



TOWARDS DEMENTIA FRIENDLY FAITH COMMUNITIES

A REPORT ON THE REDBRIDGE FAITH FORUM PROJECT 2014/15

‘Exploring everything you wanted to know about Dementia but were afraid to ask’



Five Dementia Awareness Sessions held at faith venues across Redbridge

- 18 September 2014 at St Francis of Assisi Church, Barkingside,
- 7 October 2014 at Ilford Islamic Centre, Ilford,
- 17 November 2014 at Redbridge Jewish Community Centre, Sinclair House, Woodford
- 22 January 2015 at Singh Sabha London East Gurdwara, Seven Kings
- 24 February 2015 at Ilford Hindu Centre, Ilford.

One thematic focus at the Redbridge Faith Forum's (RFF) Women's Day Conference 2014, was raising awareness about dementia. From this event there was evidence of the need to raise awareness more widely including within and across faith communities. RFF was successful in receiving grant from the Community Development Fund 2014-15 to run a project entitled 'Towards Dementia Friendly Faith Communities'. The project comprised five dementia awareness raising sessions held at various faith venues in Redbridge over a period of six months to enable those of different faith communities and neighbourhoods to attend at a convenient venue. The sessions were held on:

- 18 September 2014 at St Francis of Assisi Church, Barkingside,
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The grant was match funded in kind, in particular by the Alzheimer's Society in the services of a fully trained presenter ~ Alli Anthony. Alli gave very informative talks at all sessions, explaining clearly what dementia is and how it affects people's lives - both those who live with dementia and their care givers. She explained fully how people with dementia can be helped to "Live Well with Dementia". She also explained how people can become Dementia Friends and Dementia Champions within their communities. The latter involves one day training in order for the participant to become a presenter themselves and thus further the awareness within their faith community. In practice all attending the sessions became dementia friends and at least one person from each faith group took information on becoming a dementia champion. At the time of writing the report confirmation of training had not been received, although RFF is confident that it will be completed.

This report includes a commentary following each of the sessions. The hosts at each of the faith venues were generous in welcome and use of their premises. Their generosity is much appreciated. There were people from different faiths present at each of the venues. This was real evidence that people realised that dementia can occur in any, and all faith communities. There was honesty expressed by participants that dementia is frequently seen as a stigma which can lead to denial and in some cases to isolation for those living with the disease.

At most sessions (equipment permitting) there was a power point presentation. This was very supportive particularly where participants had English as an additional language. The screen illustrations helped to focus on the information being given.

At each session the Redbridge 'Information Pack for People with Dementia and their Caregivers' was available and well received. The pack is currently being updated and is available will be available on Redbridge i as well in libraries and medical centres. Alli also recommended texting CONNECT2 on 70660 to request a free 'Staying Connect Kit'. There were requests at all sessions for information on services and support available in Redbridge.

Every session was well if not very well received in terms of gaining insight into the needs of people living with dementia (90%) and gaining understanding of the needs of care givers (82%). When asked what was most interesting /informative, the most frequent comments included:

'understanding that there are different types of dementia' 'the conditions that are a prelude to the disease', 'This is a problem ~ I thought I'd gone mad. So now I make an appointment to discuss with my GP', 'understanding how to see life from the perspective of a person with dementia', 'dispelling myths'. 'interesting and reassuring that it (dementia) doesn't necessarily come with ageing', 'thank you for explaining things so well'

And for care givers 'the difficulties for carers', 'Alli's personal experience as a care giver'.

Additional - follow up

People attending one or more of the sessions were eager for more information on how to get support and what services are available in Redbridge. As a result, RFF came full circle with the Women's Day Conferences 2015 and organised an evening for six different support groups to present information on their service and support available. The support services and presenters included:

- Alzheimer's Society - Alli Anthony & Caroline Wairia
- Age UK – Monique Debsie-Smith
- Redbridge Concern for Mental Health- Regina Byrne
- Carers Trust EHHR - Claire Taylor
- Sikh Community Care Project - Jasbir Sangar
- Redbridge Carers Support Service - Shamshia Ali.

Redbridge Respite Care Association also were in attendance with an information stand. This event was part funded by the former Area 3, 5 and 6 Committees which had allocated funds for Women's Workshops and the Women's Day Conference. It was very well attended (40) and very well received ~ see separate report 'Caring for those living with dementia and their caregivers' on RFF Website. The presenters also said how useful it had been to be able to publicise their work to a wide audience.



'Thank you for organising this important conference. It is always good to refresh our knowledge on the different provisions whilst meeting/catching up with colleagues from different services. During the evening I even managed to register some new carers and many have taken information away. The professional networking provided an opportunity to exchange details, one of which is already looking positive in enhancing the lives of our unpaid young adult carers. Well done on delivering a

successful event which was also well attended.' Shamshia Ali

'I absolutely echo Shamshia's words – many thanks for an interesting evening.' Alli Anthony.

'I also totally agree with both the emails below from Alli and Shamshia. Jenny and I felt it was a thoroughly successful evening and from the responses I have just read in your lovely thank you letter, I see the audience felt so too. I am pleased to have been a part of it as part of Carers Trust EHHR.'

Further support and advice was also requested and arranged by the Sikh Women's Alliance. They booked in a session with Alli Anthony specifically for the women's group.

The Alzheimer's Society has been working with Sikh communities in producing a booklet giving specific guidance and support to the Sikh community. A member of the Singh Sabha Gurdwara acknowledged that there was stigma attached to dementia within the community which he hoped they would be able to address. He received a copy of the booklet with view

to discussing with the management committee, how they might extend their own in-house awareness raising with Alli Anthony.

Other additional follow up

The chair of RFF attended a premier performance of a play by the EKTA Project - *Action for Asian Elders and Carers*. The play entitled 'Dementia's Journey' aims to bring about awareness in an attempt to dissolve the social barriers that prevent the community from addressing the onset of dementia in their families. The focus of the play is to raise awareness in the South Asian community. This play is based on EKTA's direct experience of the confusion and difficulties faced by the elders and their carer's. Following the viewing RFF publicised the performance of the play at the Methodist Church Hall in March 2015 particularly across the faith communities with large representation of the South Asian Community. It was very well attended and received.

There follows reports of the sessions at different venues of the 'Towards Dementia Friendly Faith Communities' project. The report on the first session is more detailed as much of the information was repeated at subsequent sessions.

Session 1: 18 September 2014 at St Francis of Assisi Church



A very warm welcome was extended to twenty people of different faiths (and none) at St Francis of Assisi Church for the first of five sessions organised by Redbridge Faith Forum (RFF) on the topic 'towards dementia friendly faith communities'.

It is estimated that over 3,000 people in Redbridge are living with dementia. As dementia can affect anybody regardless of faith, gender, age or any other background it is more than likely that it affects people from every faith community. Despite this a high proportion of people feel that there is a stigma attached to those with dementia. RFF has organised five repeat, dementia awareness raising sessions at different faith community venues. The sessions are open to all who wish to attend wherever it takes place whether they belong to the faith group of the venue, to another faith group or none.

Jacquie Grieve (Chair of RFF Management Committee) opened the session by introducing Alli Anthony from the Alzheimer's Society. Alli has much experience in leading awareness raising sessions. She presented the facts about dementia clearly and sensitively, emphasising that:

1. Dementia is not a natural part of ageing.
Although dementia is more common among over-65s it is not that case that everyone will develop it as they get older. Statistics indicate that 2 out of 3 will not develop dementia.
2. Dementia is caused by diseases of the brain.
There are a number of diseases that cause changes in the brain. The most common is Alzheimer's disease. Each of the diseases affects the brain in a slightly different way. The pattern and pace of progress of each disease is different.
3. It is not just about losing your memory.
While dementia does usually start by affecting short term memory it can also affect the way people think, speak and do things. Dementia can also affect mood and motivation. Alli talked about value of the memory clinic where specialists are able to diagnose the type of dementia. GPs are the first port of call if there are memory problems, confusion and or disorientation.
4. It is possible to live well with dementia.

Dementia cannot be cured but there is much that can be done to help. Medication may help people with some kinds of dementia or can help with symptoms that often accompany dementia, like anxiety or insomnia. It is important to go the doctor as soon as you suspect there is a problem.

5. There is more to a person than dementia. (*It is important in our faith communities that we help fellow worshippers to maintain some of their faith practices and not be excluded ~ JG*)

Alli gave us many insights into the needs of those living with dementia and their care givers. She spoke from personal experience that brought a personal touch to support the facts she presented. She encouraged many to become a 'dementia friend'. Being a Dementia Friend is about being aware of how you can make your community dementia friendly by taking small steps. We were invited to think of one action that would help someone living with dementia. One participant said she would be more patient when visiting someone living with dementia in a care home. To find out more about how to become a Dementia Friend visiting www.dementiafriends.org.uk

Alli also spoke about becoming a 'dementia champion'. This involved one-day's-training to enable you to lead on awareness raising sessions within your own communities. One person requested further information on this. Another arranged a follow up meeting with Alli and a group of women from the Sikh Community with view to the women becoming dementia friends and /or dementia champions. More can be found on the same website above.

Participants at the session shared some of their own experiences of being a care giver to a relative or neighbour living with dementia. Alli ably responded to questions raised such as whether dementia was a hereditary disease. She said that genetic dementia is very rare. Dementia through the generations increases the risk but does not necessarily mean you will develop it. She was able to allay a number of personal concerns. She spoke about strategies that may help prevent or delay vascular dementia (one of the forms of dementia); these include exercise ~ suggestion 10,000 steps a day! ~ and eating a sensible diet including the five vegetables and fruit a day.

Some at the meeting asked for more information on what services are available for those living with dementia and their care givers. Jacquie distributed the Redbridge 'Information Pack for People with Dementia and their Caregivers'. This is also available on Redbridge. Jacquie and Alli also recommended texting CONNECT2 on 70660 to request a free 'Staying Connect Kit'.

Fifteen of the twenty people attending the session completed an evaluation at the end of the session. (Two people had to leave the session early ~ other commitments ~ were not able to complete an evaluation). From evaluations completed 14 said they gained more insight into the need of people living with dementia. Some said that what they found most interesting or informative was '*understanding that there are different types of dementia*'. They said they had gained a better idea and even a much better understanding of the needs of care givers.

Jacquie Grieve thanked Alli for helping us understand more about dementia and ways in which we can help our faith communities and people in Redbridge generally become dementia friendly. She reminded all that the session will be repeated at the Ilford Islamic Centre Albert Road on Tuesday October 6 30 to 8.00 for those who could not attend this session but wanted to learn. Many took flyers for the next and subsequent sessions to share with work colleagues and others in their faith communities.

As a follow up to this first session Alli is running a 'Dementia Friendly' session with the Sikh Women's Alliance on Sunday 5 October at the Gurdwara Singh Sabha



Session 2: 7th October 2014 - Ilford Islamic Centre



This second session, which was attended by around 30 people from the local community, followed the same agenda as the previous session. Introductions were made by Phil Butcher - Vice Chair of RFF.

It is important to note that this event attracted people from a range of backgrounds and ages. The event, which was hosted by the Ilford Islamic Centre, welcomed people from a range of faith backgrounds.

Alli Anthony, again led the event and gently took a very attentive audience through the reality of Dementia in our society and how best we can help those who are affected by this debilitating and degenerative illness.

The presentation was well balanced and well-paced and enabled ample time for a comprehensive question and answer session.

Of the 30 people who attended 22 completed evaluations. Over 86% of the respondents rated the session as good or very good. Comments were similarly supportive and one respondent said that this session 'prompted a visit to the GP'.

During the evening Phil Butcher also advertised the follow up sessions and also other work that RFF is involved in.



Session 3: 17th November 2014 Redbridge Jewish Community Centre (RJCC)



This the third (repeat) session in the series of five was hosted by RJCC. A warm welcome was given to the 20 people of different faiths who attended.

This was a special session in this series, as it was an RFF and RJCC partnership event for Mitzvah Day action. This is a day focussing on good deeds ~ not as a one off activity but as an enduring legacy. It is a day for interfaith activity fitting well into 'Interfaith Week'. Jacquie Grieve (RFF) in opening the session highlighted that this was an excellent example of interfaith work. We were encouraging people to become dementia friends and or dementia champions which would also be an ongoing 'good deed'.

Alli Anthony once again gave a clear and comprehensive presentation on aspects of dementia. Her examples of caring for a relative living with dementia really brought home to the majority of those present (with one exception), the realities of living with dementia and being a care giver.

Sixteen of the twenty people attending the session completed an evaluation form at the end of the session. Fifteen said they gained more insight into the needs of people living with dementia. Some said that what they found most interesting or informative was *'understanding that there are different types of dementia'*. On information received one of the 'older generation' present thought they would take up the advice on healthy eating and exercise to help delay the onset of the disease. They would also be making an appointment with their GP to checkout concerns. There was general consensus that participants had a better idea of how to be a dementia friend. Two asked for more information on becoming a dementia champion. Both these actions will work towards a positive, ongoing impact from the evening.

Positive suggestions were made for future meetings, which RFF will take on board. In particular one of the following two sessions will be held at a different time of day. We will ensure people have a step by step guide to becoming dementia champions.



Session 4: 22nd January 2015 Singh Sabha London East Gurdwara



The Sikh Community hosted this fourth of the five sessions. Mankamal Singh of the Gurdwara Management Committee also member of the RFF Management Committee, welcomed everyone. As is the tradition with the Sikh community there was a generous finger buffet provided from the langar. This was very much appreciated. As in previous sessions there were people of different faiths present. There were also children present who took great interest in describing the stages of making a cup of tea - one of the activities for the session. Alli Anthony again presented the session and asked

people to undertake this activity to fully appreciate how many small steps are required in making the cup of tea. Many people, as in other sessions missed out some important steps such as turning on the tap to fill the kettle or having turned it on not mentioning to turn it off. All were surprised at the number of discreet actions required to complete the overall task. One claimed with much pride and amusement that he could make a cup of tea in one action - he simply asked his wife for it!

Members of the Sikh community said that there was much stigma still attached to dementia. Many did what they could to hide any evidence that someone in the family was showing symptoms of the disease. This is not an uncommon reaction but can be dangerous. Examples were given which included people being locked in the house to prevent them wandering only to be hurt when a fire started with no one around to call the fire brigade. The Alzheimer's Society has been working with other Sikh communities in producing a booklet giving specific guidance and support to the Sikh community. Mankamal gratefully accepted a copy and said he would be presenting it to the Gurdwara management committee with view to organising further training for the community.



Of the 27 people attended the session 18 completed an evaluation. A good proportion (12 of 18) had not attended a RFF event previously. They thought 'the whole evening was very interesting'. One who had made special child care arrangements to attend said 'I was glad I made the evening'. 83 % said they had gained much insight into the needs for people living with dementia with 94% saying they had gained more understanding of the needs of the care givers. The sharing of concerns and experiences by Alli and others attending, helped in seeing how dementia affects all. Most said they had a good idea regarding being a dementia friend or becoming a champion and one said they would sign up to become a Dementia Champion.



Session 5: 24th February 2015 Vishnu Hindu Parishad (VHP) Centre



Following requests made at previous sessions, this, the last of the five took place in the afternoon at the VHP Centre. It was very well attended (49). Vinaya Sharma of the VHP provided a generous range of finger food. A significant number of women in



attendance had limited command of English. Alli Anthony and Vinaya did an amazing double act with Alli skilfully adapting the messages to short passages and Vinaya translating. There also were others able to translate in support. The need for translation led to some time constraints which were compounded by the arrival of the Dial -a - Ride bus. This service is a great boon for women to get to and from the centre; however strict timing meant many had to leave before the end of the session. One disadvantage of this was that there was little or no time for completing evaluations by the majority present. Of the 49 attending three evaluations were completed. Nevertheless these responses and verbal feedback indicate that the messages re dementia were well received. Participants applauded *'the effort made to accommodate non-English speakers'*, *'Alli's personal experience'* and *'found it all very interesting and reassuring that it (dementia) doesn't necessarily come with ageing'*. One person indicated that they would sign on to become a dementia champion.

To find out more about how to become a Dementia Friend visit www.dementiafriends.org.uk