

Dementia Friendly Gurudwaras



2014

A Toolkit to making your Local Gurudwara Dementia Friendly

This toolkit is designed to support you in making your local Gurudwara Dementia Friendly. It will hopefully provide some food for thought, and have some practical applications.

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A GUIDE TO MAKING YOUR LOCAL GURUDWARA DEMENTIA FRIENDLY

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INTRODUCTION

What is Dementia Friendly?

Dementia friendly is the term adopted in national and local campaigns to make our communities, business and services more accessible and less discriminating to those living with dementia.

Why is it so important?

There are 800,000 people living with dementia in the UK. This figure is set to rise.

People with dementia face many challenges going about their daily lives. These include going shopping, using public transport, socialising and getting involved with their community. When they face difficulties, it adds to their stress, and can lead to people reducing or giving up their community involvement and becoming isolated.

Unfortunately people's lack of understanding and impatience can make these problems worse.

A study conducted in 2003 by Bowes and Wilkinson examined the views and experiences of dementia among older South Asian people, as well as their families and carers. It demonstrated, "overwhelmingly negative experiences of dementia, with poor quality of life, desperate needs for support, lack of access to appropriate services, little knowledge of dementia, and isolation from community and family life."¹

Another study by La Fontaine et al looked at perceptions of ageing, dementia and ageing-associated mental health difficulties amongst British people of Punjabi Indian origin. The findings suggested that, "ageing was seen as a time of withdrawal and isolation, and problems as physical or emotional; cognitive impairment was seldom mentioned. There was an implication that symptoms of dementia partly resulted from lack of effort by the person themselves and possibly from lack of family care. Therefore people should overcome their own problems and family action might be part of the solution. There was a sense of stigma and a lack of knowledge about mental illness and services, alongside disillusionment with doctors and exclusion from services."²

How can the Gurudwara help?

Organisations such as Gurudwaras have an important role to play in ensuring people with dementia can continue to live their lives to the full and be an active part of their communities for as long as possible.

The Gurudwara is a hub for local Sikh communities. Besides providing a place for spiritual worship, it is a centre for learning traditional scriptures, languages and Sikh arts. It is also a vital space for individuals to access community support and companionship.

As the population of the UK ages, there is an increasing proportion of elderly congregation members. Longevity is widely recognised as the most significant risk factor in developing Alzheimer's disease (the commonest form of dementia). Because of the vital role played by Gurudwaras in the community, they are ideally suited towards raising awareness of dementia and tackling its implications and ongoing stigma within the Sikh diaspora.

ABOUT THE PROJECT

To enable the UK Gurudwaras to fulfill their potential in tackling the issue of dementia, the Dementia Friendly Gurudwaras Project was born. A group of Sikh individuals who were passionate about this issue decided to focus on one Gurudwara initially. The aim was to present it as a role model Dementia Friendly Gurudwara to act as a template for other Gurudwaras looking to follow suit. The Gurudwara chosen was the Ramgharia Gurudwara in Bradford.

Since the onset of this initiative, the Dementia Friendly Gurudwaras project at Ramgharia Gurudwara Bradford has:

- Modified the environment of the Gurudwara to make it more Dementia Friendly
- Raised awareness and provided education amongst key sevadars (volunteers) of how to interact with people with dementia
- Created over 50 Dementia Friends within the congregation through workshops
- Set up virtual and physical information portals on Dementia
- Initiated a monthly memory café at the Gurudwara where people with dementia and their carers can share their experiences and support one another.

More broadly, the Dementia Friendly Gurudwaras project has been recognized both nationally and internationally for its work and was the Voluntary Organization winner of the 2014 Alzheimer's Society Dementia Friendly Awards. The project has also begun preliminary work with other Gurudwaras across the country.

MAKING A START

This toolkit is designed to support you in making your local Gurudwara Dementia Friendly. It is not meant to be prescriptive but will hopefully provide some food for thought, and have some practical applications for you in your work. We believe the following key steps are useful to consider.

Recognizing the problem

The first step is to recognize that dementia affects everyone including Sikhs. The literature^{1, 2} suggests that there is a real problem regarding the lack of accessibility to dementia services and support in South Asian communities. Furthermore, lack of awareness and fear leads to stigmatization of those with dementia. Since its inception, the Gurudwara's role was to welcome all and provide an environment of comfort and safety. Gurudwaras therefore have a responsibility to ensure that the space within their four walls is Dementia Friendly.

Deciding to act; understanding the needs of the community

A project like this is better handled within a team. It is advisable to recruit individuals with similar thinking and who are committed to making a difference to those with Dementia. After a group has been formed, brainstorming can begin on the different ways of making your Gurudwara Dementia Friendly. It can be helpful to discuss your thoughts and plans within a focus group. This group ideally should consist of people with Dementia and/or their carers so that they can provide suggestions based on their own experiences at the Gurudwara. At this stage we are happy to be contacted to help review and develop your action plan.

Approaching the management committee

Once a formal action plan has been decided, this will need to be presented to the management committee at your local Gurudwara for their approval. It is important to engage with the management committee as their support will enable the project to grow. Whenever change is suggested, obstacles may arise. It is important to emphasize during consultation with committee that:

- One of the fundamental tenets of the Gurudwara is openness and inclusiveness
- Dementia affects 1 in 3 people over the age of 65
- A Dementia Friendly project will raise the profile of the Gurudwara in the local community
- The project will improve accessibility to the Gurudwara for all
- Because the project is volunteer led, there are minimal costs involved for the committee.

Reaching out and engaging people with Dementia

Once management committee approval has been gained, you can begin to implement the agreed action plan. In the example of Ramgharia Gurudwara Bradford, we used a variety of methods to engage people with Dementia, their carers and the wider congregation. These are listed below

- Informal face-to-face discussions
 - Dementia can be a difficult issue to discuss in an open forum, so informal conversations on a one-to-one basis can help break down barriers and encourage open dialogue. Ideally a group of individuals from the project team should be nominated to begin engaging the congregation members. These conversations can take place in the Gurudwaras at any time in a casual but confidential manner.
- Environmental changes
 - A review of the Gurudwara should be conducted to highlight areas that people with Dementia might face difficulty interacting with. Typically these include finding the bathrooms, identifying where to remove shoes, and navigating around the Gurudwara between the Divaan Hall, Langar Hall and classrooms. These problems can be addressed through the use of pictographs accompanied with English and Punjabi signs.
- Physical Information portal
 - The stigma of dementia sometimes means that talking about Dementia openly can be a bridge too far for some. People should have the opportunity to take leaflets and information booklets to read in their own time, both in English and Punjabi. This can encourage open dialogue at a later stage. These can be downloaded freely from the Alzheimer's Society website and from the Dementia Friendly Gurudwaras website:
<http://dementiafriendlygurudwaras.com/resources/punjabi/literature>
<http://dementiafriendlygurudwaras.com/resources/english/literature>
- Workshops
 - Dementia Friendly workshops can be a useful way of educating small groups of keen individuals on the basics of dementia. To organize a workshop at your Gurudwara you should contact your local Alzheimer's Society representative who will be able to facilitate this. Those sevadaars wishing to run such sessions themselves can undergo a 1 day training course called Dementia Champions Training, run by the Alzheimer's Society at locations across the country. Places can be booked on their website. Although the workshop is run in English, the content can easily be delivered in Punjabi by individuals who are bilingual.

- Memory Café
 - A memory café is an ideal setting to allow people with dementia and their carers to share their experiences and support each other in a friendly environment. This can be run on a monthly basis with a few dedicated sevadars present to answer any questions and sign post congregation members to appropriate local services. Local Alzheimer's Society representatives can also attend such sessions to improve accessibility to these services.
- Lectures
 - To raise awareness amongst the wider congregation, lectures in English and Punjabi on aspects of dementia can be arranged in the main weekly Divaan at the Gurudwara. These lectures can be delivered by local Sikh healthcare professionals known to the congregation. Alternatively the Alzheimer's Society may be able to provide you with local contacts who can deliver such sessions bilingually.
- Children's classes
 - One of the key aims of the Dementia Friendly Gurudwaras project is to reduce the stigma associated with Dementia. One of the most effective ways of doing this in the long term is to improve education amongst the younger generation. Short 15 minute sessions can be delivered to children attending weekly Gurudwara classes. These sessions can briefly outline what Dementia is and how children can help people with memory problems.

Networking

A number of local organizations will be able to help your local Dementia Friendly Gurudwaras initiative grow and develop.

We would recommend you join your local Dementia Action Alliance (DAA). The DAA is a group which brings together organizations and communities to help them become more Dementia Friendly. By joining your local DAA you will be put in contact with similar organizations in the region where you can share ideas and work together for the betterment of all. To join you local DAA visit www.dementiaaction.org.uk .

The Alzheimer's Society has local coordinators in each region who can provide advice and guidance for your project. To find out whom your local contact is visit: <http://www.alzheimers.org.uk/localinfo> .

The Dementia Friendly Gurudwaras Organization hopes to act as an umbrella organization for local Dementia Friendly projects in Gurudwaras around the UK. By keeping in touch with us we can all work together and share our experiences of helping Gurudwaras become Dementia Friendly.

HOW CAN WE HELP?

The Dementia Friendly Gurudwaras Project offers several services to help you make your Gurudwara Dementia Friendly. These include;

- A review of your Gurudwara with a view towards making it Dementia Friendly
- Providing assistance in developing a workable action plan
- A mentor scheme to provide ongoing support and advice

- “Dementia Friends” workshop delivered in English and Punjabi at your Gurudwara for congregation members including children and sevadaars until such time as local sevadaars have completed their Dementia Champions training
- Full access to our virtual information portal.

RESOURCES

Virtual Information Portal

The Dementia Friendly Gurudwaras organization has developed an online information portal which contains

- Audio podcasts in Punjabi on Dementia-specific topics
- Links to English and Punjabi literature published by the Alzheimer’s Society
- Promotional videos highlighting the background to the organization and its aims and objectives
- Video clips on Dementia Friendly workshops
- Audio interviews of people’s experiences of Dementia in the Sikh community; the good, the bad and the ugly.

REFERENCES

1. Bowes A, Wilkinson H. ‘We didn’t know it would get that bad’: South Asian experiences of dementia and the service response. Health Soc Care Community. 2003 Sep;11(5):387-96.
2. La Fontaine J, Ahuja J, Bradbury NM, Phillips S, Oyebode JR. Understanding dementia amongst people in minority ethnic and cultural groups. J Adv Nurs. 2007 Dec;60(6):605-14.

FOR FURTHER INFORMATION

Please visit:

www.dementiafriendlygurudwaras.com

www.alzheimers.org.uk

www.dementiaaction.org.uk

APPENDIX

Forming a Dementia Friendly Gurudwara Project; Seven Stage Model

