



HOW FAITH GROUPS ARE SUPPORTING
PEOPLE LIVING WITH DEMENTIA,
THEIR FAMILIES AND THEIR CARERS

ABOUT FAITHACTION

FaithAction is a national network of faith and community-based organisations involved in social action. We empower these organisations by offering support, advice and training – we help the ‘doers’ do. We also have a key role in facilitating partnerships, sharing good practice between organisations and between sectors, and acting as a connector between government and grassroots organisations. We work to highlight the contribution that faith-based organisations are making to communities up and down the country. We know that the extent and impact of this work, and the reach of faith-based organisations into communities that are often marginalised, mean that faith is too significant to ignore.

FaithAction has been a member of the Health and Care Voluntary Sector Strategic Partnership every year since its inception in 2009, working with the Department of Health, NHS England and Public Health England. As the faith ‘voice’ within the Strategic Partnership, we ensure that faith is taken into account in the development of new health policies and initiatives. We believe that faith-based organisations have a role to play in raising health outcomes, particularly among communities that typically suffer from health inequalities. Our report, *The Impact of Faith-Based Organisations on Public Health and Social Capital*, looks at this issue in more detail. You can read more at www.faithaction.net/report.

THANK YOU

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Photograph by Alzheimer's Society

INTRODUCTION: WHAT IS DEMENTIA, AND WHY SHOULD FAITH GROUPS BE INTERESTED?

Dementia is an umbrella term that describes the symptoms that occur when the brain is affected by certain diseases or conditions – for example, Alzheimer’s disease or a series of strokes.¹ Symptoms may include memory loss and difficulties with thinking, problem-solving or language.

There are 850,000 people living with dementia in the UK – a number expected to rise to over a million by 2025. Already an estimated 21 million people in England have a close friend or family member living with dementia. And, according to Alzheimer’s Research UK, dementia is the most feared health condition for people over the age of 55.²

Given the scale of the issue, many people who are part of faith communities will be affected by dementia either directly or indirectly. At the same time, faith communities have something important to offer. Not only can they help support, in many ways, people living with dementia and their carers; they can also help to prevent dementia from developing in the first place.

This booklet is a collection of case studies that illustrate how faith communities from different traditions are offering these kinds of support. This is no more than an indication – of course, there is much going on up and down the country.

We would welcome further examples to add to our website:

www.faithaction.net/dementia – please contact info@faithaction.net.

¹ Information in this section provided by Public Health England: ‘Health Matters: midlife approaches to reduce dementia risk’. www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk

² YouGov Polling for Alzheimer’s Research UK, 29 November - 2 December 2013. Via Public Health England as above.

IN SUMMARY...

From the examples gathered here and from our conversations with our members, we have learned the following in terms of what faith communities have to offer people living with dementia and their carers, and what the health and care system should know about engaging with faith communities.³

WHAT DO FAITH COMMUNITIES HAVE TO OFFER?

Spiritual and emotional support for individuals affected by dementia

For example:

- A rhythm of life and a way to connect people with their faith and with others from their community, based on their deep-rooted memories, such as music and prayers known for many years.
- A sense of belonging, identity and safety.
- Pastoral support for people as they face issues connected with dementia, perhaps for the first time.
- Help with thinking through the big questions of life that dementia can raise: am I still me? Why am I here?
- The ability to uplift people through connection with others and spiritual practices such as prayer.



Photograph by Sarah Thorpe

Practical support for individuals affected by dementia

For example:

- Provision of activities or services to support people living with dementia and their carers.
- A way of connecting people with others so they are not isolated and can continue to function as part of the community, and providing opportunities for them continue to do the activities they enjoy such as volunteering, serving others or making and sharing food.
- Support with day-to-day living, such as transport and help with taking medication correctly.
- Signposting to other services, opportunities and resources.

³ In considering what faith communities have to offer we acknowledge here the framework developed by the Faith Communities Action Group, part of the Prime Minister's Champion Group as part of the Challenge on Dementia 2020.

A dementia-friendly faith community within the wider community

For example:

- A group of people who are passionate, motivated and available to help other people, who have the capacity to respond innovatively to issues connected with dementia, who share values such as care, compassion and love and who can create a feeling of welcome, calm and inclusion.
- A supportive network that works across generations, akin to an extended family – teaching children how to be good friends to older people, and offering support to people up to the very end of their lives.
- Help with challenging attitudes – for example, promoting the idea that people with dementia have something to offer the community rather than being just a drain on resources.
- An opportunity to reach large groups of people, through trusted messengers, to raise awareness about dementia and to support people to live healthy lifestyles.
- An embedded presence in communities, with the ability to link with other people and organisations locally to help build a dementia-friendly community in the wider sense.



Photograph by Sarah Thorpe

WHAT SHOULD THE HEALTH AND CARE SYSTEM KNOW ABOUT ENGAGING WITH FAITH COMMUNITIES?

- **Try not to make assumptions** – for example, that people already have an understanding of what dementia is, or that they will be willing to talk about it. Some languages (for example, some South Asian languages) have no word for dementia, meaning that, in some cultures, there is no concept of dementia beyond 'going mad', or becoming forgetful with old age.
- **Allow plenty of time.** Even people who want to help are busy and have competing priorities, often including day jobs. Take account of the major religious festivals when making plans.
- **Find out who you need to engage with in the community.** This could be a council, board or management committee with decision-making power – which may or may not include the spiritual leader(s). Can you win over someone who can act as a 'champion'? Can you address a meeting of the decision-makers? Is there anyone else who is seen as a 'trusted messenger' by the community (for example, a preacher) whom you will need to win over? This approach is more likely to lead to attitude change than an 'outsider' coming in, running an initiative and going away again.

- **Make links with institutions that train faith leaders.** The leaders themselves need knowledge, support and training in order to be able to support their communities – and they are just as likely to feel awkward or afraid about dementia as anyone else. They might also appreciate practical help – for example, knowing how to deal with people who become frustrated or angry because of their dementia.
- **Recognise the need for religious literacy.** An individual’s ability to express their faith and play a role in their faith community can be very important to their wellbeing. This needs to be recognised, as does the fact that there can be costs attached to care that provides for this kind of involvement. For organisations, faith can be an important motivating factor and provide a distinctive element to the care offered, which can be lost if the organisation ‘plays down’ the faith dimension of their work.
- **Consider the need for different approaches in different communities.** Faith communities in the UK are often made up of different cultural communities, which likely to have different views on dementia. And faith communities in one geographical area do not necessarily have links with communities of the same faith in another area.
- **Recognise that demonstrating the outcomes of a project is likely to be a challenge** in an area that still comes with stigma attached. For example, people might be unwilling to talk about the fact that involvement in the project has led to a family member receiving a diagnosis of dementia.
- **Consider what support you can offer with the following**, which faith communities identified as area in which they need help:
 - Supporting younger people with dementia, who can be very isolated
 - Good information and resources in languages other than English
 - Support with creative ways of communicating about faith in ways that do not involve words, and which tap into people’s deep memories
 - Opportunities to connect with other groups in the local area, including other faith groups, around dementia



Photograph by Sarah Thorpe

HOW CAN FAITH COMMUNITIES REDUCE THE RISK OF PEOPLE DEVELOPING DEMENTIA?

Many people do not realise that around a third of cases of Alzheimer's disease could be prevented. Faith groups can play an important role in making this message better known, and in helping people with the things that will reduce their risk of developing dementia. They can do this by:

Helping people to keep mentally active – through opportunities for social engagement, such as meeting others and volunteering; through stimulating their brains through activities such as reading; and through helping people to keep learning new things.

Helping people adopt and follow a healthier lifestyle – especially through stopping smoking. Other factors that will help are: regular physical activity; eating a healthy diet (low in saturated fat, sugar and salt); reducing alcohol consumption; losing weight if necessary and maintaining a healthy weight. It is also important to get the right treatment promptly for conditions such as type 2 diabetes and depression.

Resources to support faith and community groups in promoting a healthier lifestyle can be found at

www.faithaction.net/health-resources

WHO CAN HELP?

FaithAction is collecting a growing directory of resources that can help faith communities to support people living with dementia and their carers:

» www.faithaction.net/dementia

The case studies in this booklet will provide further ideas.

If you are from a faith community and want to know more about dementia and becoming dementia-friendly, there are experts who can help you. Here are some good places to start:

- **Alzheimer's Society** has a wealth of information about dementia, including in languages other than English, and local branches who can provide speakers to come and do a talk for your group. It also runs a specific Information Programme for South Asian Families.

» www.alzheimers.org.uk

- **Dementia Friends** is a national initiative from Alzheimer's Society that aims to change people's perceptions of dementia. You can attend a Dementia Friends Information Session, or arrange one for your community, and become a Dementia Friend. You can go a step further and become a Dementia Friends Champion, and run Information Sessions in your area; or become involved in creating a recognised dementia-friendly community as a faith group or as part of your local geographical community.

» www.dementiafriends.org.uk

- **Dementia Action Alliances** are local groups that link organisations and individuals to improve outcomes for people with dementia and their carers. They share best practice, facilitate action planning and campaign to ensure that dementia does not prevent people from living the lives they wish to.

» www.dementiaaction.org.uk

- **Dementia UK** offers one-to-one support and expert advice for people living with dementia. It provides Admiral Nurses to work with families.

» www.dementiauk.org

- **Livability** is a national disability and community engagement charity. It has worked with Alzheimer's Society to produce *Developing a Dementia-Friendly Church*, a practical guide for churches and faith communities. It also offers mentoring and training.

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

CASE STUDIES

THE DIOCESE OF LICHFIELD

The Church of England Diocese of Lichfield has funded the specific post of Dementia Support Officer, to support churches to become more dementia friendly. Sarah Thorpe works across north Shropshire, and in 2016 funding was obtained to expand the work to Stoke / Staffordshire and Wolverhampton / the Black Country. The aim is that churches will connect with people living with dementia and their carers, to create more dementia-friendly churches at the heart of dementia-friendly communities.

This work has three main areas of focus:

1. **A Sunday service** that uses the national Dementia Friends social action movement to raise awareness, helping people to understand more about dementia and to turn that understanding into action. The main Sunday church service is deliberately chosen as the platform (rather than a midweek meeting for those already interested): this underlines the issue as one for the whole church family.

In the service, there is an introduction giving [five key messages](#)⁴ about dementia. More is explained during the sermon, and a connection made with the Christian Gospel, so that the service goes beyond just information on dementia. Near the end of the service, people are invited to turn their understanding into action in a concrete way: for example, wearing the Dementia Friends badge and being open to conversation, committing to being patient when they encounter someone with dementia in the supermarket, or changing their language, talking about 'living with' rather than 'suffering from' dementia. The service ends with a commissioning prayer, which is a corporate step taken by the community, recognising that together they are more than the sum of their individual parts.

2. **A course of four sessions** on being a dementia-friendly church, for church members who are interested, offered to groups of local churches throughout north Shropshire. These sessions cover:

- Pastoral care: What are we already doing? Are we listening to people living with dementia and their carers? How do we communicate most effectively to connect with people at different stages of dementia?
- Buildings: What's the impact of our church buildings, for people living with dementia? This might include, for example, signs with pictures as well as words, and signs that show the way back from the toilets as well as the way to them. With the buildings as one element, what are the other elements that go to make dementia-friendly churches?



Photograph by Forget-me-not, Diocese of Lichfield

⁴ www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1816

- Services: With our church services, for people living with dementia and their carers, what might challenge (e.g. long services with lots of words) and what might connect (e.g. prayers and music rooted in long tradition that can touch people deeply)? Where are the moments of transformation or connection? Exploring some key themes of inclusion, mutuality, 'being with' one another and letting go.
- Community networks: In our local community, what is available to support people living with dementia and their carers? How can we best make connections, signposting people to things that will help them? What next steps shall we take to help our church and community become more dementia-friendly?

3. Support for churches to take the next steps that they identify. Ideas can be generated by sharing the stories of what other churches have done – and these lessons can also be shared across faiths. For example:

- Get someone in your faith group to attend the day-long free training to become a Dementia Friends Champion, able to run a Dementia Friends Information Session.
- Hold a discussion session after the regular weekly service or meeting, led by someone local who is involved with dementia.
- Hold a weekend focused on 'Living Well with Dementia': perhaps a Saturday morning forum, inviting along speakers who are involved with dementia, a Saturday afternoon tea dance, a Sunday morning sermon on dementia and a Sunday afternoon quiet, reflective dementia-friendly service.
- Open up your building to a local group that would like to run a course or sessions for people living with dementia or their carers, such as Alzheimer's Society or the local Memory Service.
- Link with the local business forum to run a Dementia Friends session in your building for local businesses and shops, getting together a team of volunteers to go into each shop with an invitation to the session and a copy of the Alzheimer's Society booklet, '[How to help people with dementia: A guide for customer-facing staff](#)'.⁵
- Host a Dementia Friends session.
- Use your organisation's news sheets and notice boards to advertise groups, sessions or events available locally to support people living with dementia and their carers.
- Host a regular event for people living with dementia and their families, like the Forget-me-not tea that runs monthly in Sarah's church, or Forget-me-not film that another church runs locally, providing a cuppa and cake and showing a film.



Photograph by Forget-me-not, Diocese of Lichfield

⁵ www.alzheimers.org.uk/customerfacing

Sarah's work also involves building partnerships, such as taking part in the Dementia Action Alliance, getting to know the local Memory Service and Clinical Commissioning Group, and finding out what Alzheimer's Society, Age UK and others are doing locally and how local people can become involved. She makes sure ideas and stories from different churches are shared to help inspire others, including through her blog (see below).

Tips for a dementia-friendly faith community

Name dementia without fear. This will help people to face the issue and will open up conversations.

One person reacted very strongly when the subject of dementia was brought up in their church, angrily asking why it was being discussed. However, by the end of that week, this person had gone to see their GP, and was eventually diagnosed with dementia. This had evidently been a sensitive topic for them, but the fact that the subject of dementia had been raised publically meant that the members of the church have been able to support the person on their journey with dementia.

Have open doors – both in the sense that dementia is discussed at gatherings of the congregation, and that specific support is offered to people in the community who are living with dementia and their families.

Emphasise that this is about taking one step at a time. It's not about having to 'buy into' a big package of work. Such a step could be as simple as naming someone in the church as dementia coordinator.

Be there with people. Remember that you don't have to be an expert: some of the most powerful things we can do are the simplest, such as just staying in step with people who are living with dementia as their patterns of life change. Hearing their pain, recognising what they are going through, and knowing enough to do some simple signposting can make a big difference.

Expand your knowledge a little, so that you can help in practical ways. Find out whether your local library has got a set of books on dementia; have a look at the fact sheets on the [Alzheimer's Society website](#);⁶ look up local services on [Dementia Connect](#)⁷ or your local [Dementia Roadmap](#),⁸ look up the Age UK information on the [blue badge scheme](#),⁹ [powers of attorney](#),¹⁰ [making a will](#)¹¹ or [Attendance Allowance](#).¹² You don't have to be the expert, but you may be able to signpost people on.

Work with others. Faith groups are embedded in communities and have deep resources to draw on in order to offer people support. When they work with local experts like Alzheimer's Society or Age UK, the combination is very strong.

Further information

» salopdementiafriendlychurch.co.uk

⁶ www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200465

⁷ www.alzheimers.org.uk/local-information/dementia-connect/#!/search

⁸ dementiaroadmap.info

⁹ www.ageuk.org.uk/travel-lifestyle/people/driving/the-blue-badge-scheme

¹⁰ www.ageuk.org.uk/money-matters/legal-issues/powers-of-attorney/power-of-attorney

¹¹ www.ageuk.org.uk/money-matters/legal-issues/making-a-will/why-make-will

¹² www.ageuk.org.uk/money-matters/claiming-benefits/attendance-allowance/what-is-attendance-allowance

TOUCHSTONE, LEEDS

Touchstone is a mental health organisation based in Leeds. Touchstone's BME (Black and Minority Ethnic) Dementia service is funded by adult social care with the aim of raising awareness about dementia among BME communities. Ripaljeet Kaur, Senior BME Dementia Worker, is reaching out to faith groups to raise awareness about dementia.

The strategy

Ripaljeet made contact with faith leaders at two mosques, three Sikh Gurudwaras and a Hindu temple. She arranged a meeting with the leadership committee of each of the places of worship, where she could deliver an awareness-raising session. The aim was that this would build capacity among community leaders, in the hope that they would go on to disseminate their new knowledge more widely – bearing in mind the fact that faith leaders are often trusted messengers within their communities. After each of these meetings, Ripaljeet was able to run a session on dementia with the whole congregation.

Challenges

Arranging the initial meetings was a challenge, as the committees meet in a voluntary capacity and their members are busy. For example, there were religious festivals and many functions at one of the sites during the months originally scheduled for the meeting, so it took much longer than anticipated to find suitable times for the sessions. In some cases a slot was made available in a pre-existing meeting where leaders would already be gathered. In some – although by no means all – cases, the male committee members were not completely comfortable being addressed by a female speaker, but in general the faith leaders were keen to learn and be involved.



Photograph by Alzheimer's Society

The future

Most of the faith groups have asked Ripaljeet to continue to work with them, and one of the mosques has stated its desire to become dementia friendly. The project is being internally evaluated, with findings available in February 2017.

Further information

» www.touchstonesupport.org.uk/services/bme-dementia-service

BANGLADESHI DEMENTIA CAFÉ, EAST LONDON MOSQUE

Reaching out with faith and culture

Monday Memory Sitting is a dementia café for Bengali/Sylheti language speakers who have dementia, and their families and carers. It is an Alzheimer's Society initiative and takes place at the East London Mosque and London Muslim Centre – a venue chosen because of its reach into the local community and the convenience for the many people who attend prayer at this large mosque. The club provides an opportunity for people affected by dementia to receive information and support, to take part in enjoyable activities and to share experiences and advice with others in similar situations.

Due to growing demand the café has increased from one to two sessions per month, with an average of 35 people attending each time. The activities offered include reminiscence (for example, sharing memories of home life in Bangladesh), arts and crafts, quizzes and seated exercises. A bilingual (English and Bengali/Sylheti) Café Facilitator runs the activities with help from bilingual staff and volunteers, and banners and leaflets are produced in Bengali. Most of the reminiscence materials used are culturally specific to help the attendees to engage in group activities. Experts also visit to give talks about subjects such as diet, diabetes, eye care, and welfare benefits. A light halal lunch is provided.

The importance of partnership

The café has arisen out of wider partnership working between Alzheimer's Society and Faith in Health, which provides training to Imams and religious leaders on health-related topics, together with the NHS (Tower Hamlets Clinical Commissioning Group and what is now East London NHS Foundation Trust). Past activities have included dementia awareness training sessions for Imams. One such event was attended by 120 Imams and covered topics including what dementia is, looking after someone with dementia from an Islamic perspective, dementia medication and the local services available. The sessions were run with the help of a translator, which participants felt to be very important in making the event a success.

Alzheimer's Society also supported the Head Imam at East London Mosque to give a sermon to raise awareness about dementia and other health issues for older people, at a gathering attended by over 4,000 people. Following the sermon, volunteers were on hand with further information: 800 leaflets were given out, and one-to-one advice sessions were held in a 'dementia information bus' provided by Faith in Health and Alzheimer's Society.

The partners have put the success of these initiatives down to the fact that the organisations have trusted in each other's different expertise, which has led to a willingness to go 'above and beyond' for each other.

Further information

- » www.eastlondonmosque.org.uk/content/faith-health
- » www.alzheimers.org.uk/info/20082/living_with_dementia_magazine/258/a_successful_businessman_who_won_t_let_dementia_tarnish_his_personal_pride (an article featuring one of the dementia café's participants)
- » www.youtube.com/watch?v=xGzyYEps-bw (a short film about dementia services in Tower Hamlets)

JEWISH CARE

Jewish Care provides health and social care services for the Jewish community in the UK. Some of its services, which include a number designed to support people affected by dementia, are:

- A helpline for anyone in need of guidance, support or information
- A community support and social work service, which can identify what support, care or services a person needs, provide advice, coordinate and act on the person's behalf with local authorities, and signpost them to other services as required
- Home care and residential care services
- Community centres and specialist dementia day centres
- Services for carers
- Education within the community – e.g. a 'dementia friendly' programme for synagogues

Dementia support services

Jewish Care sees faith groups' response to people living with dementia as having three aspects: making sure the physical environment is dementia friendly; raising awareness about dementia within the community as a whole so that people affected can be supported by their community; and providing support for the personal spiritual life of individuals affected.

Further information on some of Jewish Care's specific services is below.

Family Carers Team

This team is dedicated to supporting adults who care for people with an illness or disability. In the majority of cases, these are carers who are supporting people living with dementia. The help offered is centred on what the carer wants and needs: this might mean visiting them at home, meeting in a local café, or offering support via phone or email. The team provides a safe and confidential space for carers to share their concerns, signposts them to information and services and, where appropriate, advocates on behalf of the carer and the person they care for with services from the statutory and voluntary sectors.

Community services

'Singing for the Brain' groups and 'Memory Way' cafés offer a safe, supportive environment designed to decrease isolation both for people living with dementia and for their carers. This is in recognition of the fact that while carers will bring the person they care for to activities only if they can see a clear benefit for that person, carers themselves need support too; these groups provide ways for Jewish Care to ensure it supports both parties.

Singing for the Brain has been running in partnership with Alzheimer's Society, and is designed to provide stimulation and social support, to enhance the wellbeing of those living with memory loss and also to support and uplift their carers. Carers have reported seeing a physical change in those they care for following the singing sessions, and a 'boost' which carries on beyond the session itself. The sessions also engage with people's spirituality: for example, they will always include some well-known Hebrew songs and will link with Jewish festivals through the year.

Memory Way cafés are groups for carers and their friends or family members living with dementia. Professional support workers are always present, while engaging activities and speakers on topics of general interest are offered. These have ranged from talks on health and care issues to visits from museum curators and kosher wine tasting sessions. Tea is served from crockery and good quality refreshments are always available, which is just one way of communicating that the people who attend are valued and special.

Education

Jewish Care's dementia friendly programme helps synagogues to improve the support they offer. Synagogues commonly have a social welfare aspect to their work, and those responsible for coordinating this have been proactive in approaching Jewish Care for help. In response, Jewish Care has used the national [Dementia Friends](#) social action movement to run awareness-raising sessions, supplemented with its own bespoke training.

This training is typically delivered in an evening session and attended by a group from the synagogue congregation made up of people who might have a relative or friend living with dementia, or be someone who is themselves developing the condition. The training covers topics such as what dementia is, how to go about getting a diagnosis, tackling isolation, and how to communicate with someone who has dementia.

Synagogues will often take action as a result of these sessions, for example in making changes to the physical environment of the building, or identifying and ensuring they support people who are at risk of isolation.

What faith communities can offer

Jewish Care has found that when people from a faith community come together for mutual support with others of a like mind and similar life situation, this can help to reinforce their sense of identity – which is particularly important for people who have dementia. Services which bring people together with others from their community and help them to remain a part of that community are therefore very important. Furthermore, the rhythm of life of a faith community – for example, celebrating festivals and, in the case of the Jewish community, the weekly Shabbat – can help to reinforce the sense that people belong and are safe.

Jewish Care provides training on the Jewish way of life for all of its staff, so that everyone, whether Jewish or not, has common ground and can bring the knowledge into their support for those they work with. This kind of training is also offered to local authorities and other partner organisations.

Challenges

- **Support for faith leaders.** These are the people to whom individuals often turn for guidance and reassurance, and for pastoral and spiritual care – but faith leaders are as likely as any other person to feel afraid or awkward when it comes to dementia. Such leaders therefore need training.

Those within the health and care system looking to make links with faith communities could usefully begin by contacting the institutions that train faith leaders (rabbinical schools, seminaries, etc.) to ensure that leaders are equipped to offer the best support they can to their communities.

Faith leaders themselves also need to show leadership of their communities in terms of ensuring that people affected by dementia get the support they need.

- **Religious literacy of local authorities.** Local authorities understandably want people to access services in their local neighbourhood. However, such services tend not to take into account an individual's faith background, which, as highlighted above, can be an important part of a person's identity.

Local authorities may not recognise the importance for an individual's wellbeing of being able to celebrate religious festivals, or their entitlement to have access to a specific diet while in residential care – and may not recognise that there is a cost involved to care that provides for these specifics (for example, kosher food tends to be more expensive than non-kosher food).

- **Supporting younger people with dementia.** This is a challenge as numbers of people in this group who are also members of the Jewish community are low, and such people may not want to access services used mainly by older people. These younger people therefore tend to be very isolated.

Further information

» www.jewishcare.org/how-we-can-help-you/services/dementia-services



Photograph by Phil Keevil for Jewish Care at the Sam Beckman Day Centre for People Living with Dementia

DEMENTIA ENABLERS, CUMBRIA

Dementia-friendly churches in Cumbria

Churches Together in Cumbria is running an initiative to make every church in the county dementia friendly by 2020. It sees a dementia-friendly church as:¹³

- A church that is welcoming and inclusive towards people with dementia and their carers
- A church where the church leadership and other members of the congregation help people with dementia to feel safe and orientated within the church environment
- A church where it is OK to get confused and forget things
- A church where people with dementia and their carers feel that they are valued members of the congregation, stay involved in church activity, and do not 'fall off the radar'

Through this initiative, it is hoped that every church will be able to support people after a diagnosis of dementia, make sure that services are welcoming and accessible for people with dementia and carers, and continue to support both if the person with dementia can no longer attend or moves into residential care.

The initiative has wide support among church leaders from different denominations, including the Bishop of Carlisle, the Chair of the Methodist District and the Area Presidents of the United Reformed Church. David Richardson, Dementia Coordinator for Churches Together in Cumbria and one of the initiators of the scheme, says it is generally recognised that dementia is an area that the church needs to address, particularly as Cumbria has a higher proportion of the population who are elderly in comparison with the whole of the country.

Local action: the role of the Dementia Enabler

In order to realise the goal of every church in the region becoming dementia friendly, it was decided that action at a local level was crucial. A letter was sent to all churches in 2016 inviting them to identify someone within the congregation who would be willing to give a lead within the church (or, in the case of smaller communities, within a group of churches) as a volunteer 'Dementia Enabler'. 65 Dementia Enablers were identified as a result.

Being a Dementia Enabler does not mean that the person becomes responsible within their church for everything related to dementia. Rather, they take the lead in making dementia 'everyone's business', helping the whole group to become aware of the needs of people living with dementia and to respond appropriately. In nominating the Dementia Enablers, church leaders undertake to support them in their role and give due consideration to their recommendations for making their church dementia friendly.

Dementia Enablers are encouraged to become Dementia Friends, tying in with the national movement, and to encourage others to become Dementia Friends also. This sets the effort by the churches within the wider context of communities becoming more dementia friendly.

¹³ Definition provided by Dr Elizabeth Anderson, Dementia Adviser in the Diocese of Leeds

To equip Dementia Enablers for their role, a two-day workshop was run in 2016 in association with the Christian disability charity Livability. This included a Dementia Friends session, as well as addressing the 'how', 'what' and 'where' of a dementia-friendly church, and information on local support services for people with dementia. A further round of recruitment in 2017 will adapt the workshop to take place via half-day sessions around the county (as it was recognised that transport difficulties made it difficult for some people to attend one central day) followed by a further day.

The aim is that Dementia Enablers gain an awareness of the support services that are available in their local community for people affected by dementia, and encourage their local church or group of churches to become dementia friendly in terms of welcome, worship and environment. An audit tool has been developed in the form of a questionnaire, to help churches assess where they could become more dementia friendly and how they will do this. For example, they are asked to consider who within the church has dementia and where those people live (are they alone? Or in a care home?), how the physical environment of the church might need to be changed to better support them, and what links the church has with others in their area who want to make the community dementia friendly.

A Dementia Reference Group, drawn from across the church denominations and across the county and including representation from Alzheimer's Society, supports David Richardson to oversee the initiative. He produces a bi-monthly newsletter for Dementia Enablers to enable the sharing of information and encouragement, while local meetings also provide support. The first annual Cumbria Churches Dementia Conference was held in November 2016. A number of the delegates came from outside of Cumbria, suggesting that awareness is being raised around the country.

What can faith communities learn from this?

David wants other faith communities to pick up from the Cumbria initiative the challenge of asking themselves what they are doing to become dementia friendly. He is also keen to raise awareness of the importance of churches and other faith groups in continuing to support people throughout their journey with dementia, up to the very end of life. He emphasises that is not just a case of facilitating a person to keep attending the faith group in the early stages of the disease, but also of being honest about the nature of dementia and of not giving up on a person when things become difficult later on. One way in which this can happen is for faith groups to sustain links with care homes.

Further information

- » www.churchestogethercumbria.co.uk/dementia-friendly/757-making-every-church-in-cumbria-dementia-friendly-by-2020.html

AGA KHAN SOCIAL WELFARE BOARD

Valuing older people

The Ismaili Muslim community, in line with the rest of the country, has an ageing population. The values and principles of the community place great significance on caring for everyone as part an extended family. The elderly members of the community are valued as an important group and considerable emphasis is placed on supporting and providing care for them, seeking always to maintain dignity and maximise quality of life for every individual. The Aga Khan Social Welfare Board, whose members serve in a voluntary capacity, looks after a number of national and regional volunteer teams responsible for supporting this expanding group within the community.

Seniors' Clubs

Among its initiatives the Board runs a national network of Seniors' Clubs, on a weekly or fortnightly basis. The clubs are located across London, Manchester, Birmingham, Leicester and other areas of the UK. A club will typically last for two hours and include an exercise session, a talk or presentation and light refreshments, with occasional visits to areas of interest.

Tackling, preventing and understanding dementia is an important objective of the Board. The clubs contribute to this indirectly through the presentations and by helping their members to understand more about wellbeing and a healthy lifestyle. Clubs work with subject experts to share knowledge, with contributions from the field of medicine and from Alzheimer's Society.

By encouraging creativity and purposeful engagement, the clubs provide mental and physical stimulation for older people, alongside a sense of purpose. Significantly, they also reduce isolation and loneliness and improve people's connectedness with their community.

The Circle

The Aga Khan Social Welfare Board also runs The Circle: all-day programmes in a similar format to day centres, which occur on a weekly basis in London and Leicester. On average 115 people per week attend, taking part in a range of activities such as playing games, singing and various workshops, which again provide physical and intellectual stimulation. Participants have the chance to socialise together, eat and learn about how to maintain a good quality of life.

The Seniors' Clubs and Circle activities therefore provide a range of interventions from practical advice to emotional support and awareness-raising to de-stigmatise dementia. A representative of the Social Welfare Board comments:

"There has been a mindset change within the community such that the families of people living with dementia feel able to bring their loved ones out to socialise with others rather than keeping them at home. Thanks [go] in large part to the clubs and Circles for inspiring this change."

Volunteer case workers

Behind the scenes, the Aga Khan Social Welfare Board looks after a great deal of case work, supporting individuals and families in many ways including through signposting to different sources of information. It also provides advice on health and wellbeing, practical support in navigating GP and other services, and emotional support for families as they help their elderly members.

Its network of trained Social Support Volunteers are a group of patient and compassionate individuals who give their time to visit the elderly and infirm, and others who may be facing family disharmony, ill health, financial problems or other social issues. The volunteers make weekly or fortnightly visits, depending on their assessment of the need, to families and individuals who may be in their own home or in a nursing or residential home. On a visit, the volunteer will sit with people and may say prayers with them or take them some home-cooked food. The Board tries to maintain continuity with the same volunteer visiting the same individual to help prevent confusion.

Volunteers undergo training in communication and other 'soft' skills, assessments and safeguarding; importantly, they are also checked by the Disclosure and Barring Service (DBS). Their training also covers dementia, including how to recognise the signs, how to communicate with someone who has dementia and how to support the family. Volunteers may liaise with social services on behalf of individuals or their families, and the organisation is in the process of arranging Dementia Friends training.

The cornerstone of the Board's support is this team of regular volunteers who provide their time and expertise to shape a programme that is community focused with elderly members at its core. One volunteer comments,

"My work with the Social Welfare Board helps me as much as it helps those I regularly visit. It keeps me active and gives me a sense of self. Although it is hard to see individuals who need help, I am glad I am able to support them."

Further information

- » www.theismaili.org/community
- » www.theismaili.org/ismailicentres/london/webcast-professor-patrick-pietroni-darwin-international-institute-study (Information about a project on the role of compassion in health)

DEMENTIA FRIENDLY GURUDWARAS

The need for greater awareness

Awareness of dementia tends to be particularly low among South Asian communities. In recognition of this, the Dementia Friendly Gurudwaras project, based in Bradford, uses the Gurudwara as a community space to spread the message about dementia.

The project, founded by two doctors alongside other healthcare professionals and carers of people with dementia, was initially run within the local Gurudwara where the group worshipped. The group conducted research within their congregation through a validated questionnaire, and found that awareness of dementia, its risk factors, management options and the impact it has on lives was low. However, according to Dr Bhajneek Grewal, one of the project volunteers, these findings provided a useful baseline for the group in understanding the awareness within the community, allowing them to shape their programme of activities.

Given the existing low level of awareness, and the fact that dementia can be a difficult subject to tackle, the project group decided to start with measures to educate the community about dementia. Around 40 people from the Gurudwara attended a Dementia Friends workshop. Based on the Alzheimer's Society initiative, and delivered by an Alzheimer's Society trainer, the workshops look at the facts around dementia and how people with dementia see the world. The group wants to adapt this training into Punjabi and run it on a regular basis, allowing more members of the community to access it. The project has also used a lecture model, where dementia-related messages are delivered during Sunday services, and targets children and young people through specific classes to provide them with a lifelong awareness of dementia and its effects.



Photograph by Dementia Friendly Gurudwaras

The group has also made physical changes to the Gurudwara to make it more accessible to those living with dementia. Volunteers involved in the project are available for people to speak to on a one-to-one basis about their concerns.

Support for Gurudwaras

The intention is to make the project's website, dementiafriendlygurudwaras.com, into a virtual information portal for Gurudwaras. The site already hosts links to advice leaflets produced by Alzheimer's Society in English and Punjabi – which are also printed and placed in the Gurudwara – as well as podcasts and videos highlighting the importance of awareness and what can be done to raise it. The website also hosts a toolkit based upon the activities and learning done by the project, to help other Gurudwaras become dementia friendly.

Challenges

The project has found formal measurement of outcomes difficult, especially as it is primarily an education programme. It is challenging to find families who are willing to talk about the impact that the project has had – such as where their increased knowledge has enabled them to get a diagnosis of dementia or to support a family member – largely due to the stigma that still surrounds dementia in many Punjabi families. While the project group knows that many families have benefited from the programme, and while people are willing to share stories of how things were before the project existed, they are less willing to discuss the project's effects on their own lives.

The project group found engagement with the community difficult as dementia was not a common conversation topic and there were a lot of misconceptions around the condition. They found that developing relationships with people and encouraging them to take part in the programme really helped with this. Time was also a big challenge, as the project is mostly run by healthcare professionals who volunteer to give their spare time to the programme. The support that the project received from the Gurudwara's management committee was seen as being vital to the success of the initial project. The success of the project in extending to other Gurudwaras will depend on their management committees' willingness to embrace change.



Photograph by Dementia Friendly Gurudwaras

The importance of culture

The project has emphasised the cultural rather than the religious aspects of the Gurudwara, using the Gurudwara as a space to engage the community. Since Sikh communities within the UK are made up of different cultural communities, these cultural communities are likely to have different views on dementia, so a package of support appropriate to each community is likely to be necessary.

The project won the best Voluntary Organisation Award at the 2014 Alzheimer's Society Dementia Friendly Awards, and has received lots of press coverage from this. It is hoped that this will spread the project's message, so that more Gurudwaras around the UK become dementia friendly.

Tips

- **Raise awareness and knowledge**
 - The first step is to highlight that the problem of dementia exists. Dementia can be a difficult subject to tackle and a lot of education is needed in order to break down barriers.
 - Don't assume that people have an existing knowledge of what dementia is. Work to establish that knowledge within the community.
 - Help people understand that dementia is an illness caused by physical changes in the brain – it is not 'going crazy', or 'just getting old'.

- **Ensure you have 'buy-in'**
 - Any education initiative needs to come from within the community itself. Having someone from an external organisation come in, do some activity and go away again will not change attitudes in the long term – it is far better to get a group from within the community on board.
 - In faith groups like Gurudwaras that are run by committees, it is essential to get the approval of the committee before progress can be made. Invest time in petitioning committee members, 'selling' the idea that your initiative will be of benefit to the whole community. Get at least one member on board and allow for the time needed for the issue to be presented to the committee and approved.
 - Make a plan for your activities over, say, six months, and ensure that your volunteers know what is expected are able to dedicate the time needed to achieve it. This will help to avoid people saying 'I don't have the time!' at the last minute.
- **Make use of existing resources**
 - Work with outside organisations such as Alzheimer's Society and Dementia Action Alliance. These organisations can provide the information, support and training that you need – there is no need to try to do it all on your own.
 - Do the Dementia Friends Champion training provided by Alzheimer's Society. Even if you do not reproduce this exactly with your community, it provides a template for the main things you need to cover.

Areas where faith groups need support

- **There is a lack of resources available in Punjabi**, compared with the wealth of information available in English. Younger generations of the community do not speak Punjabi as fluently as the elders, so even though they might have good knowledge about dementia, producing resources in Punjabi is a challenge. The Dementia Friendly Gurudwaras team is working to address this but more needs to be done.
- **Raising awareness nationwide**: while the Dementia Friendly Gurudwaras project has worked locally in Bradford, there are large Sikh communities in other cities, who could make a big difference to providing support to people living with dementia through replicating the Dementia Friendly Gurudwaras initiative.

Further information

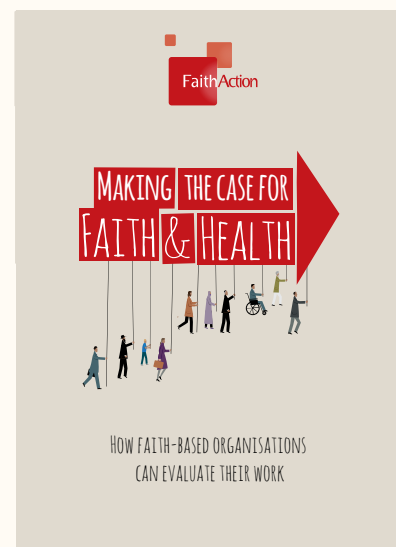
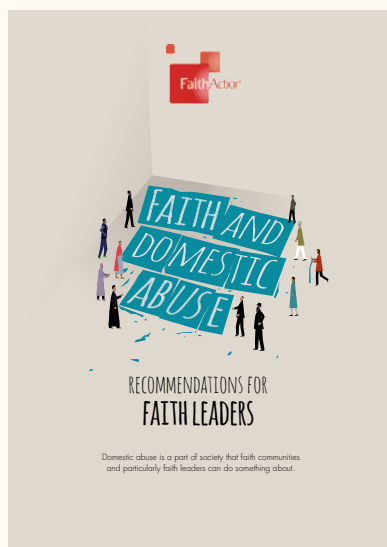
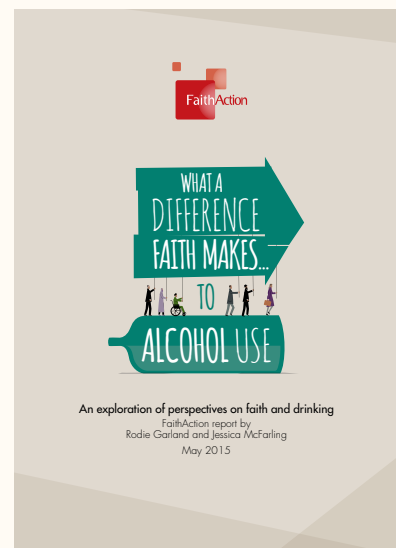
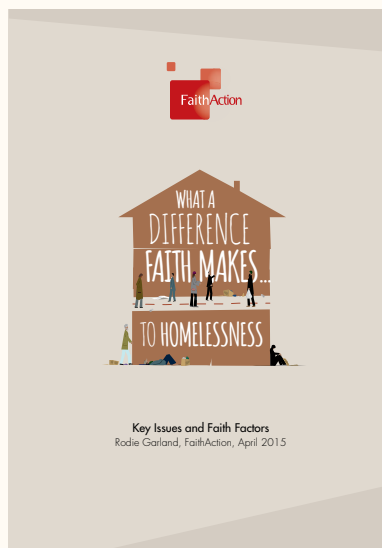
- » dementiafriendlygurudwaras.com

FAITHACTION'S HEALTH AND SOCIAL CARE WORK

FaithAction works to highlight the difference that faith makes, and to support and inspire faith-based and community organisations to improve health and wellbeing in their communities. Our Making the Case for Faith and Health guidance helps organisations to evaluate their work and show its impact.

Further information and publications are available at www.faithaction.net

Contact us at info@faithaction.net or 0845 094 6350.



Friendly Places is FaithAction's initiative to raise awareness of the significant and positive role that faith communities can play in the support of mental health. Sign the Friendly Places pledge and find articles, tips and resources to help your faith group become more mental health friendly at

www.faithaction.net/friendlyplaces



Because faith reaches the parts that nothing else can

www.faithaction.net

