

Pastoral Care for Carers

The person with Dementia is not the only person affected by the disease. Family carers, especially spouses, will find that their caring role is life changing and consequently they may have specific pastoral needs. The demands of caring are both rewarding and challenging, particularly for those who take on the task of caring in the home.

The carer may feel under pressure to ignore his/her own physical, emotional and spiritual health and wellbeing.

The pastoral support that a carer may need will vary depending on the individual circumstances; these are likely to change as the illness progresses. Different carers will have different expectations of their role, e.g. spouse/partner, child or a sibling. Behavioural changes in the person can be harder for the carer to deal with than symptoms such as memory loss. As the illness progresses and the carer witnesses changes in the person's character and personality, there may be grieving for this loss.

Much of the help that is available to the carer centres around support for their physical and emotional wellbeing. As a community of Christ, we are concerned for these aspects but also their spiritual wellbeing.



Exercising a Pastoral Ministry to Carers.

- Be prepared to give the carer your time. Exercise a Ministry of Presence. If possible, avoid situations where you may have to rush off to another appointment.
- Exercise a Ministry of Listening. You may be the only other person he the carer gets a chance to speak to that day. Do not be embarrassed with silence or try to fill it. Do not try and suppress any anger or frustration they may express; these are normal emotions.
- It is beneficial for carers to have a break and to engage in social contact with others. Church life can offer a variety of ways of providing this; Sunday Services, mid-week meetings, special social events and soon. They may need encouragement to do this without feelings of guilt. Be aware of the activities available and be invitational.
- If you promise to do something for the carer, make sure it is done. Better not to promise rather than break a promise.
- When praying in a pastoral visit, remember the needs of the carer as well as the person with dementia.
 - If the carer would normally have taken Communion, and can no longer attend to do so, consider Home Communion. Discuss with the Minister if you think this may be needed.
 - Arrange the next visit in advance to ensure the date and time will be suitable.

Sources of Information

The Alzheimer's Society and The Alzheimer Society of Ireland provide extensive useful information and guidance for those recently diagnosed with dementia, their families and carers.

Contact:

The Alzheimer's Society: www.alzheimers.org.uk. National

Dementia Helpline: 0300 222 1122

Email: helpline@alzheimers.org.uk.

The Alzheimer Society of Ireland: www.alzheimer.ie.

National Helpline: 1 800 341 341

Email: helpline@alzheimer.ie.

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SPIRITUAL CARE IN DEMENTIA

Guidance for Ministers, Church Visitors and Family



Church of Ireland
Church and Society Commission

This guide has been prepared to assist ministers, church visitors and family to communicate with people with dementia and their carers and to connect with them on a spiritual level.

Introduction

When members of the church family develop dementia, they can gradually become isolated and feel marginalised. Many are anxious about communicating with people who have dementia and stay away, feeling that their visit brings no benefit. The following words from a person with dementia, challenge us to think differently:

"There is no stage in this journey at which you must abandon all hope of connecting with me. You can minister to my spirit in song, prayer, ritual and your spiritual presence alongside me."

The following sections provide basic information on the nature of dementia, practical tips for communication, identifying spiritual needs, responding to those needs and considering carers.

What is Dementia

Dementia is the gradual and progressive loss of intellectual function - caused by several diseases, the commonest being Alzheimer's. It is not a disease in its own right but a group of symptoms which can vary from person to person.

It can manifest itself with difficulties in:

- Remembering things
- Interpreting what is going on
- Concentrating and thinking things through
- Understanding instructions
- Starting a task
- Assessing risks
- Learning new things
- Identifying familiar people, places and objects
- Reasoning and making judgments
- Being able to plan

It tends to progress and get worse as more symptoms appear and become more severe. The problems which may occur in the stages if the illness could be:

Mild

- Short-term memory loss
- Forgetting appointments
- Losing objects
- Failing to attend to matters e.g. not paying bills

Moderate

- Losing track of time
- Getting lost – even at home
- Forgetting names
- Failing to recognize familiar people

Severe

- Neglect of self
- Need for supervision full time

Relating to the person with dementia

It is important to remember that no matter how disturbed a person's mind may be they retain the dignity of a human being. These points are designed to help us develop and maintain a meaningful and satisfying relationship for both parties.

Do:

- Try to understand what the person is trying to communicate or do
- Jog their memory if they don't know or have forgotten something
- Try not to contradict or argue with them if they have a fixed idea which is wrong; if possible, "Go with the flow"
- Remember that direct questions about their life may be hard for them to answer and cause distress
- Look for clues in what the person may be saying or doing in order to understand what they may need or want
- Help the person to perform a task rather than do it for them
- Explain what you are doing or plan – don't expect they themselves will understand

- Remember their feelings and emotions are probably still intact
- Remember you may need to negotiate something that has to be done
- Avoid closed questions – person will often respond, "No". Instead of asking, "Would you like to go for a walk?" rather ask, "Where would you like to walk?"
- Speak simply, clearly and not too quickly.

Don't:

- Talk down to the person, or treat them as a child
- Make fun of unusual behaviour. Try to understand it
- Dismiss what they say to you
- Rush the person; give them time mentally and physically – to think and move
- Force them to do things – use gentle persuasion
- Try to talk over the TV, radio or other noises and distractions.

Spiritual Needs

Always remember that a person with dementia is a person with a spirit, feelings, personality and a life story.

The person needs;

- To feel connected; to God and people;
- To have a sense of belonging; to family, church or groups;
- To be loved and to love
- To have a sense of hope
- To be able to share; a moment, a memory, an emotion;

The Pastoral Visitor's Response

The guiding principle of spiritual care of people with dementia is to recognise and believe that every person has an intact soul, be willing to give your time and presence to that person, and be authentic in your expression of loving kindness and concern. Prepare for your visit, especially if you did not know the person before the onset of dementia. Talk to family or those who did know the person, their personality, gifts, church interests, hobbies, occupation, favourite hymns, special scriptures, names of their family and anything else significant.



Prompts such as a familiar magazine, well known poetry or a familiar object may assist in retrieving memories and create a sense of well-being.

Conversation which requires memory can cause frustration so converse in the present moment, eg talk about the weather, the flowers, the room, the photographs, admire the colour of clothing etc.

Use touch if the person appears comfortable with hand holding, smile and make eye contact. If they talk, try to understand the thoughts or emotions behind the words, which may be muddled.

Try to access faith memories, using old photographs of church events or singing age appropriate, well known or favourite hymns.

Read very familiar scriptures such as the 23rd Psalm or a known favourite scripture

Pray the Lord's Prayer or recite the Creed; keep prayers short and simple.

In advanced disease when there is neither verbal nor non verbal response, try humming a familiar tune or use recorded music or recite the words of a hymn such as 'Jesus loves me this I know' while stroking the hand or cheek to indicate your presence and human contact.

