

Blackpool Teaching Hospitals Chaplaincy Department

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Spiritual Care and Dementia

Blackpool Teaching Hospitals



NHS Foundation Trust

Dementia resource videos

- <http://www.scie.org.uk/socialcaretv/video-player.asp?v=personwithdementiamemories>
- <http://www.scie.org.uk/socialcaretv/video-player.asp?v=gettingtoknowthepersonwithdementia>
- <http://www.scie.org.uk/socialcaretv/video-player.asp?guid=50b36f4e-1dao-4e4a-bd05-b1ff09d93f91>

Dementia: the context

- 1. The **Medical Model** of Dementia = an 'organic mental disorder'. Emphasises what is going on in the brain; a cure for dementia and medical treatments.
- 2. The **Social Model** of Dementia = developed as an alternative and considers how the person with dementia is influenced by other people, society and the environment. Believes a person's condition is further influenced by society's negative view. How the media can devalue rather than recognise significant roles that can still be played.
- 3. There is a view that dementia should be considered more as a **disability** so to emphasise '**person-centred care**'. Therefore, adaptations should be made to allow functioning.
- *ref. Dementia Awareness. D.Moore and K.Jones, Pavillion 2012*

Dementia: the context

- Umbrella term for numerous illnesses
- Affects everyone differently
- Different stages of dementia have very different symptoms and effects
- Ageing population/rising dementia cases
- Significant number of patients in any acute hospital and care setting will have dementia
- Significant rise in faith communities of those with dementia and / or those caring for them

An 'Umbrella Term'

'main' types:

- Alzheimer's Disease
- Vascular Dementia
- Dementia with Lewy Bodies
- Fronto-temporal dementia



These are only a few as the Alzheimer's Society (2007) estimate there are a 100 different types

Effects of Dementia

- Cognitive, physical, social and emotional
- Loss of memory/rational thought
- Loss of communication skills
- Disinhibition
- Fear of 'ceasing to be'
- Isolation
- Depression
- Feelings of failure/uselessness/worthlessness

Effects of Dementia

- Long-term memories can seem more real, sharper or more immediate
- Time does not have same meaning: living in the present moment
- Long-term memories and skills (artistic, musical...) often remain
- May be able to recognise people/things even when he/she cannot identify them

Effects of dementia: on others

- Sense of grief, loss “of the person” they knew
- Pressures of providing care
- Fear – can cause alienation
- Sense of helplessness
- Dilemma of making specific choices
- Challenges society’s understanding of what it means to be a human person

Spiritual Needs

- Relationship/connectedness v isolation
- Spirituality at the core of the person: it remains even when rational self appears lost
- Need to make a contribution to others
- Spiritual and Religious care is crucial (esp. spiritual care for those who have no connection to an established faith)

“My every molecule seems to scream out that I exist, and that this existence must be valued by someone! Without someone to walk this labyrinth by my side, without the touch of a fellow traveller who understands my need of self-worth, how can I endure the rest of this uncharted journey?”

Diana Friel McGowin

What can we do?

- “Moments of illumination” not uncommon
- Persistence and patience
- Recognise that a person is more than their rational/cognitive self
- Likes/dislikes, interests/enjoyments remain
- Be attentive to body language
- Be with the person where they are: his/her memories of the past may be real now
- Do not be afraid of silence

What can we do?

- Short, simple sentences; avoid abstract ideas
- Recalling positive memories / familiar items
- Reintroduce yourself at each visit
- Importance of continuity/consistency
- May not remember you, but may appreciate you at the time
- Emotional impact of visit may last well beyond the patient's memory of it
- More is possible than we might first think!

Role of chaplaincy

- Visits; religious and spiritual needs of patients
- Provide symbols/images that may help patient
- Provide prayer resources for patient & families
- 'Neutral' listening ear
- Promoting the dignity and value of the person
- Guard against the danger of somebody just being a "ghost of the past"
- Moral issues re: treatment
- Bring something from our own traditions

Faith Community Environments

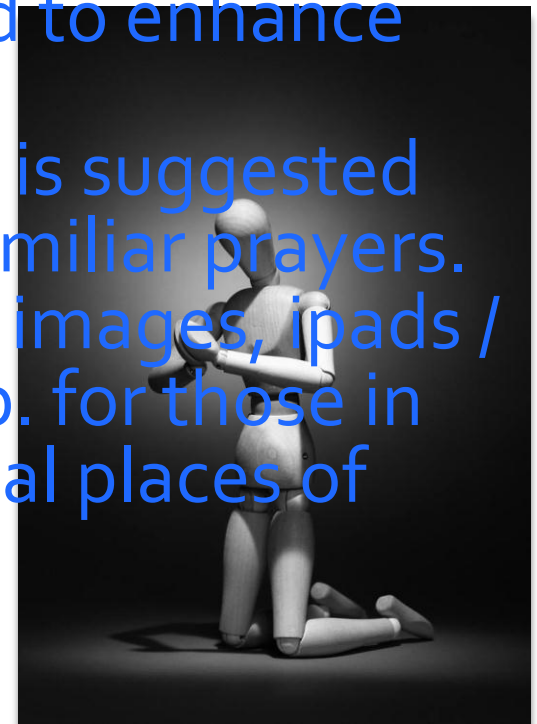
- Familiar environments
- Need to think about refurbishments / new faith buildings
- It is important how people 'connect' with familiar faith community furnishings / religious items / icons / statues / stained glass / deities / religious texts / hymn books / prayer books etc.
- Are they 'dementia friendly'?
- DVD link:
 - http://www.careknowledge.com/dementia_england.aspx

Use and significance of Music

- Familiar faith music (hymns, songs) – need to think about use of unfamiliar / modern songs and how they relate to the person with dementia
- Other music
 - <http://www.youtube.com/watch?v=RkzhDEJWt5c>
 - <http://www.youtube.com/watch?v=8rDhV1Tm1LI>
 - <http://www.youtube.com/watch?v=fyZQfop73QM>
 - http://www.youtube.com/watch?v=3mz9Vy_LNu8

Prayer and Devotion

- When there is a struggle to recall many things, people who have had or currently have faith connection often recall familiar prayers and liturgies.
- Consider things to touch and hold to enhance worship
- When speech may become lost it is suggested many will still be able to join in familiar prayers.
- Consider visual prompts, familiar images, ipads / tablets / powerpoint / photos (esp. for those in care settings away from their usual places of worship)



Final thoughts

- Our experiences impact our neurology. Dementia can be accelerated or slowed by our response to it.
- “Dementia is as much a relational disability as it is a physical or neurological one.”
(John Swinton)
- Importance of attitude: someone with dementia does not cease to be a person.
- Chaplaincy’s role in sharing this understanding

“the individual is seen by the nurse as a whole person who does not just need to be washed, fed and changed, but a person who deserves to be washed, fed and changed – in a respectful, gentle manner that acknowledges the other’s unique humanity. Only a nurse who feels and conveys compassion can perform these essential ordinary tasks in this manner.”

Canada Parry

“And as the ‘things of this world’, which the modern world has come to rely upon for meaning, necessarily diminish in importance and begin to disappear, if carers for persons with dementia are to maintain hope and a sense of the meaningfulness of life, as is the case with those for whom they care, the source of that hope and meaning must increasingly be that which transcends the earthly dimension, namely, the things of the spirit.”

Stephen Sapp

What Chaplains already do...

- Regular and consistent visits to patients with Dementia regardless of stage of disease
- Support of relatives / carers
- Chaplaincy Volunteer support
- Use of familiar prayers and liturgy that is easily recognised by dementia sufferers with a faith background
- Recognise spiritual care needs of patients with dementia and respond appropriately (for those with / without religious practice)

Resources

- Stirling Dementia Services Development Centre: <http://dementia.stir.ac.uk/>
- Care Knowledge Dementia Map for England: http://www.careknowledge.com/dementia_englishland.aspx
- Life Storey Network: <http://www.lifestorynetwork.org.uk/>
- Dementia Action Alliance: <http://www.dementiaaction.org.uk/>
- The Dementia challenge: <http://dementiachallenge.dh.gov.uk/>
- The Dementia Pledge: <http://www.dementiapledge.co.uk/>
- Welcome Me As I am: <http://www.welcomemeasiam.org.uk/>
- Spirituality and Mental Health Forum: <http://www.mhspirituality.org.uk/>
- Time to Change resources: <http://www.time-to-change.org.uk/churches>
- RC Bishops Conference and 'Day for Life' resources: <http://dayforlife.org/Home/Publications>
- Church of England Mental Health Matters: <http://www.mentalhealthmatters-cofe.org/>
- Care Knowledge reports by Jackie Pool: http://www.careknowledge.com/developing_excellence_in_dementia_care_and_delivering_on_the_social_care_commitment_25769807749.aspx
- Caritas Social Action Network (CSAN) – to view / obtain the film: 'It's Still ME, Lord...': www.csan.org.uk

Resources

- Social Care Institute for Excellence (SCIE) – various dementia care videos & resources: <http://www.scie.org.uk/publications/dementia/resources/dementia-videos.asp>
- The Pastoral Care Project – week of prayer for dementia: - http://pastoralcareproject.org.uk/Week_of_prayer_for_dementia.asp
- NHS Choices, dementia information: <http://www.nhs.uk/Conditions/dementia-guide/Pages/about-dementia.aspx>
- 'Spirituality and Faith in Dementia' (Royal College of Psychiatrists) - <http://www.rcpsych.ac.uk/pdf/David%20Jolley%20and%20Susan%20Benbow%20oSpirituality%20and%20Faith%20in%20Dementia%201.5.06.pdf>
- **10 Helpful; Hints for Carers: Practical Solutions for Carers Living with People with Dementia**, University of Stirling, Dementia Services Development Centre: www.dementia.stir.ac.uk
- Royal College of Psychiatrists Spirituality Special Interest Group: <http://www.rcpsych.ac.uk/workinpsychiatry/specialinterestgroups/spirituality.aspx>
- The Butterfly Scheme: <http://butterflyscheme.org.uk/>
<http://butterflyscheme.org.uk/department-of-health-movie/>

Resources

BOOKS

- **Ageing, Spirituality and Well-Being**, ed. By Albert Jewell, JKP Publishing 2004
- **Spirituality and Personhood in Dementia**, ed. By Albert Jewell, JKP Publishing 2011
- **Spirituality and Mental Health Care: Rediscovering a 'Forgotten' Dimension**, John Swinton, JKP Publishing 2001
- ***Dementia and Spirituality: a perfume always remembered***, Ben Bano, Susan Mary Benbow and Kate Read, see Chapter 12 of **Spirituality and Mental Health**, ed. by the late and much respected Peter Gilbert, Pavillion 2011
- **Dementia Awareness: A Care Quality Guide for Health and Social Care Staff and Carers**, David Moore and Kirsty Jones, Pavillion in Practice Publishing 2012

FILMS:

- **EX MEMORIA** (includes training and awareness information <http://exmemoriafilm.co.uk/>)
- **The Waiting Room**
<http://www.bing.com/videos/search?q=the+waiting+room+dementia&docid=4748405445756397&mid=DA414ED84AE71E089699DA414ED84AE71E089699&view=detail&FORM=VIRE1#view=detail&mid=DA414ED84AE71E089699DA414ED84AE71E089699>
- **Dementia in the Movies** (including Dame Judi Dench in IRIS:
<http://alzheimers.about.com/od/booksmagsandmovies/tp/AlzheimersMovies.htm>)

So what next?

- Further awareness sessions??
- Increased faith community engagement???
- Other Ideas????
- What will you take away from today?????
- May 16th 2014 (feel free to ask!)

