The Spiritual Care of People with Dementia.

A report based on the project undertaken by Sue Barrance

Dementia Voice,
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1. Introduction.
The Director and Board of Dementia Voice had, in about 1996, become aware of a developing but uncoordinated interest in the spiritual care of people with dementia. It was decided to try to obtain funding to undertake a project to achieve better understanding of this emerging area of interest and to explore ways to promote the care of people with dementia, in a way, which recognised and nurtured their spiritual life. The Sir Halley Stewart Trust kindly provided funding for a project worker and Sue Barrance was appointed. She invited three priests, Walter Barbour, John Foskitt and John Rogan, together with the Director of Dementia Voice, Professor Jane Gilliard, to act as an advisory committee for her and the project. Despite the composition of the group no one of them believed that spirituality was the same as having religious beliefs.

2. What is understood by spiritual care for people with Dementia?

The group struggled with this question. They wanted their statement to affirm a holistic approach, which sees care of the spirit as the essence of, and resulting from, good care practice. They wanted to speak to everyone whether or not they had a religious faith. They have therefore used secular language with the intention that it is inclusive of both secular and religious understanding.

Statement of understanding of spiritual care for people with dementia;

‘All people have a spiritual dimension in their lives. It is of the essence of every person whether or not they have a religious faith and is the response of the person’s innermost being to the influences that act upon it.

The spirituality of people with dementia, and their families, carers and the professionals who work with them is therefore of the greatest importance.

Spiritual care is not the preserve of specialists – rather such specialists must work with all the people who are involved in caring for the person with dementia. All must have an understanding of the qualities and values they affirm and seek to encourage.
The attitudes and approach outlined below aim to assist towards a greater measure of fulfilment in the lives of people with dementia, and those who care for them.

For people with dementia;
The spiritual life of a person is not ended by dementia and can be supported and affirmed by respecting that person as a unique individual through holistic caring practice.

Alongside appropriate physical care, this requires:
• Fostering a sense of identity
• Encouraging a sense of belonging and security
• Giving and receiving affection
• Respecting the need for space, privacy and dignity
• Listening and responding, with or without words, with patience and respect
• Empowering occupation and participation
• Providing special occasions and making everyday special
• Being alongside in times of unsupportable distress
• Helping to maintain faith practices and contact with faith groups
• Welcoming and affirming the contribution which people with dementia can make to the spiritual life of others.

For their families, carers and professionals
Those who care need to have their own spiritual resources recognised and affirmed by their friends and family, their work colleagues and employers and by the wider society. This can be assisted by organisations like Dementia Voice which:
• Recognise the spiritual essence of caring
• Increase public awareness of the nature of dementia
• Improve availability of information and training in good care practice
• Support terms and conditions of employment which value caring
• Encourage support from local communities and faith groups.'
3. Current awareness of spiritual needs of people with dementia.
During the project Sue Barrance talked to a large number of individuals who work with people with dementia and who have a personal commitment to spiritual care. She also raised questions about the need for spiritual care with groups of the various professionals in the field and with various faith groups. She found that she could discover only a small number of people who were working directly to promote spiritual care for people with dementia but she talked with a wider group about the spiritual dimension of care in the Health Services and with pastoral care for older people.

The following points arose from Sue Barrance’s discussions:

1. There seems to be a greater awareness of the need for spiritual care for patients in NHS Hospital Trusts than in Primary Health or Social Services care. However many more people with dementia have experience of the latter forms of care than of hospital care.

2. Some nurses have pioneered a personalised and holistic approach to care which can be seen as a form of ‘secular spirituality’.

3. Despite the fact that people who live in residential Homes now tend to be older and more mentally and physically frail than in the past, not all Homes have found ways to help residents with their own dying and death or with that of others around them. Hospices have developed a form of spiritual care especially for people who are dying but those with dementia enter hospices only rarely and usually as a result of some other condition.

4. There seems to be an increasing interest in religion and spirituality amongst some gerontologists, psychologists and psychiatrists reflected in recent conferences.

5. In a Health Service Guideline (92)2, entitled Meeting the Spiritual needs of Patients and Staff, the original wording of the Patient’s Charter referring to ‘religious beliefs’ has been changed to ‘spiritual needs’. This seems to recognise that while the majority of patients and staff may not have religious beliefs they all have spiritual needs. This may mean that gradually a wider group of staff will accept that it is their responsibility to provide for others’ spiritual needs and we will no longer rely so heavily on professionals with a religious training.

6. There are no guidelines on the provision of spiritual care for Social Services establishments, nor for the private health or care sector.
7. The training of all staff in the importance of the spiritual wellbeing of residents and patients is as yet little developed.

8. Some congregations have well organised systems of pastoral care to keep members suffering from dementia in touch with fellow members and services. Others have not started on this or have chosen, with their limited resources, to concentrate on, for example, young people. Training events for parish priests, ministers and chaplains may be a useful, albeit slow, route to change. Support and encouragement from overarching bodies like the Christian Council on Ageing and the Senior Chaplain to the Methodist Homes are playing an important part in raising awareness and providing relevant and helpful leaflets and books. However many people with dementia and their families are not part of any religious group and, on the whole, religious establishments are struggling even to look after their own. It is difficult to develop ways of bringing a recognition of secular spirituality to community organisations and to individual families.

4. Some useful organisations and journals

A. Organisations - Among many organisations with which Sue Barrance had contact, the following were particularly relevant: -

ALISTER HARDY SOCIETY
Honorary Administrative Secretary
FREEPOST
Westminster Institute of Education
Harcourt Hill
Oxford
OX2 9BR
☎01865243006
www.charitynet.org/~RERC

NATIONAL SECULAR SOCIETY
25 Redlion Square
London
WC1R 4RL
☎020740431226
www.secularism.org.uk
THE RELIGIOUS SOCIETY OF FRIENDS
Friends House
173 Houston Road
London
NW1 2BJ
www.quaker.org.uk

METHODIST HOMES/CHRISTIAN COUNCIL ON AGEING
PUBLICATIONS
Epsworth House
Stuart Street
Derby
DE1 2EQ
☎ 01332296200

CCOA DEMENTIA PROJECT
c/o The Chaplaincy Centre
St. Nicholas Hospital
Gosforth
Newcastle upon Tyne
NE3 3XT
☎ 01912736666 ext.28820

WESLEY COLLEGE
Henbury Road
Westbury on Trym
Bristol

THE ISLAMIC FOUNDATION
www.islamic-foundation.org.uk

HOSPITAL CHAPLAINCIES COUNCIL
Church House
Great Smith Street
Westminster
London SW1P 3NZ
B. Journals that may carry relevant articles:

METHODIST HOMES/ CCOA PUBLICATIONS
Epsworth House
Stuart Street
Derby
DE1 2EQ
📞01332296200

BISHOP JOHN ROBINSON FELLOWSHIP NEWSLETTER
The Chaplaincy
Spirituality and Pastoral Care Service
South London and Maudesly Trust
The Maudesly Hospital
Denmark Hill
London
SE5 8AZ
📞02087153959

THE JOURNAL OF DEMENTIA CARE
ESCO Business Services
Robjohn’s Farm
Vicarage Road
Finchingfield
Essex
CM7 3LJ
📞01371810433

ALZHEIMER’S SOCIETY NEWSLETTER
Gordon House
10 Greencoat House
London
SW1P 1PH
📞02073060606
www.alzheimers.org.uk
5. Training Programmes.
During the project Sue Barrance designed and ran two programmes. One was entitled *The Spirit of Dementia Care* and the other *Spiritual Care for People with Dementia*. Anyone who is interested in organising one of these workshops for church, professional or community groups should get in touch with the Training Officer at Dementia Voice, Neil Stamp. He can arrange for a facilitator to run either programme.

6. Database for literature on spirituality and dementia.
The literature directly on spirituality and dementia is very slight. Sue Barrance widened her search to include more general accounts on spirituality and ageing, spirituality as implied in the holistic approach to nursing, bereavement counselling and books on death and dying. She also included guides to other than Christian faith traditions, chaplaincy journals and clergy training material.
The database can be obtained from the Information Officer at Dementia Voice.
Sue Barrance wrote that awareness of the need to recognise that there is a spiritual dimension to care is growing and the time seems right to continue the work she began in this project. The following are some suggestions for future action:

1. Including the spiritual life of people with dementia in the existing training programmes for care staff, nurses, medical students, trainee general practitioners, social workers, psychologists and other professional groups who work with people with dementia.
2. Developing ways of understanding the kind of spiritual care that is needed by people from ethnic minority backgrounds and creating appropriate training and support services.
3. Creating imaginative ways of supporting the spiritual life of those who care for people with dementia on a day-to-day basis.
4. Creating ‘spiritual groups’ in care homes, day centres and hospital wards.
5. Developing hospice care for people with dementia
6. Finding ways of enabling people with dementia to speak about their own spiritual lives.

8. Can you help?
If you would be interested in developing any of the ideas in this paper please get in touch with Professor Jane Gilliard, at Dementia Voice.

The Board and the Director of Dementia Voice would like to thank Sue Barrance and her advisory group for all the time and thought they have put into this project and this report.