CHRISTIAN COUNCIL ON AGEING DEMENTIA GROUP

Dementia and Spirituality
An introductory reading list

This list has been produced by the Christian Council on Ageing Dementia Group. It does not aim to be comprehensive but should be of interest to those caring for people living with dementia and concerned about their spiritual needs. Items are listed in chronological order beginning with the most recently published. The majority of books and articles listed here can be obtained either through the Library and Information Service at the Stirling Dementia Services Development Centre or from the organisations listed at the end. A considerably longer bibliography of relevant publications is also available for academic researchers. For further copies of this list (price £2.00) or for the longer bibliography (price £3.00) please send a cheque payable to CCOA to Alison Johnson, 33 The Plain, Brailsford, Ashbourne, Derbyshire, DE6 3BZ. Copies can also be downloaded from the web http://rps.gn.apc.org/leveson/resources/study-ccoa.htm

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### 2005

<table>
<thead>
<tr>
<th>Author</th>
<th>HIGGINS, Patricia</th>
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<tr>
<td><strong>Title</strong></td>
<td>Bringing spiritual light into dementia care.</td>
</tr>
<tr>
<td><strong>Source</strong></td>
<td>Journal of Dementia Care 13(2), March/April 2005, 10–11.</td>
</tr>
<tr>
<td><strong>Abstract</strong></td>
<td>A description of the Candlelight Group which brings together a small group of people with dementia in a day hospital in Sutton, Surrey for a regular act of worship. The project won the Queen’s Nursing Institute/Alzheimer’s Society award for excellence and innovation.</td>
</tr>
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<tr>
<th>Author</th>
<th>HIGGINS, Patricia and ALLEN, Richard</th>
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<tr>
<td><strong>Title</strong></td>
<td>Lighting the way: spiritual and religious care for those with dementia.</td>
</tr>
<tr>
<td><strong>Source</strong></td>
<td>London: South West London and St George’s Mental Health NHS Trust, 2005.</td>
</tr>
<tr>
<td><strong>Abstract</strong></td>
<td>A booklet describing the establishment, principles and ethos of the Candlelight Group for people with dementia in day care, together with weekly service outlines for the whole year.</td>
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<tr>
<th>Author</th>
<th>KIRKBRIDE, Susan (ed)</th>
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<tbody>
<tr>
<td><strong>Title</strong></td>
<td>Restoring the soul: A selection of favourite hymns. Sung by choirs and members from Morningside United Church, Christ Church Morningside and Morningside Baptist Church, Edinburgh.</td>
</tr>
<tr>
<td><strong>Source</strong></td>
<td>Stirling: Dementia Services Development Centre, 2005.</td>
</tr>
<tr>
<td><strong>Abstract</strong></td>
<td>A CD of favourite hymns for older people chosen by people with dementia intended mainly for use in care settings.</td>
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<th>Author</th>
<th>KIRKBRIDE, Susan</th>
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<tr>
<td><strong>Title</strong></td>
<td>A restorative for the soul.</td>
</tr>
<tr>
<td><strong>Abstract</strong></td>
<td>The author explains the background to a collaborative production of a CD of favourite hymns for older people based on a survey carried out with a sample of people for whom the CD was intended, many of whom were living with dementia.</td>
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### 2004

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<tr>
<th>Author</th>
<th>GOLDSMITH, Malcolm</th>
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<tr>
<td><strong>Title</strong></td>
<td>In a strange land: people with dementia and the local church – a guide and encouragement for ministry.</td>
</tr>
<tr>
<td><strong>Abstract</strong></td>
<td>This book, written by someone who has spent many years as a parish priest, is full of reflections and suggestions for ministry with people with dementia, either in church congregations, care homes or families.</td>
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<tr>
<td><strong>ISBN</strong></td>
<td>0–95304–946–9</td>
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<tr>
<th>Author</th>
<th>GOLDSMITH, Malcolm</th>
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<tbody>
<tr>
<td><strong>Title</strong></td>
<td>Spirituality, religion and faith in dementia care.</td>
</tr>
<tr>
<td><strong>Source</strong></td>
<td>Journal of Dementia Care 12(4), July/August 2004, 28–30.</td>
</tr>
<tr>
<td><strong>Abstract</strong></td>
<td>A reflection on what religious and spiritual ideas have to offer to people with dementia and on relations between churches and people with dementia.</td>
</tr>
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</table>
Author: HAMMOND, Gaynor and TREETOPS, Jackie
Title: The wells of life.
Abstract: The writers explore from their considerable experience how to capture moments of worship with people who have dementia, tapping the resources that lie within.

Author: KILLICK, John, HAMMOND, Gaynor and KNOCKER, Sally
Title: Seeing the person beyond the dementia.
Abstract: Papers presented at a Leveson seminar in 2004. In ‘Touching the strings at the centre of your heart: learning love from people with dementia’, John Killick describes his work in communicating with people with dementia. Gaynor Hammond speaks of reminiscence and the memory box in ‘Rediscovering the person through sharing memories’ and in ‘Reaching the parts that matter: connecting with the whole person through activities’, Sally Knocker examines the needs of older people with dementia, suggesting that time, attention, human contact, conversation, a friendly smile are some of the most important gifts we can offer.

Author: LLOYD, Murray
Title: Understanding spirituality: tuning in to the inner being.
Abstract: A retired geriatrician from New South Wales, Australia, discusses a step-by-step approach to a view of dementia care through ‘spiritually enhanced active listening’ which engages fully with the person with dementia in the context of their spiritual needs and expressions.

2003

Author: DEMENTIA
Title: Dementia, Religion and Spirituality.
Source: Dementia The International Journal of Social Research and Practice, 02(03), 2003.
Abstract: Special issue. Contents:
Jon C Stuckey and Lisa P Gwyther, Editorial: Dementia, religion and spirituality
Lisa Snyder, Satisfactions and challenges in spiritual faith and practice for persons with dementia
Towako Katsuno, Personal spirituality of persons with early–stage dementia: Is it related to perceived quality of life?
Jon C Stuckey, Faith, aging, and dementia: Experiences of Christian, Jewish, and non–religious spousal caregivers and older adults
Carol J Farran and Mary Horton Elliott, Spirituality in multicultural caregivers of persons with dementia
Marcie C Nightingale, Religion, spirituality, and ethnicity: What it means for caregivers of persons with Alzheimer’s disease and related disorders
Robert M Lawrence, Aspects of spirituality in dementia care: When clinicians tune into silence
Helen Gilmour, Faith Gibson and Jim Campbell, Living alone with dementia: A case study approach to understanding risk
Daphne Wallace, Spiritual Care and the Person with Dementia: The Development of Guidelines to Support Staff Working with People with Dementia
Rose–Marie Droes, Franka J M Meiland, Myra Vernooij–Dassen and Willem van Tilburg, The Meeting Centres Support Programme: An Effective Way of Supporting People with Dementia Who Live at Home with their Carers
Latifa Ismail and Jennifer Mackenzie, Convening and facilitating support groups for South Asian family carers of people with dementia: experiences and challenges.
Author: HIGGINS, Patricia
Title: Holding a religious service for people with dementia.
Source: Journal of Dementia Care 11(3), May/June 2003, 10–11.
Abstract: Written from the viewpoint of a charge nurse, this article looks at how holding a religious service can enrich life and well-being for people with dementia. This has extended into a weekly Candlelight Group on the ward which meets for prayer.

Author: JEREMIAH, Margaret
Title: Alone with dementia.
Abstract: A moving personal account from a Quaker perspective of the unfolding of a dementing illness from a loving partner taking on the role of ‘carer’. It illustrates some of the triumphs and failures of current services.


Author: JEWELL, Albert (ed)
Title: Ageing, spirituality and well-being.
Abstract: This book brings together the papers from the international conference with this title held in Durham in 2002. The papers explore how the particular spiritual needs of older people can be defined and addressed and how meaningful care and support can be given. It includes a chapter by John Killick entitled ‘Magic mirrors’.


Author: MacKINLEY, Elizabeth (ed)
Title: Mental health and spirituality in later life.
Abstract: Explores the relationship between mental health, spirituality and religion including the search for meaning, cultural issues, spiritual issues, dementia and depression. Includes a chapter ‘Dementia – a spiritual journey towards the divine’ by Christine Bryden who writes about her faith and her Alzheimer’s disease.

ISBN: 0–7890–2123–4

Author: McDONALD, Suzanne
Title: Memory’s tomb: dementia and a theology of Holy Saturday.
Abstract: In the first in a new series of Aspects of Ageing Papers, the author attempts to find a theological language for dementia in the light of Alan Lewis’s exploration of Holy Saturday as a ‘no man’s land’ and time of waiting. She relates this to Malcolm Goldsmith’s ‘remembered by God’ model and concludes that ‘we can offer the true depths of God’s promise that our identities are upheld in God’s own remembering’.

Author: READ, Kate, PHILLIPS, Jill, TIBBS, Margaret Anne and JOHNSON, Alison M
Title: Dementia: improving quality of life.
Abstract: Papers presented at a Leveson seminar in 2003 including an overview of the nature of dementia; practical hands-on examples of a person-centred approach based on research carried out at MHA Care Group, a consideration of the important issue of communication with people with dementia and an exploration of ways in which faith survives or fails to survive under this assault on the self. An additional paper looks at the importance of
everyday activity for people with dementia and a bibliography suggests further reading in the field of dementia and spirituality.

Author ROFF, Lucinda Lee and PARKER, Michael W  
Title Spirituality and Alzheimer’s disease care.  
Abstract A growing body of research evidence underscores the importance of spirituality in late life adaptation to chronic disease. Similarly, religious coping has been found to be a significant source of support to family members and carers of people with dementia. Despite these trends, interventions that explicitly take into account the spirituality and religious traditions of persons with Alzheimer’s disease and their families are rare. This article explores some of the ways that spiritual and religious concerns can be more fully incorporated into Alzheimer’s disease care.

Author SHAMY, Eileen  
Title A guide to the spiritual dimension of care for people with Alzheimer’s disease and related dementia – more than body, brain and breath.  
Abstract Edited by Albert Jewell, this is a fully revised edition of ‘More than body, brain and breath’ (see below).  

Author WATTIS, J and CURRAN, S (editors)  
Title Practical management of dementia: a multi-professional approach.  
Abstract The book is aimed at all healthcare professionals involved in the care of those with dementia. In a chapter ‘Spiritual aspects of dementia’, Daphne Wallace outlines the various aspects of spirituality and person-centred care as applied to those with dementia. Being, rather than doing, in the carer as well as the person with dementia is necessary to enhance care of the person.  
ISBN 1–85775–931–1

2002

Author AIREY, Jo, HAMMOND, Gaynor, KENT, Pam and MOFFITT, Laraine  
Title Frequently asked questions on spirituality and religion.  
Abstract A booklet produced by four project workers in response to the questions they are frequently asked about spirituality and religion and the relationship between the two.

Author ALLEN, Brian  
Title Religious practice and people with dementia: a resource for carers.  
Abstract Religious belief and practice is for some people with dementia a vital part of their spirituality. This book contains basic introductory information to five major world faiths (Christianity, Hinduism, Islam, Judaism and Sikhism) with prayers and sacred readings.
Author: BRUCE, Errollyn, SURRE, Claire and TIBBS, Margaret Anne
Title: A special kind of care: improving well-being in people living with dementia.
Source: Derby: MHA Care Group, 2002.
Abstract: The report of research commissioned from the Bradford Dementia Group shortly before the death of Professor Tom Kitwood. A longitudinal study of 93 residents with dementia in ten MHA care homes, it found that their well-being was very fragile and could easily be upset by what might otherwise seem to be small events and trivial interactions and that the special understanding of staff played a key role in contributing towards well-being.

Author: CHRISTIAN COUNCIL ON AGEING
Title: Living with dementia: resources from Christian organisations.
Source: Derby: CCOA and Methodist Homes, 2002
Abstract: Details of publications and resources from Christian-based organisations which aim to assist people living with dementia and their carers.

Author: HAMMOND, Gaynor
Title: The friendship club: a practical way of caring.
Source: Leeds: Faith in Elderly People, 2002
Abstract: An account of an innovative club founded in a local church where people with dementia and their carers are welcomed and supported by trained volunteers.

Author: HAMMOND, Gaynor
Title: The memory box.
Abstract: An explanation of the memory box containing treasures from the past which can help an older person with dementia to retain their identity and personhood.

Author: SAUNDERS, James
Title: Dementia: pastoral theology and pastoral care.
Abstract: Puts forward an argument for a Christian understanding which is inclusive of people with dementia. Includes advice on pastoral care for the person with dementia.

Author: STRATEGIES FOR LIVING PROJECT
Title: ‘Taken seriously’ – The Somerset Spirituality Project.
Abstract: The Somerset Spirituality Project examined the religious and spiritual needs and resources of mental health service users/survivors, mostly through interviews. This research confirmed the users’ perception of need for spiritual care.

2001

Author: CANTLEY, Caroline (ed)
Title: A handbook of dementia care.
Abstract: Presents an overview of the current knowledge in the field of dementia care. In three sections: the first, ‘Understanding dementia’, looks at the biomedical and clinical perspectives, the psychological perspectives, personhood, sociology, philosophical and
spiritual aspects, experience of people with dementia, carers; the second, ‘Practice knowledge and development’, looks at practice development, assessment, care planning and management, ethnic minorities, communication, therapeutic activities, care settings and the environmental design, ethics; the third, ‘Policy, organisations and research’, covers policy, organisations, quality, involving users, research and practice. See especially the chapter on philosophical and spiritual perspectives by P A Coleman and Marie Mills.

**Title**: Visiting people with dementia.
**Source**: Derby: CCOA and Methodist Homes, 2001.
**Abstract**: Suggestions for people making visits, particularly pastoral, to people with dementia.

**Title**: Worship for people with dementia.
**Source**: Derby: CCOA and Methodist Homes, 2001.
**Abstract**: Suggestions for developing a Christian act of worship for people with dementia.

**Title**: Healing where night shadows meet.
**Abstract**: Looks at how real communication in dementia care requires a meeting or a relationship at depth in the moment, a kind of spirituality that often acknowledges and affirms the unseen nature of a person. Fourteen references.

**Title**: Older people and the churches.
**Abstract**: The two chapters by Larine Moffitt and by Gaynor Hammond and Jackie Treetops discuss the dangers of people with dementia being marginalised by the churches.

**Title**: Communication and the care of people with dementia.
**Source**: Buckingham: Open University, 2001.
**Abstract**: Looks at the challenges, opportunities and ethical dilemmas associated with interacting with people with dementia. It assists readers to ‘understand the need to see the “me” within the “he” or “she”’.

**Title**: The spiritual dimension of ageing.
**Abstract**: Gives clear and practical guidance to health, social care, and religious practitioners seeking to identify and meet the spiritual needs of elderly people in their caring role. Some mention of spirituality and people with dementia.
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<tr>
<th>Author</th>
<th>Title</th>
<th>Source</th>
<th>Abstract</th>
<th>ISBN</th>
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<tr>
<td>NARAYANASAMY, Aru and OWENS, Jan</td>
<td>A critical incident study of nurses’ responses to the spiritual needs of their patients.</td>
<td>Journal of Advanced Nursing 33(4), February 2001, 446–55.</td>
<td>Study aimed at describing what nurses consider to be spiritual needs, how nurses respond to these needs, typifying nurses’ involvement in the spiritual dimension of care and illustrating the effect of nurses’ intervention in this area. Concludes that a model of spiritual care may be developed from this study. Relevant to person-centred care of the person with dementia. 35 references.</td>
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<tr>
<td>NATHAN, M M</td>
<td>Overcoming barriers to spiritual care.</td>
<td>Sacred Space 2(4), 2001.</td>
<td>This paper addresses the problems identified in the article above and looks at methods of overcoming them.</td>
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Author: SWINTON, John
Title: Spirituality and mental health care: rediscovering a ‘forgotten’ dimension.
Source: London: Jessica Kingsley, 2001
Abstract: Explores the connections between mental health or illness and spirituality and draws on these to provide practical guidance to people working in the mental health field, including dementia.

2000

Author: CORLEY, G (ed)
Title: Older people and their needs.
Abstract: Includes a chapter by P Huxham, ‘I’m not very religious but … ’ He writes from the experience of 35 years as an Anglican priest in parish and hospital ministry. Stories from those he encountered in distress and need and of the staff who cared for them are woven into a helpful exposition of the need for time and training for effective caring for the spiritual needs of all in care, particularly those with dementia.

Author: EVERETT, Debbie
Title: Spiritual care: stretching the soul.
Source: Journal of Dementia Care 8(1), January/February 2000, 20–21.
Abstract: Gives a personal view of her work as chaplain attending to the spiritual needs of people with dementia at a continuing care centre in Edmonton, Canada.

Author: HAMMOND, Gaynor and MOFFITT, Laraine
Title: Spiritual care: guidelines for care plans.
Abstract: Booklet written to assist staff in residential and nursing homes to consider the spiritual needs of people with dementia within the context of their existing care plans.

Author: JEWELL, Albert
Title: Grow old along with me.
Abstract: Includes a chapter on ‘Dementia and old age’.
ISBN: 0–7197–0983–0

Author: KILLICK, John
Title: Openings.
Abstract: Consists of poems composed from the edited words of people with dementia with photographs described by Carl Cordonnier as ‘a collection of faces, for memory’.
Author: McSHERRY, Wilfrid
Title: Making sense of spirituality in nursing practice: an interactive approach.
Abstract: An accessible introduction to issues concerning the spiritual dimension of nursing practice. It draws extensively on case studies, illustrating application to practice, and encourages readers to reflect on what spirituality means to them.
ISBN: 0-443-06356-7

Author: NEAL, Isobel
Title: Towards a Christian understanding and response to dementia: implications of an understanding of dementia for spiritual care.
Abstract: Honours dissertation looking at how the Christian community may respond to dementia and attend to the spiritual needs of people with dementia. Well thought out philosophy and theology, including case studies and literature review. 64 references.

Author: THORSON, J A (ed)
Title: Perspectives on spiritual well being and aging.
Abstract: Suggests that people who participate in a spiritual life may have an easier time coping with the losses that occur as a result of ageing.

Author: WRIGHT, Stephen
Title: Spirited discussion.
Abstract: Explains the tools used to communicate with people about their spirituality. Relevant to people with dementia. Six references.

1999

Author: COGGINS, David Lindsay
Title: Poetry and art inspired by caring: the creative response as a coping strategy for the emotional and spiritual needs of the carer.
Abstract: Shows how creative expression in poetry and painting restored meaning to the life of a carer of a person with dementia. Gives examples of the poetry that brought healing and wholeness. Five references.

Author: HOWSE, Kenneth
Title: Religion, spirituality and older people.
Abstract: Looks at the significance of religion to well-being in elderly people. Draws on research from the United States and current experience of religious organisations. Chapters on religious commitment in the UK, social policy and action, well-being, and meeting needs for spiritual support. 200 references.
Author  JONES, Moyra  
Title  Gentlecare: changing the experience of Alzheimer’s disease in a positive way.  
Abstract  Useful book describing a prosthetic model of care that maximises client function by providing services designed to compensate for the deficits caused by Alzheimer’s disease and related dementias. Covers dementias and their effects, assessment (mental, physical, socio-cultural, spiritual and environmental), care programmes and activities, activities of daily living, communication, meals and diet, home and designing of environment, and the family as carers and volunteers.  

1998  

Author  BRUCE, Errollyn  
Title  How can we measure spiritual well-being?  
Abstract  Explores how particular attention needs to be paid to the spiritual well-being of people with dementia, not making the assumption that this is being addressed in person-centred individualised care. Two references.  

Author  FROGGATT, Alison and SHAMY, Eileen  
Title  Dementia: a Christian perspective.  
Abstract  Two papers originally published in 1992 on the spiritual well-being of people with dementia: ‘God within confusion’ by Alison Froggatt and ‘Ministry to elderly confused people’ by Eileen Shamy. It includes an updated introduction and bibliography.  

Author  GOLDSMITH, Malcolm  
Title  Dementia, ethics and the glory of God.  
Abstract  The text of a lecture originally delivered in 1997 at a Christian Council on Ageing Newcastle Dementia Project conference in Durham. Covers seven specific ethical, spiritual and person-centred issues for a person with dementia, and relates the personhood approach to his understanding of the glory of God.  

Author  JEWELL, Albert (ed)  
Title  Spirituality and ageing.  
Abstract  A collection of seventeen essays on spirituality and ageing with five relating specifically to dementia. The book grew out of the Sir Halley Stewart Project, which aimed to raise awareness of the spiritual needs of older people and encourage interest in the spirituality of ageing. 123 references.  

Author  MOFFITT, Laraine  
Title  Practice guide  
Abstract  Guide to assist in the replication and setting up of similar projects to the Newcastle Dementia Working Group Project looking at the local spiritual needs of people with dementia. Project looked at pastoral care; patterns of worship, education and training in church, health and
social care and carers groups; and the development of networks, good practice, theological reflection and training materials.

**ISBN** 1–89809–611–6

**Author** MOFFITT, Laraine

**Title** The spiritual needs of people with dementia.

**Source** Derby: Sir Halley Stewart Age Awareness Project, 1998.

**Abstract** One of a set of ten booklets produced by the Sir Halley Stewart Age Awareness Project. The author urges strongly from her experience in the CCOA Dementia Group Newcastle Project that people with dementia have exactly the same spiritual needs as everyone else.

**ISBN** 1–902452–04–6

**Author** TIBBS, Margaret Anne

**Title** The heart of the matter.


**Abstract** Paper presented at the Alzheimer’s Disease Society Conference ‘Personhood’ on 10 December 1998. Emphasises that to care effectively for the person with dementia and their personhood it is essential to include spirituality. Spirituality is not necessarily religion.

1997

**Author** CHRISTIAN COUNCIL ON AGEING DEMENTIA PROJECT

**Title** ‘Is anyone there’.

**Source** Newcastle upon Tyne: CCOA, 1997.

**Abstract** A 20-minute video concerned with the spiritual needs of people with dementia designed as a training tool. Looks at issues such as the distinction between spiritual and religious needs. Accompanied by two booklets; one for care staff, ‘Spiritual needs: workshop leader’s notes’ which provides ways of assessing and tending to spiritual needs and the second for those with responsibility for the pastoral care of people with dementia, ‘Guidelines for worship and prayer’. Explores the need for ritual and has suggestions for leading worship.

**Author** DYSON, Jane, COBB, Mark and FORMAN, Dawn

**Title** The meaning of spirituality: a literature review.


**Abstract** A literature review on the meaning of spirituality. Suggests that spirituality is not synonymous with religion and that it is unhelpful in the provision of individualised or person-centred care to adopt this restrictive view. 58 references.

**Author** ELLIOT, Hazel

**Title** Religion, spirituality and dementia: pastoring to sufferers of Alzheimer’s disease and other associated forms of dementia.

**Source** Disability and Rehabilitation 19(10), 1997, 435–41.

**Abstract** Illustrates how religion and spirituality can be related to people with dementia and how churches as organisations can assist them. Also covers ways of minimising communication difficulties and the provision of simple services for people with dementia living in residential care. Touches on the problems which may occur when a practising minister develops dementia. Twelve references.
Christian Council on Ageing 13 Dementia and Spirituality: An introductory reading list

Author KILLICK, John (ed)
Title You are words.
Abstract This is a moving collection of poems representing the work of John Killick during his time as writer in residence for Westminster Health Care. It represents, in poetic form, an exploration of the progressive loss of ability of people with dementia to communicate verbally with fellow human beings. He reveals how much the capacity to express emotion is retained even when language is severely disrupted.
ISBN 1–87479–032–9

Author MARSHALL, Mary (ed)
Title State of the art in dementia care.
Abstract Fifty contributions on issues, areas of practice and new approaches covering therapy, advocacy, communication, buildings, training, technology, policies, sub-groups, staff sex, spiritual needs and drugs. These give an overview of the challenging and innovative area of care and service provision for the person with dementia. Of particular relevance is chapter 49 by Froggatt and Moffitt.
ISBN 0–90413–999–9

Author METHODIST HOMES FOR THE AGED
Title Quality Standards Manual (QSM) for care within a residential setting.
Abstract Manual produced by Methodist Homes to assist in the implementation of a quality standards system in a caring organisation. Three areas are addressed: the setting out of clear principles, aims, objectives and standards for residential homes; suggested procedures to be followed in order to monitor, audit, inspect and evaluate services; and feedback to facilitate the development of new services and improve current ways of working. The manual is organised in three parts: the quality policy; care principles and standards; and references. Topics covered in the manual include dementia care, volunteers, training and staff development, risk assessment, abuse, purchasing, advocacy, spiritual care, Dementia Care Mapping, wandering, aggression, restraint, sexuality, personal care, communication and activities of daily living.
ISBN 0–95262–394–3

Author REGAN, Dominic and SMITH, Jef
Title The fullness of time: how homes for older people can respond to their residents’ need for wholeness and a spiritual dimension to care.
Source London: Counsel and Care, 1997.
Abstract Explores good practice in relation to the spiritual and personal values of residents in residential and nursing home care.

Author SHAMY, Eileen
Title More than body, brain and breath: a guide to spiritual care of people with Alzheimer’s disease.
Abstract A guide to the spiritual care of people with dementia as understood by a Methodist who specialised in ministry to people with dementia. Covers the challenges of Alzheimer’s disease and related dementia, spirituality and holistic/person-centred care, worship, pastoral care, supporting carers and future developments. Very personal account of a ministry with many
experiential examples. Reference list, suggested reading list for communication and visiting people with dementia. See above for new edition published in the UK in 2003.

ISBN 0–90881–578–6

1996

Author CLARK, Elizabeth
Title The Identification and assessment of spiritual needs.
Abstract Paper produced as part of the Joint Care in the Community Project, Kent Ecumenical Council, describing spirituality and how this fits in with religious experience.


Author EVERETT, Deborah
Title Forget me not: the spiritual care of people with Alzheimer’s.
Source Edmonton, Alberta: Inkwell, 1996.
Abstract Book looking at the spiritual care of people with dementia. Examines areas of ministry that are viable and effective, considers the ethical issues involved in addressing the spiritual needs of people with dementia, illustrating both from experience. Three references.

Author GOLDSMITH, Malcolm
Title Hearing the voice of people with dementia.
Abstract Based on a series of interviews with people with dementia and professionals working in the field, an extensive literature search and a consultative document sent to over 1000 people, this book, written by a Christian minister, looks at the disempowering experience of dementia and means of communication.

Author GOODALL, Margaret
Title Freed to be themselves, if they can only find themselves.
Source Journal of Dementia Care 4(6), November/December 1996, 8,11.
Abstract Letter to the editor from the chaplain at Westbury, the specialist dementia care home, in response to an article by Laraine Moffitt. Very sensitive appraisal of spirituality in people with dementia, how spirituality is expressed and the need for us to help people with dementia find themselves.

Author KECK, David
Title Forgetting whose we are: Alzheimer’s disease and the love of God.
Abstract Offers a Christian understanding of and response to the difficult theological, spiritual and pastoral problems raised by Alzheimer’s disease.

Author MOFFITT, Laraine
Title Helping to recreate a personal sacred space.
Abstract Looking at how individualised care has always helped to meet spiritual needs and the importance of the creation of a personal sacred space. Four references.
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<th>Author</th>
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<tr>
<td>OLDNALL, Andrew</td>
<td>A critical analysis of nursing: meeting the spiritual needs of patients</td>
<td>Journal of Advanced Nursing 23, 1996, 138–44.</td>
<td>Explores some of the difficulties in arriving at a definition of spirituality and examines the extent to which nursing theories incorporate the concept of spirituality. Acknowledges there is a lack of this area in nursing training. 43 references.</td>
</tr>
<tr>
<td>POST, Stephen G</td>
<td>The moral challenge of Alzheimer’s disease.</td>
<td>Baltimore: Johns Hopkins University, 1996.</td>
<td>In this challenging book the author looks at all aspects of dementia in terms of the moral challenges that arise. He gives clinical examples which highlight the day-to-day dilemmas that arise for those involved. Towards the end he looks at the vexed issues of resuscitation, assisted dying, withdrawal of treatment and euthanasia – words that need definition and clarity to enable coherent and meaningful debate.</td>
</tr>
<tr>
<td>TREETOPS, Jackie</td>
<td>Holy, holy, holy: the church’s ministry for people with dementia: suggestions for action</td>
<td>Leeds: Faith in Elderly People, 1996.</td>
<td>An account of a ministry amongst people with dementia including chapters on spiritual needs, suggestions for action and the memory box.</td>
</tr>
<tr>
<td>KITWOOD, Tom</td>
<td>The new culture of dementia care.</td>
<td>London: Hawker Publications, 1995.</td>
<td>Based on practitioners’ experience and research, this book sets out elements of a care culture where the person with dementia comes first. Topics covered include cultures of care, challenge to stage theory, communication, well-being, sexuality, spirituality, genetics, day-care, sheltered housing, volunteers, dementia care mapping, training and organisational change.</td>
</tr>
<tr>
<td>KITWOOD, Tom</td>
<td>Brighter futures.</td>
<td>Derby: MHA and Anchor Housing Association, 1995.</td>
<td>The report of a research project identifying the conditions most likely to promote the well-being of people who have dementia. This research was conducted at a time when the ‘new culture of dementia care’ was beginning to spread and replace the old, restrictive and institutionalised care. References are helpful in outlining research and writing up to 1995.</td>
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ISBN 1–87479–017–5
ISBN 0–90617–830–4
<table>
<thead>
<tr>
<th>Year</th>
<th>Author</th>
<th>Title</th>
<th>Source</th>
<th>Abstract</th>
</tr>
</thead>
<tbody>
<tr>
<td>1994</td>
<td>FORBES, Elizabeth J</td>
<td>Spirituality, aging, and the community-dwelling caregiver and care recipient.</td>
<td>Geriatric Nursing 15(6), November/December 1994, 297–302.</td>
<td>The purpose of this study was to examine the concept of spirituality and the relationship between the caregiver’s and the care recipient’s concept of spirituality in order to identify its influence on the emotional well-being and the coping ability of both. Sixteen references.</td>
</tr>
<tr>
<td>1994</td>
<td>FROGGATT, Alison</td>
<td>Tuning in to meet spiritual needs.</td>
<td>Journal of Dementia Care 2(2), March/April 1994, 12–13.</td>
<td>Article about meeting the spiritual needs of people with dementia. Three references.</td>
</tr>
<tr>
<td>1993</td>
<td>GREEN, Jennifer</td>
<td>Death with dignity: volume II.</td>
<td>London: MacMillan, 1993.</td>
<td>Follows her earlier book (see below) featuring the basic spiritual needs of people who are dying within different religious groups: Christianity, Christian Science, Jehovah’s Witnesses, the Mormon Church, Zoroastrianism, Rastafarianism and the Afro–Caribbean community. An aid to nurses.</td>
</tr>
<tr>
<td>1993</td>
<td>SCOTT PECK, M</td>
<td>Further along the road less travelled.</td>
<td>London: Simon and Schuster, 1993.</td>
<td>A sequel to his earlier book ‘The road less travelled’. In it he addresses issues of personal growth and spiritual development which affect us all. He emphasises the need to examine our lives and aim for a higher level of understanding of the complexities of life.</td>
</tr>
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1992

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<thead>
<tr>
<th>Author</th>
<th>TREETOPS, Jackie</th>
<th>Title</th>
<th>Source</th>
<th>Abstract</th>
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<tr>
<td></td>
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<td>A daisy among the dandelions: the church’s ministry with older people; suggestions for action.</td>
<td>Leeds: Faith in Elderly People, 1992.</td>
<td>Description of a ministry amongst older people, and helpful suggestions of ways in which spirituality can be fostered in later life.</td>
</tr>
</tbody>
</table>

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Christian Council on Ageing  16  Dementia and Spirituality: An introductory reading list
1991

**Author**  GREEN, Jennifer  
**Title**  Death with dignity: meeting the needs of patients in a multicultural society.  
**Abstract**  Compiled to help nurses meet the cultural and spiritual needs of dying patients. Looks at the basic features of several different religions: Islam, Hinduism, Sikhism, Judaism, Buddhism and the Baha’i faith.  
**ISBN**  0–333–54971–6

**Useful addresses**

**Stirling Dementia Services Development Centre**, Iris Murdoch Building, University of Stirling, Stirling, FK9 4LA, Tel: 01786 467740, E-mail: eileen.richardson@stir.ac.uk

**The Leveson Centre for the Study of Ageing, Spirituality and Social Policy**, Temple House, Fen End Lane, Temple Balsall, Knowle, Solihull, West Midlands, B93 0AN.

**MHA Care Group**, Anne Dobson, Epworth House, Stuart Street, Derby, DE1 2EQ.

**CCOA Publications**, 19 Eldred Road, Liverpool, L16 8NZ.

**FiEP**, Gaynor Hammond, 29 Silverdale Avenue, Guiseley, Yorks, LS20 8BD.

**Counsel and Care**, Twyman House, 16 Bonny Street, London, NW1 9PG.
DEMENTIA CARE. A Health Foundation improvement report Identify Innovate Demonstrate Encourage. The Health Foundation is an independent charity working to continuously improve the quality of healthcare in the UK. Authors Matrix evidence Spotlight on dementia care: A Health Foundation improvement report is published by the Health Foundation, 90 Long Acre, London, United Kingdom, WC2E 9RA ISBN 978-1-906461-33-1 © 2011 The Health Foundation October 2011. Amended in December 2011. This report brings together some of the best available knowledge on dementia. With information from national guidance, academic research and third sector reports, it tells a story that we at Alzheimer’s Society, and everyone with dementia and their carers, are very familiar with. Spiritual care in the NHS must be both inclusive and accepting of human difference. As we learn to listen better to the particular needs of different people, so we equip ourselves for work which is more fulfilling and effective. The provision of spiritual care by NHS staff is not yet another demand on their hard pressed time. It is the very essence of their work and it enables and promotes healing in the fullest sense to all parties, both giver and receiver, of such care. This learning resource will, I hope, be seen as a useful contribution to the diverse area covered by the term “spiritual car... Dementia is a general term for a chronic or persistent decline in mental processes including memory loss, impaired reasoning, and personality changes. Alzheimer’s disease is the most common form of dementia, accounting for 60-80% of all cases of dementia. It is also the 6th leading cause of death in the United States, and over 5 million Americans are currently living with Alzheimer’s disease. Alzheimer’s disease and most progressive dementias do not have a cure. While the disease inevitably worsens over time, that timeline can vary greatly from one patient to the next. Caring for a loved one c