

**PILGRIM
HOMES**

SERVING
OLDER CHRISTIANS

special
publication

How to **help** dementia sufferers



Pilgrim Homes (formerly known as The Aged Pilgrims' Friend Society) is a registered charity and a registered provider of social housing.

Charity No. 242266 : RP No. A0822

Evangelical and undenominational in ministry for older Christians

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Practical guide lines to help carers provide the right support for those suffering from dementia.

*'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.'"*

Matthew 25:40

SINCE 1807
MORE THAN

200
years

SERVING
OLDER
CHRISTIANS



We will never know the real value of ministering to people with dementia this side of heaven.

But we do know that Christian fellowship is essential for the spiritual wellbeing of those who live with it – both the sufferer and the caregiver. It was expressed powerfully by Christine Bryden, a former Australian government executive diagnosed with dementia, at a conference some years ago. She said:

“As I lose an identity in the world around me, which is so anxious to define me by what I do and say, rather than who I am, I can seek an identity by simply being me, a person created in the image of God. My spiritual self is reflected in the divine and given meaning as a transcendent being ... as I travel toward the dissolution of my self, my personality, my very ‘essence’, my relationship with God needs increasing support from you, my other in the body of Christ. Don’t abandon me at any stage, for the Holy Spirit connects us. ... I need you to minister to me, to sing with me, pray with me, to be my memory for me ... You play a vital role in relating to the soul within me, connecting at this eternal level. Sing alongside me, touch me, pray with me, reassure me of your presence, and through you, of Christ’s presence.”

GUIDE LINES

This leaflet gives some guidelines and tips on how to make the most of the time spent with both sufferers, and caregivers. Remember, they are God’s children, Christ’s purchased possession.

This leaflet has been produced by Pilgrim Homes’ Louise Morse and Roger Hitchings, authors of ‘Could it be dementia? Losing your mind doesn’t mean losing your soul.’ Published by Lion Monarch it gives valuable information and puts dementia into a Christian context.

JUST DO IT!

The first important tip is — just do it! Never assume that frailty and confusion excludes the work of the Holy Spirit. Hebrews 13:5. On the contrary: when we committed our lives to Christ He gave us His Holy Spirit, and promised that He would never leave us, or forsake us.

PRACTICAL SUGGESTIONS

Some practical suggestions, before your visit:—

- 1/** Unless you already know the person very well, find out as much as you can about them. They will have a personal history, which will include deeply held beliefs and values. Some phrases will be especially meaningful and comforting to them, and can act as triggers for good or for bad! Find out from the caregiver, or the carer in their nursing or care home as much as you can about these.
- 2/** Check whether or not they need a hearing aid, or spectacles, and make sure they have them available and use them.



- 3/ If you are engaging in devotions, or any spiritual activity, use the version of the Bible and the types of hymns that they are familiar with. 'How Great Thou Art' is more meaningful to older people than the more modern, 'How great is our God', for example, and the old King James version than more modern translations. This is very important, as older memories stay intact longer than later ones – remember, your preferences are irrelevant! It's what they know and can relate to that matters.
- 4/ Take notice of their background in the way you speak and pray. Some may prefer prayers read from the Book of Common Prayer, whereas some prefer spontaneous prayer. Reading familiar prayers can be a great comfort when someone is struggling with uncertainty.
- 5/ Find out how they like to be addressed. First names may well be acceptable, but let them decide, or ask their caregiver, who knows them best.
- 6/ The sense of touch is very important to some people with dementia. Check with the caregiver or the carer at the home. If the individual likes to hold hands, hold hands very gently, remembering the fragility of old age. Sometimes the individual likes to touch you – perhaps stroking your arm. Be sure you know in advance.



During your visit

Remember, when you minister to one of the Lord's people you are touching the Lord Himself! Matthew 25:40 says, *'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."*' What a wonderful privilege!

- 1/ Keep each session brief and direct.
- 2/ Sit close, if appropriate, and maintain good eye contact – and a relaxed, friendly expression. People with dementia are particularly sensitive to body language and unexpressed emotion.
- 3/ Speak clearly, and not too quickly.
- 4/ Be consistent in all you do and say. Avoid hurrying or quick changes of activity or subject.
- 5/ Do not condescend or talk 'across' them. Involve them in everything you say and do.
- 6/ Never scold, humiliate or correct them. Remember, their cognitive abilities are damaged. Your visit is meant to encourage and uplift them, not create turmoil and anxiety.
- 7/ Do not feel obliged to challenge their version of reality. Research shows that as the condition progresses memories are gradually lost, beginning with the latest. It may be that the sufferer is living in a world that is in the past – but it is not an imagined world. They are not being delusional. Their world is very real, but it belongs to the past. They cannot comprehend the present 'reality' because of the brain damage.
- 8/ Look for meaning in what they say and do. Try and 'look beneath'. If someone is saying something irrational, perhaps even 'gibberish', be respectful

- and try and read their body language. Always treat them with love and concern. If possible, use their 'errors' as a stepping stone for meaningful contact.
- 9/ Take everything one step at a time. Think 'linear'.
 - 10/ Focus on their remaining abilities, and do things in small steps.
 - 11/ Remember – keep it simple, keep it short and keep it sweet! Don't overload them with information or ideas.
 - 12/ Don't be afraid to repeat things, but do so gently, and with patience.
 - 13/ In coming to a spiritual activity, such as praying, reading from the Bible or singing a hymn, tell them clearly what you are about to do. Repeat yourself gently if they wander off onto a different subject. Tell them when you are going to sing and try and get them to join in. You will have found out in advance what hymns or songs are relevant to them. We all love our old favourites, and when you have dementia these old favourites are touch-stones for happy memories and feelings. Use the hymns and worship songs that are relevant to them.
 - 14/ Speak about reassuring things. Loss of assurance and loss of confidence in God are not unusual in frailty and confusion.
 - 15/ Encourage them from the Scriptures when they express guilt and fears. Make a note of Hebrews 13: 5,6, 2 Timothy 2:19, Psalm 71:18, John 20:38-30, Psalm 103: 13-14, Romans 8: 28-30, and 34-37.
 - 16/ There may be particular passages of Scripture or hymns that they will respond to more than others – don't worry about using them most of the time.



- 17/ Draw on things they will know, for example, events of their childhood, Sunday School songs, familiar hymns and well known Bible stories. Use pictures, photographs, or things that will remind them.
- 18/ Speak frequently about Christ and the cross. Talk gently, rather than preach. Don't be aggressive! Remind them of the glories of heaven, using the Scriptures when you can. John 14: 1-3, Revelation 21: 3-5, and 22: 1-4, Jude 24. There are many more you probably know well.
- 19/ If appropriate, hold the person's hand, or touch their arm from time to time. You will have found out in advance whether or not this is helpful.
- 20/ It's always good to pray, briefly, at the end of your visit. Prayer brings calm and a sense of peace as the Holy Spirit ministers.

If you have questions about any of this, please leave them on our Message Board at our website;

www.pilgrimhomes.org.uk





SUPPORTING THE CAREGIVER

The majority of caregivers are elderly spouses. Others are daughters; sons, or other close relatives, and still others are friends. They are on duty 24 hours a day, seven days a week, 52 weeks a year, often only poorly supported by others, including social care. Experts recommend that caregivers arrange respite care for their loved ones, and always bear in mind that nursing, or residential care will be inevitable at some stage. In the meantime, caregivers can seem to disappear from sight, especially from their church fellowships, as they become more and more restricted by the demands of caring. Research shows that the toll is so great that it takes an average of seven years off the lives of caregivers. They need empathy, love, and practical and spiritual support. Here are some things you can do.

- 1/** Do not allow the caregiver to be forgotten by the fellowship. Keep both them and the sufferer high on the church prayer list. Become their champion – nag people to visit and take an interest. Be their voice when they are too exhausted or preoccupied to speak for themselves.
- 2/** Be available to talk on the phone, and to visit. Let him or her know that you are there for them.
- 3/** Learn as much about the sufferer and his or her routine as you can, so you can offer regular periods of relief. Even mini ‘respite- breaks’ make a huge difference. Make a small ‘résumé’ of the individual, with the caregiver’s help, so you can extend your knowledge to others in the fellowship. It will give them confidence and encourage them to become involved.
- 4/** In conversation with the caregiver, don’t engage in criticising or speaking negatively about church life. But keep him or her aware of what is happening so they feel they still belong.
- 5/** Set up a support system so the caregiver can get to one of the Lord’s Day services on a fairly regular basis. To soak in God’s Word and be amongst His people is a great source of strength and encouragement. It helps restore emotional equilibrium.
- 6/** Make Christian audio recordings - DVDs and CDs available to them, even though their opportunity to listen and watch may be limited.
- 7/** Ask the caregiver to make a list of things the fellowship could help with. It could be cutting the grass, in the summer time, or collecting prescriptions, or helping with the shopping.
- 8/** Encourage spiritual thought in your conversation. The demands of caring can eat into personal time and private devotions can easily, and unavoidably, be missed.
- 9/** As well as visits to the sufferer, encourage visits specifically to the caregiver. It can be so demoralising to be seen as the ‘sufferers caregiver’, and not as a person who is loved and valued in their own right. Feeling worthless is a debilitating trait that is common amongst caregivers.
- 10/** When you visit the frail or confused person, involve the caregiver in your spiritual activities. If possible, take a short while afterwards to pray with the caregiver alone. Don’t be afraid to pray about the situation and the burdens of caring.
- 11/** When you spend extended time alone with the caregiver be prepared to discuss his or her problems and feelings. Encourage them to focus on the positive aspects of caring, as a service to Jesus Himself, and a calling from Him. Matthew 25:40 applies here, too. Listening is vital. Active listening

has tremendous therapeutic value, as does validating their sense of the situation. Never criticise them, or suggest they are spiritually lacking because of the negative aspects of some of their feelings. Encourage them to take a 'helicopter' view, looking at events in the light of eternity.

- 12/ Don't expect the caregiver to have time to be reading Christian books. Free time is at a premium. Only bring books and leave them if the caregiver has said they have time, and are able to concentrate on reading. A loaned book that cannot be read can become a burden and a rebuke.

IN SUMMARY

Caregivers need love and support, Christian encouragement and fellowship, respite breaks and practical help.

People suffering with dementia need much the same – love and understanding, Christian encouragement and fellowship and practical help.

'But now faith,
hope, love,
abide these three; but the
greatest of these is
love.'

1 Corinthians 13:13

Do you have tips and experiences that would benefit others? Share them on our website, www.pilgrimhomes.org.uk

- New understanding
- New approaches
- New hope

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