-1	0- 4 Correct - 0 points 1 error – 2 points More than 1 error – 4 points	
6. Say the months of the year in reverse	0- 4 Correct - 0 points 1 error – 2 points More than 1 error – 4 points	
7. Repeat address phrase John, Smith, 42, High St, Bedford	0 – 10 Correct - 0 points 1 error – 2 points 2 errors – 4 points 3 errors – 6 points 4 errors – 8 points All wrong – 10 points	
TOTAL SCORE	0 – 28	/28

Outcome from Score

0-7 = normal	Referral not necessary at present
8- 9 = mild cognitive impairment	Probably refer
10-28 = significant cognitive impairment	Refer

Diagnosis

- Screening – memory assessment
- Bloods (reversible causes)
- MRI – ischaemia and or cerebral atrophy

Need to exclude treatable causes

- Sadly rare
- If it is vascular –smoking cessation is vital, advice which is not well received

What of Treatment?

- Assessment and Diagnosis
- Planning, Care and Support
- Alzheimer's Society, Volunteers, Admiral Nurse
- Carers (professional and informal) and Respite



Medication

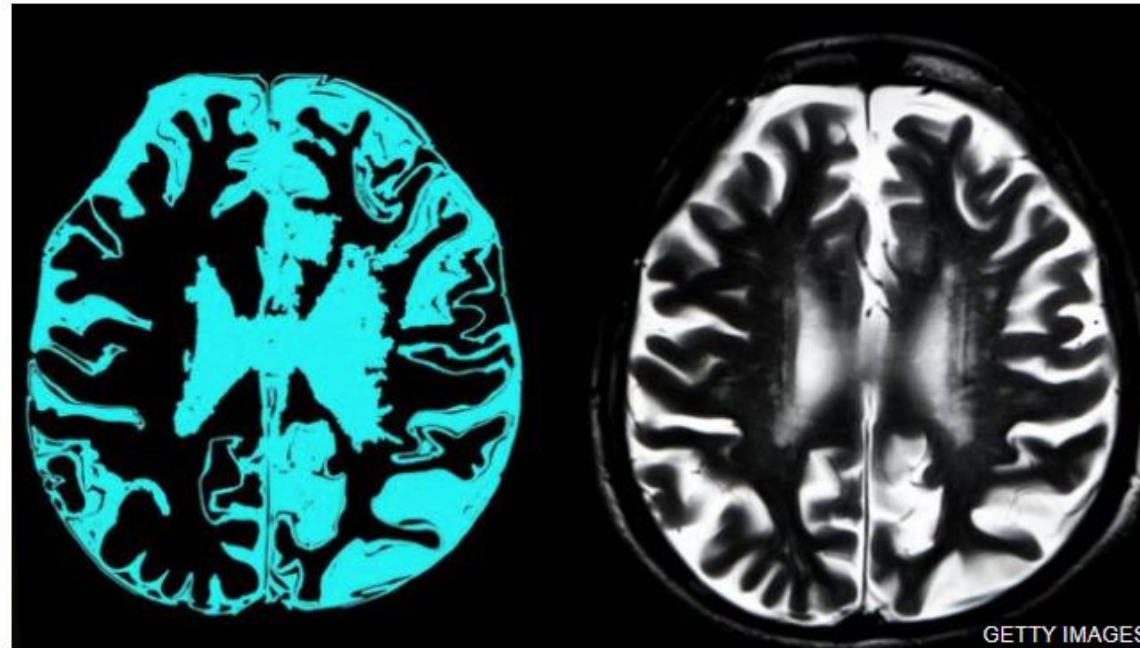
- Most of the medications available are used to treat Alzheimer's disease as this is the most common form of dementia.
- They may help to temporarily reduce or delay progression of symptoms
- ? When to stop

First drug that can slow Alzheimer's dementia

By Michelle Roberts
Health editor, BBC News online

🕒 22 October 2019

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A US drug company says it has created the first therapy that could slow Alzheimer's disease, and it is now ready to bring it to market.

Currently, there are no drugs that can do this - existing ones only help with symptoms.

Biogen says it will soon seek regulatory approval in the US for the "groundbreaking" drug, called aducanumab.

Acetylcholinesterase inhibitors

- These medicines prevent an enzyme from breaking down a substance called acetylcholine in the brain, which helps nerve cells communicate with each other.
- Donepezil (also known as Aricept), rivastigmine (Exelon) and galantamine (Reminyl) are used to treat the symptoms of mild to moderate Alzheimer's disease.
- There is evidence that these medicines can also help treat [dementia with Lewy bodies](#) and [Parkinson's disease dementia](#), as well as people who have a mixed dementia diagnosis of Alzheimer's disease with [vascular dementia](#).
- **There is little difference between these medicines in their effectiveness**

Memantine

- This medicine (also known as Namenda) is given to people with moderate or severe Alzheimer's disease, dementia with Lewy bodies and those with a combination of Alzheimer's disease and vascular dementia.
- It works by blocking the effects of an excessive amount of a chemical in the brain called glutamate.

Medicines to treat challenging behaviour

- In the later stages of dementia, a significant number of people will develop what is known as "behavioural and psychological symptoms of dementia (BPSD)". The symptoms of BPSD can include:
 - increased agitation
 - anxiety
 - wandering
 - aggression
 - delusions
 - hallucinations

These changes in behaviour can be very distressing, both for the person with dementia and for the person caring for them

- However, [there are coping strategies that can help](#)
- If coping strategies don't work, antipsychotic medicines such as risperidone may be prescribed for those showing persistent aggression or extreme distress.
- These are the only medicines licensed for people with moderate to severe Alzheimer's disease (risperidone and haloperidol) and vascular dementia (just haloperidol) where there is a risk of harm to themselves or others.
- [Antidepressants](#) may sometimes be given if depression is suspected as an underlying cause of anxiety



Spiritual Needs

- The person's spiritual needs will be individual to them, and may include questions about meaning, faith and belief.
- These needs should be addressed and respected as much as the medical aspects of care.
- Personal or religious objects, symbols or rituals (including prayer or readings) may be used.
- People with dementia usually keep older memories for longer, so they may respond to things they recall from earlier in their life such as religious readings or hymns
- www.alzheimers.org.uk

Needs of the Carer

- **Supporting the informal carer is vital**
- It is a 24 hour a day role & rapidly takes its toll
- As a carer you may have your own spiritual and cultural needs and it is important that you are supported to express these and have them met. Talk to care staff about your feelings and what spiritual and faith-based support is available
- The hard physical work of caregiving, largely done by unpaid wives and daughters, is only the visible tip of the iceberg of the problems of care

Dementia is hard

- **Dementia** is one of the hardest afflictions of old age, both for the sufferer and their carers
- **Dementia** is already a common tragedy and will become more common
- **Dementia** can steal our words, warp our personalities, and erase our memories
- **It can test our faith**
- People living with dementia are still able to learn and still have something worthwhile to contribute even if there needs to be some help to facilitate this

Faith and Dementia

- **Dementia** is a grimly stubborn and growing statistic in the unfolding story of our aging society, and it raises many issues for thoughtful **Christian** persons
- It is important to trust that people living with **dementia** can still walk with God and be spiritual
- Many people living with dementia are still able to read a Bible passage aloud so they can contribute to worship

<https://reflections.yale.edu/article/test-time-art-aging/dementia-religious-problem>

- In the real world suffering is inescapable. But suffering isn't the last word about human existence. Life and love are. We live in the hope of the resurrection.
- The ritual of the Eucharist walks us through the cycle of death and rebirth into community with God.
- It can provide help the caregiver and the person with dementia alike.

What can Christians do?

- The best things that Christians can do about dementia involve being present, welcoming, and listening.
- Many of the relevant skills are not high tech – but they do require character. We hold hands, sing songs, listen and care as best we can.
- We are the best vicars of the Christ who embodied ministry to the lonely and broken.

Questions

- Rodger Charlton
- rcc16@le.ac.uk



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Mental Capacity

Able to do the following:

- Understand the information relevant to the decision;
- Retain the information;
- Use or weigh up the information;
- Communicate the decision (by any means)

Lewy Body Dementia

- **Lewy body dementia**, also known as **dementia with Lewy bodies**, is the second most common type of progressive **dementia** after Alzheimer's disease **dementia**. Protein deposits, called **Lewy bodies**, develop in nerve cells in the brain regions involved in thinking, memory and movement (motor control)
- May present as Parkinson's particularly if memory problems in first year or vice-versa