

Salt and Light Papers provide important information and analysis to help Christians and Churches to engage with 21st century social issues

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DEMENTIA AND THE LOCAL CHURCH

Cliff Richard and his Mum, Terry Prachett, and John Suchet and his wife have recently brought helpfully under the spotlight the issue of dementia, which for too long has been the forgotten illness – the silent, invisible plague. In fact in the last decade it has become the big, unspeakable dread, just as cancer was in the mid and late twentieth century.

However, the openness and honesty of celebrities who have had to face the reality of their own dementia or that of their loved ones, has done a lot to increase public awareness and understanding, and to remove some of the stigma that attaches to this condition.

The statistics on dementia are becoming much more well-known. There are an estimated 700,000 sufferers in the UK, though this figure could be higher in view of the fact that in a recent survey, 60 per cent of GPs expressed a reluctance to diagnose dementia because of the lack of help and resources available.

A large proportion of those who care for dementia sufferers are older people themselves.

Most sufferers are over 75, although there are currently 15,000 sufferers under 65. A large proportion of those who care for dementia sufferers are older people themselves. It is estimated that dementia currently costs the Exchequer about £17 million each year, and that the number of cases will increase to 1.4 million in the next 30 years.

‘Dementia’ is an umbrella term for a range of conditions affecting brain function. These are progressive, neuro-degenerative disorders which are incurable and irreversible. There are over 100 causes of dementia, including Alzheimer’s Disease (which accounts for 58%) and Vascular (about 30%). Although there is no cure, there are some medications which ameliorate and delay the progress of dementia. The only medication that is found to be effective, Aricept, is not available on the NHS in the early stages. Sufferers can buy it for themselves, or else wait until their condition has deteriorated to the ‘moderate’ stage.

The government's strategy

The government has responded to the growing demands posed by dementia and the increasing public pressure for better services by producing a strategy paper indicating what it hopes to do in England over the next five years. The strategy sets out 17 recommendations which the government wants the NHS, local authorities and others to implement to improve the level of care services. The recommendations are focused on three key themes:

- Raising awareness and understanding
- Early diagnosis and support
- Living well with dementia

The government has also announced an extra investment of £150 million to support the local services which will deliver the strategy. Part of the strategy is to educate the general public through lessons in schools, training for employers and a national publicity campaign.

Scotland already has national targets for dementia diagnosis and care and Wales is in the process of developing its own plan.

In general the proposals for England have been welcomed in outline, with the caveat that it will be the implementation that will matter. The other main reservations which have been expressed concern the level of resources that will be available and the lack of financial commitment to research. Under the latter heading, there has been specific criticism of the postponement of the review of antipsychotic drugs – the so-called 'chemical cosh' used in some care homes to sedate people whose dementia produces anger or excessive distress.

Among the recommendations are some which are very significant:

- A national awareness campaign to tackle the stigma surrounding dementia
- Improved services for carers (this refers to 'informal carers' rather than paid workers)
- Joint commissioning strategies between local authorities and Primary Care Trusts
- A new inspection regime to monitor implementation
- Piloting a new professional role of dementia advisor to assist people and their families.

One aspect of the strategy which has received particular criticism is the proposal to set up 'memory clinics' in each town. Currently approximately 70% of GPs in England have access to such clinics. The intention is that these should assist diagnosis and enable early intervention, but many experts feel that there is a risk that memory clinics will merely create gigantic waiting lists and waste precious diagnostic time.

Another present concern is that some local councils are planning to take people out of hospitals, delay funding for them in care homes and provide instead 'care in the community.' Some councils are already beginning to do this. The evidence from the experience of domiciliary care for elderly

people who do not suffer from dementia shows that 'care in the community' is under-funded and insufficient. The demands on domiciliary services will be far higher if significant numbers of dementia sufferers are added to the workload.

The negative view of residential care implied by the promotion of a domiciliary approach is sadly reflected in some recent books on dementia emanating from Christian publishers.

The role of the local church

It will be a long time before the new public strategy begins to have an impact on the members of our congregations. We cannot wait for that, and should not do so anyway. So we need to consider now what local churches can do?

It may seem surprising, but the first thing to say is that churches need to know how many dementia sufferers and carers they have. After speaking at many different locations on this theme and assessing feedback from exhibitions at Conferences and other Christian events, it is evident to me that the invisibility of dementia applies in far too many of our churches – not just in the world at large.

Most churches will have at least one sufferer and many will have more. That will mean that there will also be people in the church who are carers or who are affected by the dementia of a close relative. It is therefore vital that pastors, elders and church leaders consider what response they should make.

A biblical understanding of the condition needs to be cultivated so that the response will not merely emulate the approaches of the world (although we should learn from them), but will properly recognise the spiritual dimension.

The attitude of despair and negativity shown by the world in response to this condition must be tempered by clear biblical thinking

Paul speaks of 'our light and momentary troubles' (2 Corinthians 4:17) and reminds us that 'in all things God works for the good of those who love him' (Romans 8:28). That means that the despair and negativity shown by the world in response to this condition must be tempered by clear biblical thinking. Dementia is a horrendous condition, but the God who orders all our steps has a purpose in what he sends.

Churches should take action in the following four areas: -

UNDERSTANDING

There is a fair amount of misunderstanding and even dangerous misrepresentation surrounding dementia in some Christian circles. Ideas that dementia may be the result of demon possession or

the effects of unforgiven sin need to be countered in a biblical way. The areas of understanding are:

- The real nature and progress of the condition and its impact on the sufferer
- The effects of the condition on carers and the sufferer's family
- The relevant resources that may be available
- Issues such as the Mental Capacity Act, advanced decisions (or directives or living wills).

These issues will be areas where sufferers and carers will struggle and need help and advice. A well-informed leadership will be an invaluable resource for sufferers and carers in our churches.

INCLUDING & VALUING

Too often, dementia sufferers and their carers can become isolated. Dementia can be a slow, long-running condition and those affected may not be able to attend church and can easily and quickly be forgotten. Those affected by dementia need to be informed about what is happening in the church and included in every possible way.

Every encouragement should be given to sufferers to attend services. Minor disturbances need to be tolerated, in much the same way as the disturbance of a small child would be. Dementia sufferers benefit from spiritual activities, such as prayer, Bible reading and spiritual conversation. Regular contact should therefore be maintained by the church to ensure that they have that opportunity. Carers too will greatly benefit from visits to the home of the dementia sufferer by people from the church. Those already living in care homes also need to be regularly visited and kept in touch. Visitors from the church can contribute greatly to the physical and mental activity of care home residents by engaging in constructive activities with them.

PRACTICAL SUPPORT

There are so many practical ways in which support can be given, from helping with washing and cleaning the house, to taking the sufferer out or sitting with him or her while the carer has a break. Every situation will be different and an assessment should be made with the carer to determine what sort of support would be most useful and appreciated.

SPECIFIC ACTIVITIES

Churches have an important role to play in supporting older people by providing visitors, lunch clubs and so on. Many already do so. But broader thinking is needed when it comes to dementia. There is great potential for proving how much Christians love each other, by the way in which they support and care for dementia sufferers and their carers, and in so doing set an example to the world.

Much more could be said about all these four things. There is a useful book on the subject, entitled *Could it be Dementia? [1]*, which gives the broader perspective. It is the only book on the market that presents a spiritual perspective while dealing with the realities of the condition. Churches may also want to look at the value of having training sessions on this issue. It is disappointing to discover how many young pastors, having completed training courses, have had virtually no input during their course on the care of older people and especially on the implications of dementia and their carers.

The issues raised by this condition will not go away, and will become a widespread, visible and dominant feature of 21st century society. Our churches must take it seriously. They have significant opportunity to contribute to the debate within the nation on this subject, and to take practical action and show what can be done.

Roger Hitchings

[1] *Could it be dementia?: Losing your mind doesn't mean losing your soul*, by Louise Morse and Roger Hitchings, published by Lion Monarch Books, and available (£7.99 plus £1.50 postage and handling) from Pilgrim Homes, 175 Tower Bridge Road, London SE1 2AL. Make cheques payable to Pilgrim Homes Trading Limited. Order form on Pilgrim Homes web site (www.pilgrimhomes.org.uk).

In a recent report, the Commission for Social Care Inspection, which is responsible for monitoring England's 18,500 care homes and thousands more home-care services, found that one in five residential care homes for the elderly in England fell short of minimum standards and rated one-third as 'poor' or 'adequate.' A contributory factor was thought to be the high average staff turnover of 20.7% per year.

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The Old Bank House, 17 Malpas Road, Newport, South Wales. NP20 5PA
Telephone: 01633 893925
Email: office@affinity.org.uk
Website: www.affinity.org.uk

affinity
gospel churches in partnership