



Dementia Project—Newsletter

Welcome to this first newsletter of the Caritas Social Action Network (CSAN) Dementia Project. The rising incidence of dementia in our ageing population is one of the biggest challenges to our Health and Social Care system, as the recent launch of the Government's dementia strategy has made us aware. There has been a developing awareness of the spiritual and pastoral needs of people with dementia and their carers. As we focus on person-centered approaches to the care and support of people with dementia and recognise their dignity and rights, we need to ensure that their spiritual needs as well as the practice of their faith are both acknowledged and met.

The CSAN Dementia Project seeks to draw on and build on good practice from faith communities with a particular - but not exclusive - focus on the Catholic Church in developing awareness of the spiritual and pastoral needs of people with dementia and their carers. It aims to ensure that those with dementia in care settings have their spiritual needs understood and met and that parishes are communities of understanding and welcome for those with dementia as well as their families. The project will be working closely with the Marriage and Family Life Project of the Bishops Conference of England and Wales.

During 2009 CSAN will be producing a DVD for all those involved in the pastoral care and support of people with dementia – including staff in residential and nursing homes and those involved in parish ministry. In the DVD we will look at meeting spiritual needs of people with dementia in the context of good practice in person-centered care. Meeting spiritual needs means helping people to feel loved and needed, to have purposeful activity, and above all to feel nurtured and cherished. People with dementia need their own sense of identity at a time when their self-worth is under threat. CSAN will also be organising a seminar during 2009 for those involved in the pastoral and spiritual care of people with dementia. More information will soon follow.

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We are interested in hearing your ideas about how the project can be taken forward or if you would like more information.

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CSAN is working with a number of residential and nursing homes caring for people with dementia which are affiliated with CSAN and we are particularly interested in hearing from parishes and deaneries interested in sharing, as well as developing good practice in this area.

CSAN has been approached by people from a number of parishes asking for help and advice in working with people with dementia and their carers. This is an area of growing interest and some suggestions from a leaflet produced by the former Social Welfare Committee of the Catholic Bishops Conference might be helpful.

As a first step it might be useful to identify some issues which can be discussed within the parish in order to formulate a parish response. Some of the questions which you might wish to consider include:

- Do we know enough about the spiritual needs of those parishioners with dementia in residential and nursing homes, or hospital wards ?
- How might we develop further our ministry for people with dementia. How might we support our Eucharistic Ministers in their ministry to people with dementia, bearing in mind that getting to know people with dementia takes time.
- Many of those with dementia and their carers might feel unwelcome in 'traditional' Masses – perhaps they demand too much concentration or they are difficult to understand. How might we better meet the worship needs of people with dementia ? Long term memory for people with dementia is often distinct. Many people with dementia find comfort in remembering familiar prayers and hymns. Consider a 'Candlelight' service, using familiar hymns and songs, participation in prayers, and appropriate use of Scriptures.
- Carers and relatives might feel marginalized and out of touch with the parish community - are their spiritual needs being addressed and met ? Can we do better in involving people with dementia in parish social activities ? So often people with dementia lack opportunities to go out and enjoy simple pleasures such as a walk in the park.
- Can we work on a wider dimension in addressing these issues – perhaps with the Deanery or in co-operation with other Churches where there are similar concerns ? The local branch of the Alzheimers Society might be a useful contact. In many areas there are Carers Support Groups which can provide much helpful mutual support. Hospital Chaplains, particularly those working with Mental Health Trusts, can be a source of advice and assistance.

- Alzheimers is a terminal illness. Are spiritual and religious issues addressed as part of end of life care in local hospitals and homes ?
- Can we set up –or get help- in setting up a parish support group ? See 'useful websites' at the end of this newsletter.

Some Prayers ²

*Blessed are they who understand
My faltering steps and shaking hand.
Blessed, they who know my ears today
Must strain to catch the words they say.
Blessed are they with a cheery smile
Who stop to chat for a little while.
Blessed are those who never say
'You've told us that story twice today'
Blessed are they who make it known
That I'm loved, respected and not alone*

And some resources...

*Lord, you will understand the grief of Mary
As she watched your pain and sadness
As your life drained away.
Be close to all who watch as
Illness relentlessly saps the vitality and life
From those for whom they care.
In those shared experiences of caring and being
cared for, may there also be
the shared experiences of your presence
and your promises of peace*

The Leveson Centre is an excellent source of information on pastoral care of people with dementia: www.leveson.org.uk

The Pastoral Care Project at Coleshill provides training and support for parish-based ministry for people with dementia. They also provide training for professional care staff including end of life care and offer a variety of resources: www.pastoralcareproject.org.uk

For ideas in supporting people with dementia and their carers in the context of pastoral and spiritual care of carers and families of people with mental illness: www.carersinthecommunity.org.uk

Footnotes:

1 A helpful guide to Candlelight Services is 'Lighting the Way – Spiritual and Religious Care for those with Dementia, by Patricia Higgins and Richard Allen (Leveson Centre)

2 These and other prayers can be found in 'In a Strange Land – People with Dementia and the local Church, by Malcolm Goldsmith