

Now that we have seen 'Its still ME, Lord'...

Our next steps as a parish or deanery – some guidelines for facilitators of parish and deanery discussions

Stage 1 - Do we know about people with dementia and their caregivers ?

We may need to consider further whom we need to reach out to in our parish ministry and what we want to offer to achieve this. This requires a planned but sensitive approach. We might want to start with the appointment of a pastoral coordinator who could already be a member of an existing group such as the Society of St Vincent de Paul. This person could act both as a link person for people with dementia and their caregivers in the community and also with care settings such as residential and nursing homes as part of the wider parish ministry which involves people who may not necessarily have a dementia. The co-ordinator could be supported by a small project group. Whether at parish or deanery level, it is essential to involve local clergy as well as parish pastoral workers.

How might we go about thinking whom we need to help ? A mention in the parish newsletter or the parish website might be one option. Word of mouth or contact through a friend or relatives might be another option but it is important that we respect the confidentiality of those involved. We could for example issue a general invitation along the lines of: 'As a parish we would like to improve our ministry to people with dementia and their caregivers. You are invited to contact....on a confidential basis if you feel that this initiative might be of help'...

Some points to remember in going about this exercise:

- No faith journey is the same - caregivers and people with dementia may have differing spiritual needs - they may not belong to the same Church or indeed be a practising member of our Church. We may need to understand to understand cultural and religious needs across the faith spectrum and know where to signpost those concerned for further help and support.
- Guidelines on confidentiality mean that staff in care settings such as hospital wards or residential homes may be unaware of someone's religion and are not able to share details without someone's permission. This can be difficult for someone with dementia. Residential Homes and hospital wards may find it helpful to have written details of the Parish and how it can be of help to a client. We might have to make ourselves known in a more active way rather than on relying on contact from the care setting.

- Relatives, family members, and members of the parish community can be a 'bridge' in helping to understand and make known someone's spiritual and religious needs. Members of the Chaplaincy Team covering hospital wards can often be a helpful link.
- People with early dementia have particular needs and may not feel comfortable in being 'grouped' with people with advancing dementia. In some areas there are specialist counselling services and support groups to address the needs of people with early dementia.
- Professionals involved in assessment and care planning need to be encouraged to think about someone's spiritual and religious needs in planning care and support for people with dementia and their caregivers.

Stage 2. Do we know about the services available for people with dementia in our area ?

A mapping exercise looking at local resources is often very helpful. There is an increasing range of support and advice services available for people with dementia and their caregivers as the National Dementia Strategy is implemented. Examples of local services include:

- **Alzheimers Society.** Local branches of the Alzheimers Society, which can often provide advice and support. Details available on www.alzheimers.org.uk
- **Memory Services.** Memory services, which comprise a multi-disciplinary team which undertakes both diagnosis as well as support for people diagnosed with dementia. These services are usually accessed following referral by a GP. The amount of support following assessment varies and in some areas there is specialist day service provision and support groups.
- **Admiral Nurses.** Admiral Nurses have been appointed in some areas with a particular brief for supporting carers. They are usually contactable through the local Mental Health services for older people and will welcome information on ways in which those with whom they work can be supported by the parish community.
- **Carers Support Services.** In many areas there are carers support services, often provided by a voluntary organisation and funded by the Local Authority and/or the NHS. Services provided can vary from individual support and counselling and it is helpful for these organisations to be aware of the support which can be offered by the parish.

- **Carers Assessment.** Carers who provide a substantial amount of care are entitled to a carers assessment. This should cover all aspects of their caring role, including their spiritual needs. There is often a small grant available to meet the identified needs of carers and this can be used creatively, for example in providing for a much needed break.

Stage 3. How can we raise awareness of dementia in our parish or faith community ?

Dementia can be misunderstood and we need to help the parish community in understanding different types of dementia and how they can affect people. This message may need to extend to people who see dementia as something to be feared. We need if possible to portray a positive image of dementia with a focus on opportunities rather than deficits.

A person with dementia have much to give as well as to receive and a profound sense of their spirituality and religious beliefs. Working with people with dementia and their caregivers can be as much a gift to us as a service. Through focusing on a person-centered approach, we can think about opportunities as much as deficits. The DVD 'Its still ME, Lord, provides a good starting point for such a message.

There are a number of ways in which the issue of dementia can be further explored, for example at weekly meetings of the Society of St Vincent de Paul or at a Deanery meeting. Your project group could consider a number of options.

A **half day session** could provide an opportunity to explore the subject in more depth. Where possible it is best to show a section of the DVD and then invite discussion. In many cases participants in discussions will have personal experience of the issues and these will need to be sensitively handled by the facilitator. Depending on the level of knowledge and interest, topics for a parish group could include:

- Different types of dementia
- The effects of dementia
- Understanding the spiritual needs of a person with dementia
- Meeting the spiritual needs of a person with dementia
- Meeting the needs of caregivers

A **shorter, two hour session** will not provide an opportunity to cover all the issues but provide an opportunity to provide awareness of some of the key issues. The first two parts of the DVD as well as the last part could be covered in this time. While the facilitator will need to give adequate time for discussion, it is important to ensure that the discussion does not get 'stuck' and that the focus

remains on pastoral implications for the parish community. Be prepared for people to 'open up' with their own experiences as many participants may have personal experience of dementia in their family.

There are some very good basic awareness resources available on-line. The Alzheimers Society publishes a detailed selection of leaflets on particular topics, all available on-line at www.alzheimers.org.uk. The Social Care Institute for Excellence (SCIE) has a good on-line learning resource available on www.scie.org.uk. A powerful tool for understanding how the spiritual needs of people with advancing dementia can be met can be found on www.memorybridge.org.

Stage 4. Making contact with people with dementia and their caregivers. This is most likely to be happening already, but the planning and awareness work already carried out will provide fresh ideas and help you to review the effectiveness of what is already being provided.

Residents in care homes and hospital wards. Some of those in care homes or a hospital ward may already be known to the parish and be on a list to receive Communion from a Eucharistic Minister. Contact by the pastoral co-ordinator with the manager or a senior member of staff (or a member of the Chaplaincy Team in the case of the NHS) over what the parish can offer can be helpful. We may want to look at when Communion is best given individually or whether there is an opportunity for a Eucharistic service. Some residents may want to get 'drawn in' even if they are not receiving Communion. It is important that we are sensitive to these needs.

It is important to encourage staff to see the broader spiritual needs of residents. While receiving Communion can be very important for a resident, meeting their spiritual needs in the daily care routines of the home can be equally important. Understanding someone's 'spiritual journey' will enable staff to develop a 'memory box' of treasured possessions which can be a source of comfort as dementia advances. Activity organisers are well placed to plan and provide reminiscence activities which can be based on treasured memories of earlier life in the parish or faith community.

The 'ministry of presence' may be very important to a person with advancing dementia and is as important as receiving Communion. You may want to consider how organisations such as the Society of St Vincent de Paul can work together with Eucharistic Ministry Teams to look at how, for example we might provide a regular visit in addition to, or as an alternative to provision of Communion.

Staff who may not have a religious affiliation may need help and support in encouraging a resident to maintain their prayer life, for example in saying grace before meals or a prayer at the start or the end of a day. The DVD 'Its still ME, Lord' is also designed to be shown to staff in care settings to raise their awareness of meeting the spiritual needs of residents. End-of-life issues also need to be addressed when liaising with staff in care homes and hospital wards. Adequate information will enable staff to ensure that relatives are involved and that specific religious requirements are understood and met.

Making contact with people with dementia and their caregivers in the community. Following an initial survey (see above), the next stage might be a short questionnaire which enables us to better understand the needs of people with dementia and their caregivers. You could ask an open-ended question such as 'How can we be of help' with a number of prompts including ways in which the parish may be of help, such as provision of transport or respite for a few hours to give caregivers a break.

And some ideas in discussions for getting involved with people with dementia and their caregivers:

At your planning sessions it would be helpful to give participants an opportunity to 'brainstorm' ways in which the parish or deanery can become involved. These are a few ideas that can be considered as the discussion develops...

- **The 'ministry of inclusion'** Some people with early dementia as well as advancing dementia and their caregivers might feel uncomfortable about attending Church. Regular visiting both to people in care settings and in the community can help to maintain contact with the parish at a difficult time. An offer of transport and encouragement could be of help. In one parish caregivers are invited to the home of a parishioner on a regular basis to catch up and chat about 'normal' life.
- **Understanding the needs of people with dementia in relation to some of our liturgy.** Can we meet the needs of people with dementia who may have particular communication needs or a limited concentration span ?
- **Signposting to other services.** Its often helpful to signpost people to local services which could be of help. You could consider the development of a 'resource bank' which consists of information on local services as well as helpful leaflets and other resources.
- **Providing respite** A person with dementia may feel more comfortable with someone they know from the parish rather than with someone they

don't know from a care agency. This can be a valuable opportunity for a caregiver to have a break for a few hours.

- **Music and Prayer.** As dementia advances, familiar music, hymns and prayers can often be a bridge to communication. Praying the Rosary can be helpful, both because of the repetitive nature of the prayer and because the tactile nature of the Rosary. Can we understand what is special to the person concerned and use this in our ministry ?
- **Eucharistic Ministry** Those receiving Communion in their own homes or in care settings may need a sensitive and flexible approach. Following discussion with Eucharistic Ministers, consider what additional training needs they may have to enhance their communication skills and allow enough time within rotas for them to provide Communion in a person-centered way. There might be an opportunity for a combined Eucharistic service in a care setting but this needs to be handled sensitively – see above.
- **Understanding cultural and religious needs from other faiths.** We may well come into contact with people from a number of faith traditions. It helps to be aware of differing cultural and religious requirements –see the resources section below.
- **'Giving back'...**Those receiving care and support should be encouraged to join or maintain their membership of parish organisations – giving something back and being part of the community promotes feelings of self-worth at a difficult time. Consider asking a person with dementia to be a 'prayer partner' for someone else, for example a young person in the parish.
- **Counselling and Support.** Do you have a trained counsellor or professional in the parish or deanery ? Caregivers often have complex and conflicting emotional needs and an opportunity to express these in a safe and constructive group setting can be very helpful. The DVD 'Its still ME, Lord' shows an example of such a group in Middlesbrough.
- **A 'quiet day' for Caregivers.** Consider the possibility of a 'quiet day' for caregivers. This could be a mixture of relaxation, discussion, prayer and reflection and could be organised on a Deanery basis.

Above all, try not to be over ambitious – one or two initiatives at a time might be plenty. Don't attempt too much and always work in close liaison with the local clergy. One or two initiatives which form part of a parish or deanery pastoral plan might be more effective than too many initiatives. In accordance with 'see,

judge, act' principles, its equally important to judge the impact and feedback from a particular initiative before going further.