FaithAction Roundtable Discussion on Dementia

7 July 2016, The Nishkam Centre, Birmingham



Summary of discussion

What faith groups can offer

- A rhythm of life and a way to connect people with their faith and with each other, based on their deep-rooted memories of (for example) hymns and prayers known since childhood.
- The power of **prayer** to uplift (the person being prayed for and the person praying) and heal.
- A way of **connecting people with others** so they are not isolated and can continue to function as part of the community eg letting them, with appropriate support, continue to do the activities they enjoy such as volunteering / serving others, making and sharing food; just noticing if someone has not been seen for a while and following up with them.
- **Practical support** for people, especially those who are isolated, eg:
 - o helping them take their medication correctly
 - o following up with people who have been absent for a while
 - o providing transport so they can still get to the place of worship or other places even if they cannot go independently
 - o calling people to remind them about services, prayer times, social events etc.
- A community of people who share values of care, compassion love etc. which is what people with dementia need. People with dementia might not remember who you are, but they will remember how you made them feel. Faith groups can create a feeling of welcome, calm and inclusion.
- An **opportunity to talk about health**: eg healthy lifestyles and how to make changes; how people are doing with their medication; a venue for health checks.
- The framework that the Faith Communities Action Group¹ has come up with:
 - A supportive network that works across generations eg teaching children how to be a good friend to older people; supporting people to the very end of their lives; offering access to resources and help for people to live healthy lifestyles
 - Help with thinking through the big questions of life that dementia can raise (eg am I still me?
 Why am I here?), and also help to challenge attitudes eg that someone with dementia is just a drain on resources
 - A great capacity for innovative responses to issues such as dementia, with people who are
 passionate, motivated and available to help other people

Examples of good practice / tips

• Forget Me Not, a monthly group run by a St Andrew's Church in Shifnal.² The group runs a short church service, with perhaps a familiar reading and hymn, plus an activity that might be a craft or a way of reminiscing. On one occasion someone from the local supermarket brought in old-fashioned food and the modern equivalents, and it got everyone talking about what they remembered. Then there is a tea, in proper china cups, which sends a message about the value of 'doing things properly' for the participants. The group is very supportive of one another. People who are carers come with people who are living with dementia, and some carers have continued to attend after their partners have died, as the group supports them and they are 'experts' who can support others through the experience of caring for someone with dementia.

¹ Part of the Prime Minister's Challenge on Dementia 2020. See www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020

² See www.standrewschurchshifnal.org.uk/forgetmenot.html

- The chaplain at the Nishkam centre asked an elderly lady living with dementia to help her learn her prayers, since this lady used to teach the prayers. This gave her a way to contribute to the life of the faith community, as she was still able to correct the chaplain on how to recite the prayers correctly. She has been supported to continue using the centre's gym and to come to other events such as coffee mornings, to combat her isolation.
- It was reported that in Bruges there was a scheme under which sympathetic businesses displayed the symbol of a knotted handkerchief, so that people who felt that they were perhaps a bit slower in their thought processes or needed a bit more understanding or time could go there and know that that time would be spent with them.
- A project in Blackheath, funded by Near Neighbours, is run by a church together with a Muslim group. Older white British ladies and Asian ladies come together to share their sewing skills: often they are very skilled but do not get a chance to use their talents otherwise now that their children have grown up.
- Activities that people reported finding popular and beneficial included:
 - Looking at and talking about old photos
 - Art / colouring
 - o Cooking and eating together, and clearing up afterwards (with help) as in the Sikh langar
 - Yogo
 - Sewing classes / 'knit and natter' groups

Other tips:

- Incorporating information on Dementia Friends into services and/or information leaflets about the faith group, so that it becomes incorporated into the thinking and worship of the group rather than being an 'add-on'
- Training someone who is known to the community and will be listened to as a Dementia
 Friends Champion, to run Dementia Friends awareness sessions
- Filming services or prayers and making the films available so that people can watch and join
 in at home

Challenges and needs

- Dementia, and mental health problems, can still be taboo in faith communities. There is a fear of getting dementia and a fear of even talking about it, due to the associated stigma.
 We need to find ways of making it easier to talk about dementia, so that people living with it do not feel so isolated. Running Dementia Friends workshops could be one way.
- Coping with people who experience quite extreme mood swings and/or are angry can be challenging

 particularly in the middle of a service or ceremony.

 We need help with knowing how to deal with and help calm someone who is frustrated or angry
 because of their dementia. Training for faith leaders could help perhaps along the lines of the
 existing Mental Health First Aid training³ or training provided for churches by Livability.⁴
- It can be difficult to communicate with people who have dementia.
 We need to find ways of moving away from being word-based to thinking creatively about using other means of communication which is part of wider inclusivity. These could include pictures, symbols, gestures and music and using these in the environment/building of the faith setting so that it is welcoming to everyone.
- Social isolation (people living alone) is a huge issue, including for people who have dementia.
 We need ways of encouraging many more people to be 'buddies' to people with dementia, so that

³ See <u>mhfaengland.org</u>

⁴ See <u>www.livability.org.uk/blog-and-resources/training-and-events/dementia-friendly-churches</u>

the offer of faith groups is not just about groups that people can attend, but friendship in daily life.

- Burn-out of carers and of volunteers, who do not work set hours.
 We need to find ways of supporting carers of people living with dementia who may be elderly themselves.
- Places of worship are not always easy to navigate for people with dementia.
 We need to think about what our buildings are like possibly using existing tools such as Dementia-Friendly Churches⁵ and Dementia-Friendly Gurudwaras.⁶
- Lack of resources.

We need funding that enables faith groups to recruit, train, organise and support volunteers, including the purchase of resources. There is a tremendous amount of goodwill; we need grants that enable people of goodwill to do what they really want to do.

Resources needed

- Worship resources that tap into people's deep memories, eg old hymns and prayers.
- Help with creative ways of communicating about faith that don't rely on words.
- Information in languages other than English.
- Opportunities for faith groups in a local area to connect with each other around dementia.
- Educational resources that remind people that dementia is a disease of the brain and does not mean a person has done something wrong.

Existing resources and useful links

- The Alzheimer's Society's Dementia-Friendly Communities accreditation information: www.alzheimers.org.uk/site/scripts/documents info.php?documentID=2136
- Information on becoming a Dementia Friends Champion: <u>www.dementiafriends.org.uk/WEBArticle?page=what-is-a-champion#.V7t97vkrK00</u>
- Anyone wanting to request a Dementia Friends Champion to come and speak should contact the Alzheimer's Society. Contact details for the Birmingham & Solihull local office are: Ground & First Floor, Unit 7-9, Olton Wharf, Richmond Road, Solihull B92 7RN Tel: 0121 706 4052
 - Email: birminghamandsolihull@alzheimers.org.uk
- The Alzheimer's Society has information on dementia available in a range of languages, including Bengali, Chinese, Gujarati, Polish, Punjabi, Swahili and Urdu: www.alzheimers.org.uk/pubsotherlanguages
- Resources on dementia on the FaithAction site: www.faithaction.net/portal/resources/faith-and-health/#group-dementia

This will continue to be updated but currently includes links to:

- o Dementia-Friendly Churches guide: www.livability.org.uk/Dementia-Friendly-Churches-Guide
- o The Church of England's *Dementia Handbook*: www.faithaction.net/portal/wp-content/uploads/Dementia-Handbook-2016.docx
- o The Gift of Years website (support for churches): www.thegiftofyears.org.uk
- o Dementia-Friendly Gurudwaras: dementiafriendlygurudwaras.com
- Jami, the Jewish mental health charity, which is able to offer Mental Health First Aid training in the London area: www.jamiuk.org
- Mind, the mental health charity (also offers Mental Health First Aid training), Birmingham office: <u>birminghammind.org</u>
- The Unforgettable website, which sells practical resources such as 'clocks' that read (for example) 'Now it's Wednesday afternoon': www.unforgettable.org

⁵ See www.livability.org.uk/blog-and-resources/training-and-events/dementia-friendly-churches

⁶ See dementiafriendlygurudwaras.com/get-involved

 Mindful Gifts – a community interest company in Darlaston, West Midlands, selling gifts for people with dementia: www.mindfulgifts.co.uk/Information-about-dementia-and-Alzheimer's

Reducing the risk (presentation by FaithAction, using information from Public Health England, *Health* matters: midlife approaches to reduce dementia risk?)

- There are 850,000 people living with dementia in the UK which could rise to over one million by 2025 and over 2 million by 2050.
- The challenge is great, but many people do not realise that around a third of cases of Alzheimer's disease could be prevented.
- Smoking is one of the biggest lifestyle risk factors for dementia. Other risk factors include:
 - o Lack of regular physical activity / a sedentary lifestyle
 - Excessive alcohol consumption
 - o Eating a poor diet high in saturated fat, sugar and salt; obesity in midlife
 - o Having Parkinson's disease, stroke, type 2 diabetes, high blood pressure
- In addition, being female increases the risk of dementia (as women live longer than men), as does being from Black and South Asian ethnic groups.
- So ways to help prevent dementia include:
 - Stopping smoking
 - o Being more active
 - o Reducing alcohol consumption
 - o Improving diet
 - o Losing weight if necessary and maintaining a healthy weight
 - o Getting depression and other diseases treated early
- Keeping mentally active is also important in preventing dementia: there is a 46% lower risk of dementia in those with high levels of mental activity than those with low mental activity.

Faith groups therefore have a role to play in helping to prevent dementia, as well as in caring for those already living with the disease. They can do this through:

- Helping *spread the message* that many cases of dementia are *preventable* and how
- Running *activities* that help people to adopt and follow a *healthier lifestyle*
- Helping people to keep mentally active, since they provide opportunities for:
 - o Social engagement meeting people and volunteering
 - o Education and keeping on learning
 - Cognitive stimulation such as through reading

⁷ See <u>www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk</u>