Faith, Culture and Dementia Conference

Alzheimer's Society
United Against Dementia

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KEY DIARY DATES

21 – 27 May:
Dementia Action Week 2018

June 2018:
Look out for faith pages being added to the Alzheimer's Society website alzheimers.org.uk

Keep in touch:
We would love to hear of any work you are doing within your communities to support people affected by dementia. Contact the team at: programmepartnership@alzheimers.org.uk

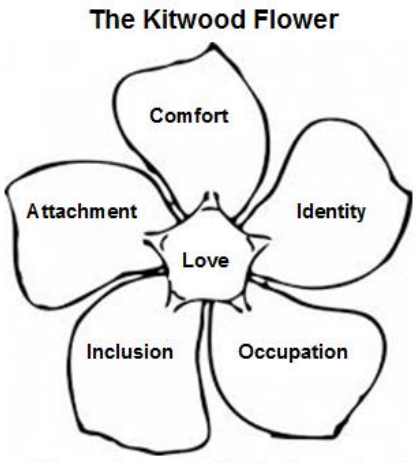
Notes from workshops

Finding solutions to the challenges people with dementia face, enabling them to continue to interact with their faith and cultural communities

Facilitated by:

- ***Padraic Garratt and Momarr Camara***
- ***Andrew Wileman and Gill Yentis***

Each workshop began by introducing Kitwood's Flower, explaining its components and using the 'inclusion' component as the starting point for discussion.



The main psychological needs of people living with dementia

Table One

A lady from the Sikh community whose mother is living with dementia told us how her mother had been excluded/dismissed from everything in her community. She said that as a widower her mother no longer has a place in the Sikh community. It is difficult because there is no word for dementia in Punjabi. She spoke honestly about how it is a journey for all family members as well as the person living with dementia.

Sometimes the caring spouse feels unable to acknowledge their partner's dementia to the outside world. Maybe they feel like that know what is best for their spouse e.g. 'I know my husband wouldn't like others to know.' There is a sense of misplaced shame or fear which stops people from accepting help.

There may be an element of the person living with dementia/their family not allowing the community to support/love, rather than it always being the community consciously distancing themselves. E.g. some people may feel like they have to stop doing things in the community once they receive a diagnosis.

Are there generational issues in rural areas given the generally older demographic?

Dementia is now the ‘D’ word just like cancer was the ‘C’ word 10 years ago.

Dementia is a hard diagnosis to receive.
A participant living with dementia in the group spoke about how he came from a health/social care background. He finds that he now can’t remember the names of people he has known for a long time. He thinks that these people feel that he is cutting them out because he no longer remembers their names. He said that he thinks education will help this – awareness of the condition but also it needs people with dementia to be open about their condition. There was acknowledgment that this is a very difficult barrier to overcome. People without a diagnosis also have a large part to play to advocate the issue.

Breaking down cultural barriers is really important. Some faiths believe that ‘what happens is god’s will’, therefore suggesting that it is the will of god for people to have dementia. This point came from a participant from the Islamic community and he emphasised the need to educate imams.

Cultural leaders are a focal point for action
One participant spoke about how hard it was get different faith groups involved. Using an example of a mosque in Lancashire, he said that he only managed to secure a DF Info Session by speaking with the imam and a social worker friend who was also a DF.

Who are we trying to share information about dementia with? Another participant told an example of how it is important in Sikhism to be around people. In education sessions, lines from the Holy Scriptures are brought in to demonstrate their points.

Information needs to be adapted for the audience

Spiritual leaders can raise awareness of dementia as part of their preaching. Talking about things leads to acceptance. This needs to be delivered in a compassionate way and inviting people to understand at their own pace. Of course faith leaders need to be encouraged to adopt understanding themselves too.
Issues with people turning up to education sessions etc. already being engaged with the issue. How do you engage with those people who do not attend?

A lot of faith groups focused on renewal at the moment, i.e. how to bring young people into the faith. This tends to be top of agendas – how do we get dementia on the agenda?

There needs to be a shift from ‘prayer’ to ‘action’. In Brent, faith groups are being looked at as the first service to turn to after a diagnosis but they are ill prepared to deal with this. Organisations trying to raise awareness of dementia are struggling to engage with local faith groups.

Faith leaders need to be rejuvenated
In Cumbria, the issue of dementia triggered the discussion of how best mid-level clergy people could influence their seniors. In a position of influence, how do we get the church leadership to listen?

The approach needs to be bottom up and top down. You need to have engaged congregations and engaged faith leaders.
Is there information overload for church communities? What should be their priorities?
“Motivation in this issue is dementia itself.”
In faiths where the faith leaders are ageing themselves, is dementia an issue too close to home?

There needs to be the willingness to do something.
Internal panic – prioritising other issues

Table Two

People can be included or excluded either intentionally or not.
People with dementia living at a Jewish Care care home significantly relate to previous identity.

What is the boundary between culture and religion? Breaking boundaries is difficult when it is the culture to be closed and not disclosing information e.g. about diagnosis.
Environment is important to whether somewhere is able to practice their faith e.g. is the chair comfortable to pray on.

Concerns that people living with dementia may disrupt the flow of a usual service and may be asked to leave.

A facilitator who works for Jewish Care but is a Muslim himself acknowledged that he thinks efforts are being made in his mosque to change this.

People with dementia can get involved with the processes of faith e.g. they could pray at home.
Places of worship may be noisy and may cause disruption for the person with dementia.
It is important to understand the behavioural changes that dementia can cause. They may make different choices.

Local, small places of worships mean that the person with the diagnosis can have more interaction with their spiritual leaders.

Disconnection of family life

Many religions teach their followers to look after/out for our neighbours. Religion needs to be brought back into the practical aspects of everyday life.
Families are under a lot of stress too, so sensitivity needs to be made for people with dementia and their families in places of worship etc.

What scope is there to use technology? Cameras in places of worship to allow for prayer at home. Live streaming of Sabbath and holy days. One participant mentioned they were already implementing this in her synagogue. Issues in that people may not know how to use technology. Life is now all online. Will people become idle? Will people use technology as a reason to not attend in person? Are we encouraging communities to become more isolated if people use technology at home rather than get out in the community?

Sometimes the issue is transport to and from places of worship.

Emphasising that dementia affects all members of the family – could this be a way to engage people in the cause?

Faith leaders should be challenged to educate at all opportunities possible, e.g. baptism, prayers etc. Or external people could be invited in to provide this education.

There are designated faith-specific media channels – these should be utilised. Can campaign on issues, prevents isolation on an issue and begins a conversation.

People don't know what they are looking for when searching for information, "you don't know what you need to know until you need to know it".

Table three

Local worship leaders have an important part to play.

Educate the decision-makers; faith-based interventions have a significant part to play.

Need evidence for faith-based intervention – could work with faith leaders for this.
NHS is beginning to realise that faith-based solutions are working for mental health issues.

People with dementia 'disappearing' from church when they are diagnosed. People may fear making a mistake in church, leaving them embarrassed and frightened. Afraid of rejection?

We need to be careful not to try to 'normalise' people with dementia. We make all these interventions to allow people living with dementia to feel normal. Is this right?

Carer perspective – maybe the person with dementia no longer attends church because the carer struggles to take them. It's a bonus if interventions can make the carer happy too.

Faith-based sections of engagement
One lady felt concerned that she felt that there was a lot of talk at the conference identifying people with dementia as a disparate group.
Quakers don't have church leaders, it's a shared responsibility amongst the congregation.
Practice of equality may make these discussions easier to understand?
Offer alternative options that are also spiritually based.

Approach faith leaders with evidence/justification about the positives
How do we present dementia as an issue to faith leaders?

One participant said that he would he automatically turn to his faith after (hypothetically) receiving a diagnosis and it seems alien that they may not understand his need/the issue. You expect faith to be there to support.

If faith leaders preach about dementia in one sermon, how much will it stick in the congregations' minds if each week is a different topic.

There is an assumption that faith-based organisations should be leading the way on dementia. Maybe very simply they just don't know what to do, in need of basic information. How can grassroots groups inform and promote management by strategic management?

Table four

Joanne – Catholic Dioceses, Paul – C of E, Bernadette – Liveability, Janet – United Reformed Church, Gill – Chinese National Health Living Centre, Samina – Public Health Hackney, Sarah T – NDAA, Sue – Anglican Church, Phil – South London Interfaith Group

Barriers and challenges:

Mariano – HQ is not accessible, for example there are lots of stairs.
We put on a lot of open classes on, e.g. Meditation and mindfulness and we have to think about how this might affect people. People come in off the street.

Do people access mainstream support and services – such as GP? Yes no issues

Gill (facilitator) – there are different attitudes towards the word dementia and a stigma attached. Where does this start? How do you break down the prejudices?

Gill (Chinese national health living centre) – people work long hours, for examples in jobs like catering they may work 12 hours a day and 7 day a week. They may also have childcare

responsibilities on top of that. Some Chinese people may be prevented from learning English and have no access to leisure.

In the memory clinics and services there are no Chinese people. Chinese become isolated – they can't communicate and they don't feel welcome at services. We set something up in China town but for people who aren't mobile, it is difficult to them. Many people don't know that you have to get a diagnosis from your GP who will make you a referral.

We need to support people to learn how to access services. We had some materials translated – the old term used for dementia means crazy / mad / demented. We translated this to mean a more literal meaning, such as disease of the brain.

It is about breaking down the barriers also for carers, and helping people to access services and support.

Mariano – the Vietnamese community have another completely different language and culture and they are often not represented at events and things. I don't think there is anyone here today. How to reach out to them? We try to recruit bilingual volunteers in communities and locally.

Phil – BAME language / pejorative associations
Same attitudes prevalent in English and Bengali cultures (this person comes from a mixed background). It is important to make information available in different languages.

Same – GPS have 75-805 of the patients – the lists they have are actually quite young. A lot of people I work with prefer an Orthodox or Jewish GP as they are more trusted. Jewish Care is in Stamford Hill but it tends to be accessed by people outside of the area.

Gill – some people live in a bubble – they are not permitted to reach out. Is this the same for others? E.g. Marriage if someone was looking for a suitor for their daughter and they knew that there was a potential match and there was dementia, schizophrenia or epilepsy in the family history then the young man would not be considered.

Lots of work with cultural and faith groups.
There are structured organisations that people can reach out to.

Gill Yentis: Kitwood flower - A model for approaching a person in a holistic way

You cannot say that all groups do this / behave in a certain way / or like something done in a particular manner.

It's difficult to talk about whole communities – you need to think about individual needs.

There are different ways to comfort a persona and we all seek comfort in different things.

Attachment will have a different meaning to different people
Occupation – this is not a job but what can people do to remain involved and connected. This could be if someone is always used to doing the flowers at church, or cooking the meals and helping with preparations in the kitchen.
People need and want to have a purpose and a role.

Inclusion – we need to find ways.
For example, the environment
Also, making sure people feel at ease and that they are comfortable.
What can the community do? Train and build up skills.

How to include a family member in celebrations
Jewish Care guideline example and leaflets accessible to all families – see attached

Barriers:

- Economics – small
- Channelled money into younger families

- ‘Out of sight and out of mind mentality’
- Investing in older people – just as valuable as, for example, a youth worker role.
- The largest cohort is older people
- How long have we known that we are an aging population?
- Aging / church
- Local authorities need to be involved and supporting communities.

Table five

Tina – Christian charity, Raj – psychiatrist, Hindu in West London, Brian – Priest from Cheltenham, Jav – Researcher at Kingston University and South Asian background, Peter – Parish, Norwich, Roxanne – Christian, Rabbi MJ – Jewish, Esther – DFC London, Sister Susan, Roman Catholic S. Wales, Alison – Leicester Diocese, Trevor – Jewish carer, Olowue – African Church.

Brian: our buildings need a lot more work to make them dementia-friendly. We need to pay much more attention. We have huge black mats and things like that – we are working on it! This experience is across the Anglican Church (generally). Some churches are different and they might engage with signage, access or lighting.

Tina: our congregational church has so many steps and there is no access for disabled people.

There is a need to be aware that these places / spaces are for the community – we must consider access.

Gill Yentis – there is still a strong stigma and embarrassment associated – the cultural or religious attitudes towards dementia or mental health are ingrained. Does anyone have experiences with prejudices?

Peter: often family members are embarrassed, the church is OK with people shouting out or walking out of a service but the families and carers get embarrassed by this. It’s self-inflicted, how do we overcome this?

Brian: embarrassment comes from grief – people are struggling with the diagnosis and the move from the person that you know and love to someone who they are not.

Rabbi: isolation affects the individual, for example, care home or home and not sure how to go about interacting with that person. Children or grandchildren don’t go and visit or people don’t take along the children in the family as they are worried about how the person with dementia may react or interact with them. Then they become isolated. They are cut off from their friends and family and this is challenging.

Jav: for South Asian it is language. Even just to translate the work dementia is means disease of the old or crazy person. In our culture, if you have depression or anxiety then you might not be classed as religious enough. So it might be thought that you did something in a past life.

What is the impact of that stigma? Shut off / don’t want to talk about it. Try to justify behaviour for example; they are just getting old, or its part of ‘normal ageing’. People will ignore the other symptoms. They are afraid to tell others as people won’t visit your house. It affects the family dynamic too – if you aren’t

doing everything then you might be seen as 'not a good wife'. In terms of community dynamics, dementia might look bad on the family and people don't understand and they stop visiting.

Some people may say that you r family has bad spirits. You deal with it as a family; people don't seek out professional help. They might look for religious help, for example the Imams but they might not know themselves. So they attribute to evil spirits because they don't know how to handle it.

Trevor: my mother couldn't talk about Alzheimer's – it was very stressful. My generation are very open in comparison about issues.

Brian: People say to me 'I don't visit anymore because they don't know me'
Do people access GPs or mainstream services? Or are people in a bubble?

People are not accessing services until they reach crisis point. People are more likely to want to talk to their Imam. They have that trust and relationship with that individual. People will approach the Imam to provide support so we need to make sure that those religious figures are armed with all the information. Expectations on religious leaders

Raj: it's about awareness and acceptance. It can be difficult to access the service and the support. That stigma still exists and there is a lack of understanding.
You have to know what it is, you have to be able to name it and you must be able to talk about it.

Esther: Pentecostal – father was a Dean. He was unable to share and to tell the church that he had dementia. He also had his driving license withheld. My sister had to ask for help and to get a lift because Dad was too proud. He was separated from something that he loved.

Brian: NHS dementia training course. Refusal to share diagnosis.

Rabbi: Stigma – is it mental health? We need more education.

Solutions

- Normalise, take away the stigma, and talk to people
- Supportive rather than a fearful approach
- Declaration of the significance of dementia

Gill Y: dementia is seeping into everyday life – so you might see a character on the soaps. This is a start! But how do you reach out to so many people? It is a normal part of life. And it is OK!

Peter: removal of barriers id good practise – irrespective of people with dementia. Dementia friendly is just part of being inclusive.

<Gill talked about Kitwood flower as per previous sessions>

Occupation is a lot of what keeps people feeling as though they belong. For example taking about a subject area that you know someone will understand.

Rabbi: my mother is in the US and she enjoys keeping busy. She has Alzheimer's. In her previous job they gave her work on the computer to do. It gives her a sense of wellbeing and feeling valued. There might be things that a person can't do but it's good to focus on what they *can.*

Identity is everything. How can we continue to include people with dementia? Barnet Jewish network encourage people with dementia to volunteer so that they can feel empowered.

L'Arche Model – as for people with learning disabilities

Often it is about educating people – so those that are coming on to a dementia ward or another setting. People need to know how to behave and what to expect.

Any more solutions? Labelling / bad behaviour, religious leaders and educating them, can't be solved by prayers, seek professional help, doctors to understand the importance of culture and religion.

Preaching to congregations
Translation of words – how about just saying the word dementia? Cancer had the same issue with different translations and slight difference in the meaning. The word cancer is now used universally.

Table six

Ruth – dementia lead (Jewish?), Georgina, Alexa - Muslim, Chris – Christian, Alex – Christian, Fern – AS, Aviva – Synagogue, Bob – Diocese (church in Wales), Christine – London Civil Society, Vlada, Church of England, Wendy – Diocese of Leicester.

What kind of barriers do you think exist around interactions with faith and communities for people with dementia?

Ruth: travel and how to get to activates and services. Volunteers are great but there are only so many. People might live in opposite direction so you can't pick up multiple people.

Christine: language – and this is emphasised when someone is living with dementia.
There is an Armenian centre in Acton and not many people in London are using this because of a lack of awareness with the language. Older people have come to the UK as older people. They have had no opportunity to learn English properly – theses older people have the memories from when they were younger. People become so isolated.

Chris: translation and cultural attitude. Dementia is translated as demented. It is linked to other aspects of mental health or might be associated with witchcraft. Much like depression or anxiety.

Chris: Alzheimer's Society might not be seen as it's there for people with dementia. People see the Alzheimer's in the name. Why did the charity change that?

Aviva: at our synagogue we sold our mini bus and that gave us a transport fund. So we can pay for people to take taxis (those in the M25) which is much better and it encourages people to come to our activities. What we'll do when the money runs out, don't know!

Ruth: all the taxi companies in Leeds are dementia-friendly. They will be briefed so they know to knock and collect the customer, to check they have their keys and they have locked the front door behind them.
Wendy: rural communities – there is not a lot that is easily accessible for people. It can become difficult to practise your faith. Having a range of activities and facilities is a challenge for rural areas.

Bob: carer reluctance. People are embarrassed about the kinds of interactions they might be having. Where someone's behaviour may be different t what they are used to, there could be an outburst or there is some element of unpredictability. They don't want to be in church. We need to increase the comfort level of the carer. Do you tell the congregation? You need to have consent from that person. Help people to recognise the signs and symptoms – you might not then need to tell everyone as people will pick up on what they see if they know what to look for.

Gill: helping people in the congregation to support other people. Synagogues are often a place not just for prayer, but they act as a

community centre, they could include toddler, bridge group, something for the over 70s. People who are using the building and volunteers must adapt to notice that people might not be participating, or they may choose to leave.

Barriers

The barriers are when people stop coming. What can we do to keep people attending? Give people more understanding, awareness and support. For example, if they see someone leave, then they could ask them if they are OK. Do they want to have a cup of tea? Then have a chat with that person.

Alexandra: people with dementia and other disabilities (such as mental health).
We are more aware. Holistic are in faith – does dementia need to be made so specific? Can it be incorporated?

Physical environment – what make it comfortable for some will make it uncomfortable for other people

Some people will say that it is good when you are preaching to have a capacity of 80% so that your congregation is full but not too full. However, for some people this may people and so much noise might be too much.

This might explain why someone is agitated or not feeling how they would normally.

Attachment – can be to people but can also be objects, for example having rosary beads, or for women taking their handbag out – they can't go anywhere without it or they are so used to having it when they don't it feels off. Maybe you notice these things about people in your community. You see them every week, or possibly day to day and you might spot these small things that make people feel at ease.

Faith and culture are part of our identities – maybe only a part of it.

Why are people connected to faith?

- Religion
- Prayer etc.
- Being part of a community
  - ➔ this may be the biggest part (– it's that **sense of belonging)**

Becoming a dementia-friendly place of worship and supporting the wider community

Facilitated by:

- ❖ ***David Richardson and Ripaljeet Kaur***
- ❖ ***Rodie Garland and David Truswell***

Table 1 and 2

- Personalise to the place of worship
- Consistent support
  - Official volunteer champions
  - Boundaries and expectations
- Engage faith leaders – more than just Dementia Friends
  - Make them aware of individual cases
- Provide access however possible

    - Doesn't have to be 24/7 could offer a service if people call in advance
- Use networks and personal relationships
    - If you notice behaviours of carers and PWD reach out
- Environment
    - Find ways around old buildings e.g. Prison chapels, cells and process
- Use faith communities to reach the wider community e/g non-believers
    - Bring them together for awareness
    - Work with other services e.g. admiral nurses and other faiths
    - Community activity e.g. gardening
- Just do it! Organic growth can be better than planning
- Dementia friendly services e.g. shorter and no sermons
- Make people aware that their faith doesn't judge (your dementia or how religious you are)

Table 3

- Courses for community leaders
- Build networks with other churches and use social media
- Measure progress and effects – but how
- Accessibility for all (not just dementia)
    - Tell people what's next
    - Use images
    - Signage
    - Simplify and slow
- Care homes
    - Travel to worship is a challenge
    - Form direct relationships with faith leaders
- Rush services with people with dementia e.g. they read the prayer
- Connect with young people e.g. schools via their curriculum
- Certificates with tangible/practical steps
    - Kite mark
    - Embark – embed – extend to community
    - Environment/services/awareness
- Train synagogue welfare officers

Table 4

What do faith communities have to offer?

- Cuppa
- Warmth
- An accepting space
- Great place if you're lonely
- Free
- Someone to listen
- Safe
- Welcoming
- Listening
- In touch with roots/personal
- Connect
- Cultural sensitivities
- Language
- Attentive listening – relating
- Care home/chaplaincy visits
- Training – Dementia Friends
- It's not wrong
- Aspirations
- Community groups and volunteers and buddy
- Community and health service overlap
- Family and friends!!!
- Collaborating!
- Hubs for community interfaith
- Love is the central theme
- A community bringing together
- Share resources and information
- Difficult conversation with care home

Table 5

What do you think faith communities have to offer?

- Aspect of extended family
- Centre of information
- Community activities (“devoid” of faith) being inclusive
- Counter loneliness and isolation
- Opportunity to support and focus on the familiar
- Identifying his or her interests/history/professional background
- Local engagement – personal and responsive
- Consistency of contact
- Reconnection to a community if you have recently moved into an area – creating a sense of belonging
- Degree of proactivity
- Programmes and facilities open to all
- Meaningful exchange and network
- Social and spiritual offer
- Reaching out and bringing others in

Practical considerations on becoming dementia-friendly

- Signage
- Volunteers
- Find a connection/tradition from their history
- Familiar prayers
- Welcoming someone in
- Consider physical environment and unnecessary obstructions
- Quiet/distraction free space
- Disabled access
- Acknowledgment of dementia in services – uphold positive feelings in the community rather than focusing on grief
- Community space for prayer
- Reach out to others in the family and include them
- Ensure consistency

Individual relationships with faith

- Connect family outside with the technical
- Family values
- Perceived reduction in spirituality to have a duty to counter/explore this
- Memory and spirituality and identity
- Multiagency - Faith interaction with services
- Local Alzheimer’s competing rather than integrated approach

Successful partnerships

- AS to a memory café signposting
- Fiddle-muffs involving people and partnerships
- An exchange meaningful wider community
- Confidence to speak about faith and dementia
- Bolder about duty
- Bridging
- Social interaction
- Offering more on an individual level

Responsibility/role for faith

- To have a responsibility
- To be active with care homes
- Care home relationship
- Examples of “asking what can we do for you”
- Deep-rooted
- Offer of prayer
- Co-ordination if key!
- Dementia connect

Table 6

What do faith communities have to offer?

- Carers/family – meet, support, signpost, relief
- Two way – community
- Help to break down stigma and negative attitudes
- Safety/individual is valued for who they are rather than contribution

- East London mosque talking about dementia in worship
- Deaf people included/interpreters
- Community awareness days
- Mental health and spirituality all different backgrounds
- AS friends – raising awareness within the congregation and outside through support
- Makes people more aware
- Dementia information within Sunday service
- Support during sermons – volunteer to make sure people with dementia and carers
- Training for confidence for community
- Roles within the church/community that are appropriate
- Opportunity for carers to socialise
- Giving carers support and empathy

Linking faith community to local community

- Local schools
- Rural places – obvious place to father
- Care home can be excluded mixing dementia and community
- Outreach carers
- Faith communities

How do local communities become activists?

- Memory nurses
- GPs, doctors, chemists
- Spiritual considerations

Dementia friendly services, sermons or prayers

Facilitated by:

- ***Charlotte Overton and Alison Mitchell***
- ***Corin Pilling and Kirstie Kalonji***

Table 1

Prayer is a broad concept. The term might put people off. Could just be reflection, quiet, chanting.

What are the benefits of prayer?

- Opportunity to speak without being judged
- Connectedness
- Can be done by a person alone or in a group

Carer worried about her identity being lost as well. Worried that when she stops going to the temple with her mum her own spiritual life will stop.

More than half the population say they pray but not that many say they belong to a faith group so prayer is a wider thing.

Lady from the Baha'i faith-key to spirituality in the Baha'i faith is doing good works- in addition to an individual relationship with God. Actions might be more difficult for a person with

dementia or become so and that could be upsetting and frustrating for them.

A lady talked about a member of her faith group who was distraught that he could no longer “be useful”. Had tried offering things for him to do like helping with setting out chairs but he still feels the loss.

There is an importance –a turning point-in allowing yourself to be served rather than being the one doing the serving. There is a difficulty in accepting that we need others and accepting help.

Practical support is important: Font size in text, lighting and creating a nice environment e.g. flowers

Being present **for** someone and **with** them.
Church of England has a very liturgical tradition. People can recite well known prayers.
But sometimes familiarity can be dangerous-one lady recounted the experience of working with someone who had been abused within a church environment for whom lighting a candle was a trauma trigger. Someone else had witnessed someone joining in reciting prayers which had triggered memories of being abused within the church. So it’s important to know the person and their experiences. Consider putting a note in the care plan. Everyone’s faith experience will be different.

Facilitator distributed different quotes about the definition of prayer which were read out.
Some definitions added by members of the group:-
“ The power of prayer is in the one who hears it not in the one who says it”. Prayers could be stumbling and incoherent.

From St Augustine:- “ Having the **intention** to pray is the prayer”
Consider supporting people to explore faith if they haven’t had it before.

Consider:-

- How would you support someone with dementia to pray
- What would you find helpful yourself by way of support

Don’t draw a hard and fast line between the spiritual and the physical.

Maybe doing something creative such as music making or drawing or making bread or making a lavender bag could be a way of expressing spirituality. An example from Jewish tradition would be the making of bread for the Sabbath-the kneading action, smells, prayers over the bread, associations from past experience and tradition creating a simple connection all the way through.

Table 2

What does prayer mean? Is the term “prayer” unhelpful?

Might put off younger people. Meditation might be more appealing.

Over half the population say they pray but not that many would say they are members of a faith group (Tear Fund research)

One third say they pray in a place of worship so two thirds are praying in daily life.
Prayer could be making a wish or being grateful. Language can be helpful but can also create distance.

If prayer is silent how can we support someone to pray?

Lady from Church of England gave an example from services in care homes. They have learnt that the space at the end where everyone is asked “What do you want us to pray for” is very useful. It generates connections. Might be just saying “God bless…x y z”.

Remembering people who are sick or struggling

How many people would say yes if asked by someone “Can I pray with you?” – mixed response, it depends on the **circumstances**.

Changing religions. Practices may change. How does that work with someone with dementia? Might they revert to earlier practices?
Prayer can be doing e.g. making a cup of tea. Helping people to explore faith.

Facilitator distributed various quotes about prayer which were read out.

“ Prayer can change the person who prays, not the person who is prayed to” was another quote contributed by a participant.

Being human-feeling sad, angry, grieving- that can be important.

Prayer/spirituality needs to include the richness of experience both good and bad.
Prayer might be too passive-waiting for something to happen rather than acting to make it happen.

Consider:-

- How to support someone with dementia to pray
- How would we like to be supported ourselves

Ideas about prayer:-

- Meditate
- Reflect
- Wish
- Connect with something that is beyond ourselves

Table 3

More than half the population pray but “prayer” covers a lot of things. Could just be quiet reflection.
What does it mean to people:-

- Comfort
- Engagement
- Connection
- Reflection

Does prayer need words? What if there are no longer words? Still possible to pray.

The Anglican tradition is very much about words but you don’t necessarily need words.

(One participant) As a Buddhist I have difficulty with the concept of prayer. Buddhist practice is about mindfulness and the benefits of meditation in shaping the mind. I have done work with people who have difficulty with words to support them in meditation. One to one work-working with the person-working on breathing in and out-quiet and peace-yogic practices. These can all be therapeutic for people with dementia and can enable them to have a spiritual experience without words. There may even be evidence that being able to exercise the mind in this way might help prevent dementia.

The “being with” a person is important. Maybe holding hands or some other form of touch but could be just being there. This is particularly important at end of life but not just then.

May be benefits in regularity – day to day practices. Is often something around **ritual,** particularly for people with dementia.

Hymns or prayers learned in childhood may come back more readily.

Benefits of music-hymns and other forms.

Dementia may limit a person’s ability to put themselves in a spiritual place. They may need someone to enable them to do that.
Quaker practice is about sitting in stillness. The meeting itself is the holding space.

Difficulty with a “them and us “ approach, for example if there are specific services that are dementia friendly. May be better to have an inclusive space for everyone.

Care homes-churches can come in but maybe should be looking at how they can facilitate people in care homes coming out to services.

In care homes there can be difficulty getting carers just to sit and be quiet.

Place is important. Flowers , music, scent – a sensory experience. Light too and maybe something visual like a nice picture or a nice view.

Lady from Unforgettable mentioned a music player they sell that can be preloaded with the person's favourite music or just something like birdsong.

Know the person-what is their background. This may help enable them to practise their spirituality. Preferences in this respect could be included in an advance statement.

Prayers and poems have a rhythm to them which may be helpful for a person with dementia. Back to what we said earlier about ritual. The Catholic rosary is an example.

Though ritual can be important it may sometimes be good to move outside the ritual and not be afraid to try new things. Buddhist gentleman was concerned about trying new things if you didn't know they would work. Consider songs with clapping and actions. Blowing bubbles could be a prayer.

Reference was made by one lady to a Radio 4 programme about someone who did music with people with dementia. Very high soprano sound was distressing but lower pitch more soothing.

Buddhist chanting is ritual-can create a collective sense of peace that can be shared by family, friends and the person with dementia all together. Creating a collective experience is important. Need to think about the faith experience not just for the person with dementia but carers and family too.

Consider:-

- How would you help a person with dementia to "pray" or have a spiritual experience?
- Give an example of how you would like to be helped to have a spiritual life

General discussion around these questions touching on points already raised above.

Table 4

- We must see prayer as a conversation between the person and someone/something else which allows you to understand yourself on a higher level.
- There is a need for an individual response to this. Transcendence into another space – communication of all kinds, from others around the person praying, will allow this through different means/methods.
- Faith/community groups must try and remember the person, even if they can no longer remember the tradition/practice.

How can faith and community groups develop dementia-friendly services?

- Creating a memory/sensory box full of things that they would have used known as a younger person. Use this box to help facilitate their prayer/practice.
- Redefining prayer. Faith leaders/members should move away from seeing prayer as reaching out for help and into a practice of thanksgiving.
- Communal/shared living can be a good support mechanism to help maintain traditional, inclusive practice.

- Day trips/journeys to local (faith and non-faith) spaces to help facilitate sensory recognition.
- Simplify language/liturgy.
- Dementia awareness across congregation. Teaching and training congregation members on how best to support their fellow worshipers.
- Involving people with dementia in the service. Giving them a role (leading prayer, delivering parts of service) and sense of purpose.
- Introduce dementia-friendly service. Short, café style, with a discussion topic which is always tangible and open.
- Using physical ways of prayer – Catholic sign of peace, for example.
- Letting go of preconceived ideas of what a sermon should *look and sound like.* Leaders should ask themselves: what is the purpose of worship? Taking elements of the traditional service and letting go of the things which may restrict a person from accessing this.
- Opening and redefining the service space. Alters in the home/dedicated space in the home for worship. Encourage leaders to come into the home and deliver parts of the service there.
- Acknowledge that some community members are more isolated than others. This can be due to an inability to travel and or/the community not adapting or being open to changing practice. This isn't just stopping them from practising their faith; it is also stopping them from accessing vital support, interaction, love and care.

Table 5

Can/should prayer deviate away from just words? Can/should we pray though non-verbal means?

- Songs, for example, can have people connecting with them through the tune, rather than the words. The power of music can allow cognitive recognition.
- Faith communities can/should allow people with dementia to connect to the essence/truth born out of praying. This approach to prayer does not need to be formulaic.

How can faith and community groups develop dementia-friendly services?

- Faith groups should look at prayer spaces as community spaces. Seeing the evolving and changing community as a journey all are invited to be on.
- The repetition of prayer/traditional practice can offer comfort and a way for the person living with dementia to identify with time/space/themselves.
- Introduce a buddying/befriending system. Invite a member of the faith group to support the person with dementia that is unique to them; person-centred.
- Finding a way to deliver a service that suits all. Realising that being dementia-friendly is being people-friendly.
- Recognise that it is faith leaders, those with authority, who hold the power to affect necessary change.
- Preserving peoples' occupation during a service. Adapting what someone is reading, for example, without taking the task of reading away from them. Adapting the text, but not patronising the person. Ensure they feel valued and retain a purpose within the community.

Table 6

What are our initial thoughts?

- We need to be opening out the idea of where faith practice should take place, and in what capacity
- Faith and community leaders need to concentrate/develop their understanding of intersectionality
- The benefit of prayers and song/music – the pleasure/level of engagement in signing prayer, for example, mustn't be underestimated for those living with dementia. The memories associated with hymns/songs can help the person living with dementia connect with the service/themselves.
- Conversely, for people who join faith later in life how do we ensure they connect without these associated memories?

How can faith and community groups develop dementia-friendly services?

- Praying *with* people. Groups need to ensure that it is a shared and open experience.
- Tapping into the person's cognitive ability to remember liturgy/prayers from childhood.
- Can the use of holding symbols help with non-verbal communication/non-verbal elements of prayer?
- Stream live services to give congregation/faith members living at home/in a care setting/unable to travel access to the service.
- Leaders/chaplains using iPads to connect with people – they have instant access to every language, signs/symbols, and appropriate versions of prayers.
- Awareness that a person living with dementia is still a person.
- Involving family members/carers/coordinators in services/their faith journey.
- 'Faith Matters' – a tool for people to use to help maintain service participation for individuals, carers/family and the wider community.
- One of the best ways to support people with dementia is to support their carers. Ensure that they are given the opportunity to access their faith too.
- Faith/community groups need to understand the importance of on-the-ground support from pastors/coordinators.

Excerpts from our powerful speeches

Jeremy Hughes, Alzheimer's Society

'Faith is an anchor to who we are, so much of our personhood is held in our faith. This continues to be the case after a diagnosis of dementia'.

'Faith is a resource, and should be utilised to support the two thirds of people living with dementia who do not feel part of their community. Small changes can be made to enable people living with dementia to continue to participate in community life'.

Rabbi Menachem Junik, Jewish Care

'From a Jewish perspective, every person has a Neshama– a soul, a spark of G-d, which shines bright and illuminates within the person. It is our potential and that is the generator that sends signals throughout the entire human being. The challenge we face is that we have to see every person with dementia as a human being. Yes, their memory is not intact but there are times and moments where they feel joy, and when the spirit of life shines within them. The power of the Neshama – the soul, can never be extinguished and faith gives us the opportunity to connect to the essence of the person and see them with value and worth.

…..A friend of mine whose grandfather is living with dementia told me how difficult it is for him to see his grandfather and especially to take his young children along. He felt it was difficult to have a proper conversation, as he is too far-gone, and his visits are less frequent at times. I could fully understand why, because it hurts when it's so close to home, a family member. But when he saw how the various different traditions that I was able to perform with his grandfather impacted upon him, and how those memories bought him back to life, it put a smile on his face, and they reconnected on some level.'

Shelagh Robinson, Quaker

'Dementia has a beginning a middle and an end, post diagnosis our faith communities can support us, help us to come to terms with the future, listen to our anger, our rage and fear until it becomes acceptance. Offer us the overlooked treasures of our faith to help and support us. When someone did this for me I was able to reframe the embarrassment of having to ask for help into an exchange of grace. And I can still do that.

In the middle stages the enabling word is the most appropriate, we still have a great deal to offer, find it, and use it. But also let your love pour over us as the struggle gets harder and harder, love us for who we are not because we have dementia.

And at the end? There is practical support of course, many people face dementia without family, with their greatest support sometimes being members of their faith community and practical support of all kinds is both needed and welcome. But there is something far beyond that. One of my abiding images from scripture is from the account of those three figures standing at the foot of the cross. Unable to do anything. Just being there, being alongside.'

Balvinder Kaur, Sikh Council UK

'We found that the vast majority of care homes were not equipped for my mother's faith needs; we struggled to find a place for her. There is such low levels of awareness in families too, fear and not knowing what to do can cause people to back off. But this can change, we need Gurudwaras to become dementia-friendly and support the community.'

#faithculturedementia

Commitments for faith leaders

- Engage with a new understanding of personhood with people with dementia at the heart.
- I would like to see dementia friends sessions promoted throughout our community
- To engage my mosque Imam to raise dementia awareness within the community
- I would like our clergy to recognise the need for awareness long before it is an issue. ‘We never know who we will meet tomorrow’.
- Unite with other leaders in support of people affected by dementia
- Our leaders need to become aware of the expertise and experience in their faith communities- to both support and release them to create communities that are helping those living with dementia participate.
- For the Archbishop of Canterbury – Is there a lead bishop for people with dementia / dementia issues. If not appoint one!
- Train church architects and DAC’s in dementia friendly church buildings
- I would like religious leaders to enable sharing of best practice within their own and other faiths
- I would like to see them promote understanding of dementia
- I would like to see more dementia friendly services available
- I would like religious leaders to be more united in promoting spiritual needs of those who live with dementia and their carers
- I would like dementia friendly prayer areas and greater support and awareness for people with dementia and their families.
- I would like to see every church in our area more aware of dementia and using opportunities to engage with those living with dementia in the community

Dementia-friendly actions

I will support people living with dementia to partake in their faith

Working together with faith communities on promoting dementia risk reduction like 'what's good for your heart is good for your brain'. Training resources and tools on dementia awareness and reducing the risk. Encouraging and supporting healthier lifestyles e.g. physical activity, reduce smoking, reduce alcohol consumption, social interaction. (Sue-Public Health England)

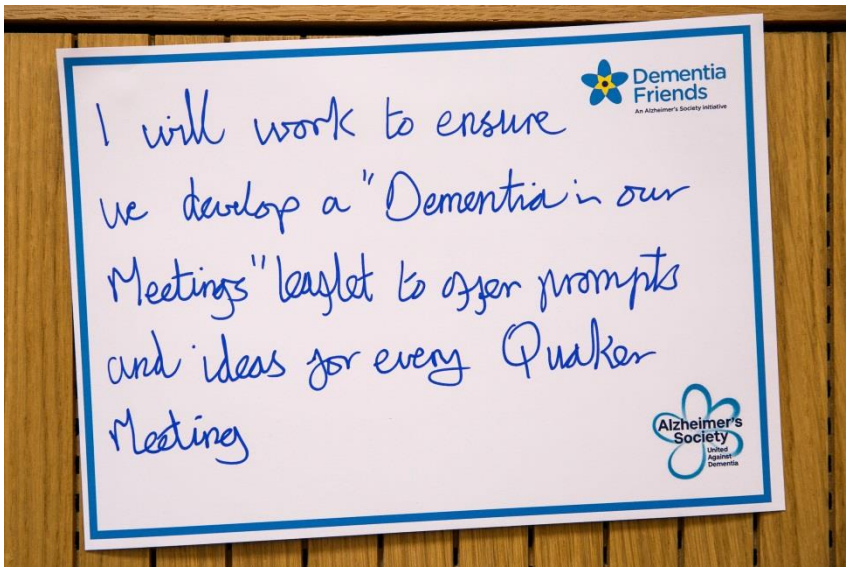
I will apply lessons learnt today and pass these on to the Global Dementia Friends Network to engage our members

I will work to ensure we develop a dementia in our meetings leaflet to offer prompts and ideas for every quarter meeting

Thank you for the affirmation- we will continue to meet the aims of our 'spirituality and dementia' project in our diocese

I will share with others what I have learnt and keep the conversation going

I will share learnings with the Global Dementia Friends network to encourage the members to approach faith groups for their work.



At the Buddhist Soe devise ways of delivering services that are dementia friendly. E.g. services based on chanting of simple mantras, devotional practices involving artefacts and human contact, simplifying language, cafes on death, dying and dementia?

This was a very encouraging and supportive event. It has re-energised me with the current project undertaken last year in my area.

Prayers

Whatever religion we belong to: Keep in touch with your relatives, neighbours and be practical with your relationship and responsibilities with God , the creator with your neighbours and communities, with the animal world and with the nature and environment according to your duties and responsibilities ordained by your religion. **Dr. Mozammel Haque, Islamic Cultural centre, London**

God , may our love for those with dementia mean we miss them whenever they are not with us. **Anon**

Lord, if we cannot remember you, please still remember me. Amen. **Rev. Chris Knight**

May Allah continue to give all the strengths and will power to continue educating the general people about dementia and raising awareness. Amen. **Momara Gamara, Jewish Care**

The name in my healing oh my God and remembrance of thee is my remedy. Nearness to thee is my hope and love for thee is my companion. **Baha'i writings**

Loving God, you know everything about us; help us to be aware of those around us. When the light of life dims and muddled minds become the normal – help us and others to be your hands of care and light to those around us sharing your incredible love. Thank you. Amen. **Anon**

Jesus, remember us, as individuals and communities, and be with us on our continuing journey to our heavenly home. **Anon**

Great spirit of life
May all people of all nations
Be inspired to enable more
Positive, life affirming language
Attitudes and beliefs in our shared dementia
Anon

Let us pray for sound minds. Let us pray for clarity and that the lord strengthens our bodies, and faith that we will be able to tackle the day and that our existence will not be supressed by such disease. Let's pray for purpose and resilience. Let's pray for patience and togetherness. Let's pray for the 80 year old self and the 65 year old self and the present, past and future will make sense one day. Amen. **Riama Patterson, Dominica Dementia Foundation**

Dear Heavenly Father, thank you for your love and care for the people with dementia and their carer. Thank you that you are God who does not forget who we are, even when we do. Thank you that your love reaches in and touches us at the deepest place and we can shine because of you. Thank you so much father for making the way for us. In Jesus name. Amen. **Alison**

Lord, let there be peace rather than distress and closeness to you rather than sadness and isolation. **Anon**

Dear Lord, give me the strength and fortitude to assist in this journey of dementia living. **Anon**