



# Mind and Soul

## Dementia: losing your mind doesn't mean losing your soul

October, 2010

First book was: 'Could it be Dementia? Losing your mind doesn't mean losing your soul.'

The view from eternity changes the perspective of *now*.



## Our Background

- In 1807 the Aged Pilgrims' Friend Society was founded, on the basis of Galatians 6:10
- In the 1970s it became 'Pilgrim Homes'. (The Pilgrims...)
- In 2010 the Pilgrims' Friend Society was formed, incorporating Pilgrim Homes, Ernest Luff Homes and the Redbourn Missionary Trust.

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Background about us.

Our homes also have sheltered housing.

Means that we can offer respite care for CAREGIVERS as well as SUFFERERS.

Missionary family stayed in a flat alongside the care home where Dad was able to have respite care.

But Mum still went in each morning to help Dad get shaved and dressed.



## Introduction

- Janet Jacob, psychogeriatric nurse, former home manager.
- Louise Morse, Communications Manager, author, Cognitive Behavioural Therapist
- Roger Hitchings, Pastor, theologian, trustee, former director of Age Concern Birmingham, and care home owner.

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Janet – very experienced at the coal face. Several years a home manager. Her Mum developed dementia a couple of years before she died.

CBT helped me understand what was happening in people with dementia. Was a journalist and broadcaster. Also have a marketing diploma – behavioural sciences is about anticipating people's needs; understanding their needs, and meeting them. Useful base for a counsellor!

Roger, very precious trustee, very experienced pastor and former care home owner, and knows more than most about the spiritual care of older Christians.

## Matthew 25:40



"The King will reply, 'I tell you the truth, whatever you did for one of the least of these brothers of mine, you did for me'".

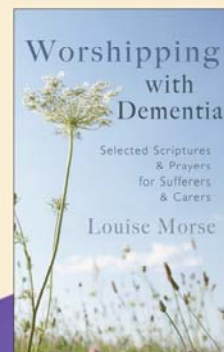
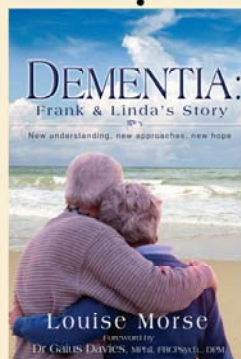
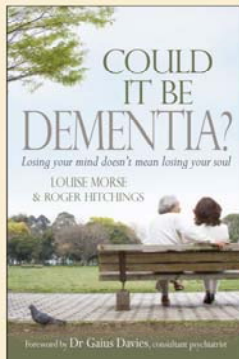
The lady with dementia was being visited by a member of her church, in one of our homes. She didn't remember the church member, but she was so 'engaged' and blessed by the visitor's attitude, and what she said. She was repeating the Scripture, 'Trust in the Lord with all your heart, and lean not to your own understanding. In all your ways acknowledge Him ...'

Enwrapped with the warmth and kindness. And the words of Scripture were resonating with her life-long, core beliefs. They brought her to life.

One of my iconic moments.

## Our background

- From 2003, more people with dementia in our homes
- Led to training and three books: -



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Other books we recommend are:

Contented Dementia, by Oliver James.

Dementia Revisited, by Tom Kitwood.

And still the Music Played, by Graham Stokes.

## How to help dementia sufferers

- When caregiving
- When befriending
- When visiting
- Remembering in church
- In practical ways
- In *being there* ...



This little 12-page booklet has been reprinted 3 times. People find it so helpful. Contains bullet points of condensed information. Free of charge.

## DEMENTIA – we're looking at -

- What it is
- How to cope with it
- What individuals/families can do
- What the church can do
- Can we avoid it?
- What's available to help
- Sources of information

Chapters in 'Could it be Dementia'? And in Dementia, Frank & Linda's story both give ideas for churches.

A shared burden.

Met a lady at New Wine who is caring for her mother with dementia. Call her Margaret. A very difficult situation. Her father refusing to accept the mother's condition, expects her to pull herself together. Shouts at her, handles her roughly – bruises. Mother now saying, 'don't let him come near me'.

Daughter at wit's end. Gave up her job to care for Mum. Belongs to a caring church. Met her at New Wine and met her some weeks later. She looked totally different. Church had prayed for her, with her, and had become 'engaged' with her and her situation.

There's a difference between knowing about, caring about, and being ENGAGED with.

**PILGRIM HOMES**  
CARING FOR ELDERLY CHRISTIANS

## Feedback, including from survey to churches

**Survey**

*How important is it to you to know the:*

	High	Med	Low
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- 1 symptoms of Dementia?
- 2 the conditions that can cause dementia that are generally treatable?
- 3 how to help and cope with people with dementia in church meetings?
- 4 spiritual support – why it is more important now than ever – what we mean by it – how to give it
- 5 how churches can help the sufferer and the family
- 6 visiting in own home and in care – practical pointers
- 7 advice on getting help, both medical and social
- 8 advice on getting a diagnosis
- 9 support and planning after the diagnosis
- 10 practical support; making the home and the church safe
- 11 praying for people with dementia
- 12 when and why residential care is the best option

*Helping people:*

- 13 how to choose a care home
- 14 domiciliary care – care in own home
- 15 information about funding care
- 16 supporting the carer/carer
- 17 What else would you find helpful in the Dementia Resources Pack?

18 How much would you expect to pay for the Dementia Resources Pack?

18 Would you like one of our specialists to come and talk? \_\_\_\_\_

19 This section is for you to put your own questions: \_\_\_\_\_

Please continue overleaf

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Very grateful to people who took the trouble to respond.

Still working on the dementia resources pack.

People took the trouble to write their additional comments and questions



## Important questions

- What exactly is dementia?
- When to seek help, and from whom?
- Control of finances and Power of Attorney
- HOW TO HELP! Challenging behaviour
- Prevention – and genetics?
- When is residential care indicated?
- How can a church fellowship help?

Definition of dementia. Many causes of dementia – not fully understood.

Social services, GP, church.

Website for PoA.

More about challenging behaviour later.

Prevention and genetics. The key thing is whatever it is that switches your genes on or off. Science of epigenetics.

Tom Kitwood's 'malign social pathology' that causes a 'malign biochemical environment' that damages neurones. From Dementia Reconsidered.

The tipping points for residential care – caregiver's health; inability to cope with challenging behaviour, physical health of patient, etc.

Things the church can do.

## Most dreaded

- Holds the place that cancer did 40 years ago
- Survey in 2008 showed many GPs preferred not to give diagnosis
- No cure on horizon – June 2010 pharma firms met to share failed drug trials
- Some medication can hold back the progression

There is an improvement in the NHS facilities for people with dementia. But patchy throughout the country. Most PCTs spent the monies allocated for dementia care on other 'priorities.

NICE has agreed that the NHS can fund drugs for people in the early stages of dementia now. Just this week.

## What is dementia, exactly?

- Dementia is an umbrella term that refers to the condition/syndrome that results from organic/neurological damage to the brain, caused by stroke (vascular) Alzheimer's disease, head trauma, metabolic disorders, Lewy Body, Pick's Disease, chronic alcoholism, or other insult.

# Dementia

- It is progressive
- It can be delayed, but not cured
- Causes are not known
- Genes are not as important as 'gene expression'
- Much advice on prevention; the best is similar to that for vascular health

Dementia itself is not a mental illness. However, some people with Alzheimer's Disease develop psychiatric and behavioral symptoms as part of the disease process. Also, people with dementia may have coexisting conditions, such as depression or anxiety. Psychiatric and behavioral symptoms, such as agitation, intense anxiety, and paranoid thoughts, may be treated with medications. Before concluding that a symptom requires treatment with medications, it is important to rule out other causes. A behavior, such as agitation, may have a variety of causes other than a psychiatric condition, such as, pain, hunger, constipation, or side effects of medication. If agitation is caused by pain, the solution would be to seek to identify and treat the cause of the pain.

EXAMPLE A woman who had limited communication skills due to prior strokes appeared agitated and repeatedly called out for help. Her behavior could appear, without further inquiry, to be irrational. In fact, she had a serious and painful infection. Her behavior was a rational response to her condition, given her limited communication skills.

## Statistics

- Figures of 750,000 or 820,000 in the UK
- Many people not diagnosed
- By 2025, one in three of us will be affected by dementia – as a caregiver, friend or family member, or sufferer
- Only a quarter of caregivers in the UK in care or nursing homes. Most cared for by relatives – usually an elderly spouse.

GPs unwilling to give a diagnosis. Daily Mail Survey 2008. It is 'morally wrong' that sufferers are not getting anything like the support that those with cancer expect, the Nuffield Council on Bioethics said in a report. It's a physical illness and should be treated as such, in the same way as cancer, said the Nuffield Bioethics Committee

## Could it be dementia?

- Not an inevitable part of ageing.
- Signs are not only memory loss.
- Disorientation/sense of dislocation
- Not able to make decisions
- Not looking after oneself
- Hygiene
- Apathy
- Depression

Bright 90 year olds. Depression is a very common precursor to dementia. Several academic studies show that isolation, and feelings of loneliness increase the likelihood of developing dementia by a significant percentage.

We are designed to live in relationship with one another. The Trinity mirrors this relational being, and this interdependence.

## Sample MMSE questions

- Three objects named: apple, table, penny. Patient must repeat and remember later
- What are these? (a pencil and a watch)
- Spell "WORLD" backwards
- Patient to copy a picture of pair of intersecting pentagons
- Follow a three stage command: Place index finger of right hand on your nose and then on your left ear

The freeze factor – being put on the spot!

## Diagnosis

- There are conditions that can cause dementia like symptoms but can be treated –
- depression, chest and urinary infections, anaemia, severe constipation, vitamin and thyroid deficiencies and brain tumours
- poor sight or hearing; emotional changes and upsets, such as moving or bereavement; or the side-effects of certain drugs or combinations of drugs
- tests are the MMSE and the Addenbrooke's test.

Stress and emotional changes, particularly in older folk



## Sample questions

- **Test Your Memory sample questions**
- Who is the Prime Minister?
- Why is a carrot like a potato?
- Why is a lion like a wolf?
- Draw the hands so the time reads 9:20 on this clock
- In what year did WW1 start?
- Please list four creatures beginning with 'S' eg. shark
- Sums:  $20-4=$   $16+17=$   $8 \times 6=$   $4+15-17=$

One of the websites commenting on this had a whole range of responses!

## The answers!

- David Cameron.
- Both are vegetables.
- Both are animals/hunters.
- 1914.
- Any creature or breed of dog is fine. Mythical creatures not allowed.
- 6, 33, 48, 2

Dr Jeremy Brown's Memory Test.

Try it yourself. TYM -Test Your Memory.

At [http://www.happyhealthylonglife.com/happy\\_healthy\\_long\\_life/2009/07/dementia-test.html](http://www.happyhealthylonglife.com/happy_healthy_long_life/2009/07/dementia-test.html)

## After the diagnosis

- Life expectancy? Depends on age at diagnosis – average AD 3 – 15 years.
- Stages of illness? Roughly, three – early, moderate, severe.
- Progression different with each person
- Is it possible to have ‘Contented Dementia’?

SPECAL – a way of caring that is kinder and more in tune with the person and the person’s reality.

It is described in Frank and Linda’s story.

And in ‘Contented Dementia’, by psychologist Oliver James.

The person who themed SPECAL, Penny Garner, reviewed the ‘Passport’ chapter in Frank and Linda’s story. And is speaking at our conferences in November.

Depends on a good Life Story.

We should all write our Life Stories.

## Things to remember

- Focus on the person, not the dementia
- The person doesn't change although they may appear to
- Focus on the person's core beliefs, on their values, on their significant events.
- Look beneath their communications for the meaning

Don't ask Questions.

Learn to love repetition. The day may come when the person can't communicate at all.

Answer the EMOTION beneath the question.



## Pilgrimage through dementia

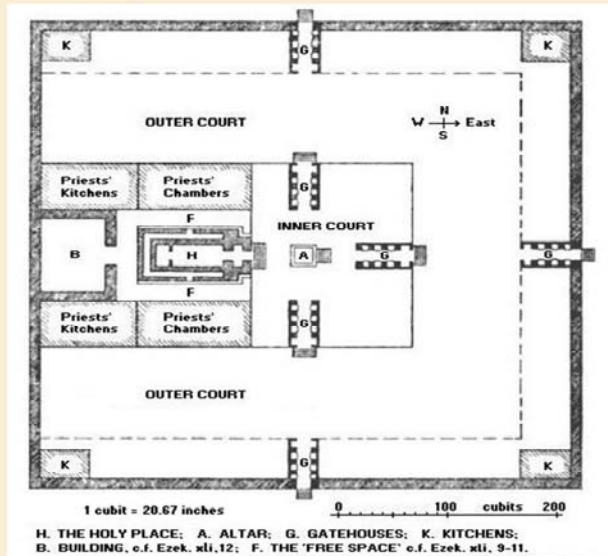
- ‘I believe that people with dementia are making an important journey from cognition, through emotion, into spirit. I’ve begun to realise what really remains through this journey is what is really important. I think that if society could appreciate this, then people with dementia would be treasured and accepted.’ Christine Bryden, high achieving executive diagnosed with dementia.

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Christine Bryden was an executive with the Australian Government. Diagnosed with dementia in her forties. Found no help available then for the sufferer, only the caregiver. Went on to write two books – ‘Dancing with Dementia’ and ‘Who will I be when I die?’. Helped to found DASNI, an organisation to provide

Now living quietly in Australia on a ranch – at least, she was, four months’ ago.

## Our tents... our temples.



Walls – externals.  
Gatehouses – senses  
Outer court – cognition/mind  
Inner court - soul, psyche  
Holy place – the place made for God/Holy Spirit

Seems a description of us, as human beings.

We have our walls – our physical bodies.

In old testament days the civic meeting place would be set in the wall of the city, near the gate. The gatehouse was the civic centre. (When Jesus said the gates of Hell would not prevail against the church he was referring to the policies and strategies of hell, not real gates.)

In our walls are our gatehouses – our senses that uptake raw data

The outer court - our cognition, our mind, the place where we process the data

The inner court – our soul, or our psyche

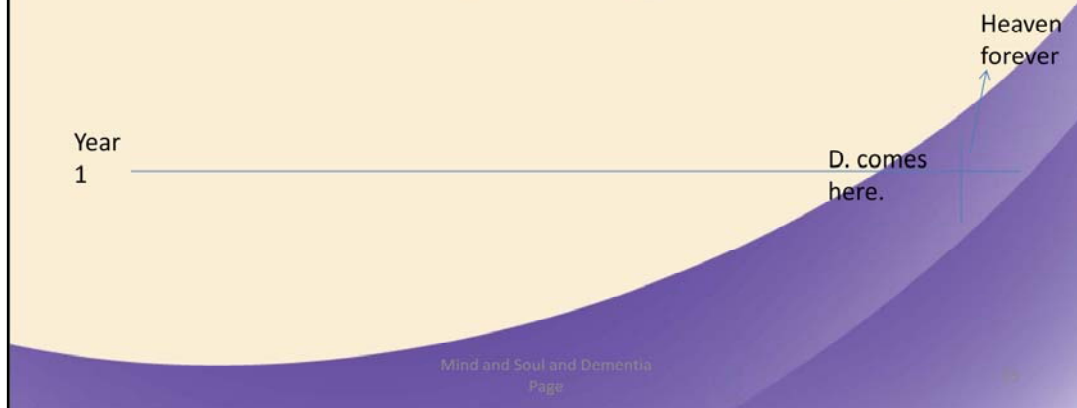
The Holy place – the place made for God, for the Holy Spirit. If this place is light, then the whole 'temple' is light.

### [Romans 8:9](#)

However, you are **not** in the flesh but in the **Spirit**, if indeed the **Spirit** of God dwells in you But if anyone does **not** have the **Spirit** of **Christ**, he does **not** belong to Him.

## An overview

- We are people on pilgrimage
- Each one of us is an eternal being
- Our lives are short, in the light of eternity



Dementia comes at the end of our lives.

We've usually had a full life until then.

## Getting on with life.

- A range of different reactions
- Some patients remain unaware
- Telling others
- Planning ahead
- Coping strategies
- Helps available varies throughout the country

Typical were the two couples Janet met at a conference, both in their late sixties.

Dr Daphne Wallace, former NHS Old Age Psychiatrist, diagnosed with vascular dementia herself, says it is important to know the diagnosis and to plan. There is still a purpose in life.

Find out what help is available from Social Services, even before you need it.

Tell your friends, your children, and your pastor.

Plan to make your home safe ... Fluorescent tape on stairs and steps, perhaps a route to the bathroom for night-time, pay attention to lighting, mirrors and shadows. Lots of things.

Get information. Social Services or your NHS dementia advisor might be able to help.

And read the books!



## The importance of relationships

- Avoiding isolation - not being abandoned
- Letting church family know your needs
- Building life story books
- Get information
- Being prepared for the future
- Anticipating/understanding your feelings

The biggest challenge with dementia is that it leads so swiftly to isolation, as people don't know how to cope with the different behaviour.

The developing focus on the plasticity of the brain – how it changes itself

London cabbies and enlarged hippocampus.

Malign biochemical environment, or benign. The vital importance of reciprocity in relationships.

Tom Kitwood said that the whole of our culture provides a malign biochemical environment.

Basis of CBT - dysfunctional thinking - as a man thinks in his heart, so he is.

## The importance of emotions for caregivers

- Negative emotions drain energy
- Negative emotions blur understanding
- 'Malign biochemical environment' damaging to neurones ... changes the anatomy of the brain
- Create unreasonable expectations
- A poor 'sense of cohesion' impacts ability to cope

A sense of cohesion – is to do with the caregiver's perception of their ability to cope. Their sense of integrity, of 'can do' because 'I have the capacity and the abilities.'

Some research shows that caregivers vary in their *perception* of the caregiver burden, depending on the strength of their SOC.

What is eminently doable for one person is impossible for another. A Samuri wrestler is not afraid of burglars – an elderly person living on their own can be.



## The importance of emotions in dementia

- Dementia sufferers can have heightened emotions
- As cognitive ability diminishes, emotions become highlighted.
- EG – may forget who you are, but remembers how he or she feels about you.
- Look for the emotion underneath the statement or question

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Caregivers – leave your negative emotions outside the door.

Body language, facial expression also talk.

## Caregiving – the Atlas syndrome

- The importance of getting the right sort of help. EG: Not someone doing the housework – someone *being there*.
- Consider respite care. For caregiver as well as sufferer.
- Dementia is a physical illness. Residential care is often as essential as hospital care.

Some Social Services providers are excellent. Linda, of Frank and Linda, has received amazingly good help and support from her SS. But in other parts of the country people have to fight their way through SS for it.

## Recognising limitations

- Studies emphasize that health care providers recognise the point at which residential care is necessary for the well-being of caregiving families.
- Caregivers continue to 'care', but the caregiver burden is greatly lifted.
- Sufferers benefit from trained teams of carers, who are also trained to care for themselves.

Tipping points – chapter in book.

## Choosing a care home

- At the outset, most spouses prefer not to consider residential care
- But most experts recommend it *at the right time*.
- Caregivers continue to care, but the burden is lifted somewhat.
- Other emotions to deal with

Dementia care is specialist care. Carers and nurses and doctors trained in it. Caregivers, generally, are not. An unequal task.

Guilt, feelings of failure, anger, frustration, all normal in caregiving - including when committing to res/nursing care

Residential care homes have teams of trained carers, who have time off – and a regular, good night's sleep!

Caregivers continue to give care to an extent. Mother had respite care in flat in one scheme, helped her husband shave and dress each morning. (He had lost the ability to speak, but he scrawled a note and gave it to her one day – it said, 'I love you.')

## The care home

- Is the home fresh and does it smell clean?
- Do residents look well cared for?
- Do staff have time for residents?
- Can you visit at any (reasonable) time?
- View the report on the CQC website
- How 'people centred' is the manager?

Trust your instincts.

Would you want to live there?

Would you feel safe there?

For Christians, spiritual support is paramount.

## The ultimate conclusion

- But as it is written:

*“ Eye has not seen, nor ear heard,  
Nor have entered into the heart of man  
The things which God has prepared for  
those who love Him.*

Life is short.

Eternal isn't.

That's where 'it's at'.





## Contacts

- [www.pilgrimsfriend.org.uk](http://www.pilgrimsfriend.org.uk)
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