“Chetha Bouljana”

Understanding Dementia Amongst The Sikh Community
October 2014
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Introduction

Working with local communities, talking and listening to people to enable them to share their views about their local health and social care services

What is Healthwatch North Lincolnshire?

Healthwatch is the independent voice for people in our community, helping to shape, challenge and improve local health and social care services. Healthwatch does this by talking and listening to people from every part of the community, and by holding services to account.

As the consumer champion for health and social care, Healthwatch gives adults, children and young people a powerful voice in local services. It works with local people to improve health and social care services and help people to get the best out of those services.

Healthwatch has three core areas of work:

- To provide information and ‘signposting’ to the public about local health and social care services.
- To offer advocacy and support to make complaints about the NHS.
- To involve local people in the provision, monitoring and commissioning of local services by:
  - Obtaining people’s views and experiences (through research, surveys, Enter and View visits, etc...)
  - Making these views and any recommendations known to those involved in commissioning, provision and scrutiny of services and to alert Healthwatch England to these issues.
Introduction

North Lincolnshire Dementia Action Alliance

Dementia Action Alliance
The Dementia Action Alliance (DAA) brings together organisations across England committed to transforming the lives of people with dementia and their carers.

There are 800,000 people living with dementia in the UK. It costs the UK economy £23 billion a year and can ruin the lives of people living with it and those that care for them.

The DAA is attempting to bring about a society-wide response to dementia. At a national level the DAA has begun to shape policy and attitudes.

Locally it galvanises action by coordinating and supporting Local Dementia Action Alliances.

The North Lincolnshire DAA works towards the following standards:

- It believes that people with dementia have the right to a good quality of life and to remain independent in their local community.
- It believes that people with dementia have the right to live well, engage in and contribute to their local communities as long as they wish to do so.
- It will address negative attitudes and raise awareness and understanding of dementia.
- It will support other organisations in becoming dementia friendly.

Communities that are dementia friendly have more opportunity to support people in the early stages of dementia. This allows people with dementia to maintain and boost their confidence and encourages them to retain their ability to manage everyday life.
Healthwatch North Lincolnshire and the Dementia Action Alliance

HWNL Pledge will:

• Raise awareness of dementia at a local level in order to help reduce the stigma of dementia and encourage people in the local community who have dementia or are worried about their memory to seek and be given patience, kindness, understanding and support.

• Help to ensure the person with dementia is not excluded from anything that they would reasonably want to do including encouraging people to use leisure, cultural and spiritual resources in the North Lincolnshire area.

• Promote the Living Well with dementia agenda across the community with the aim of supporting all members of the Alliance and surrounding community to strive for excellence in supporting people with dementia and their carers and creating a dementia friendly community in the North Lincolnshire area.

• Support raising the awareness of Dementia and signpost individuals to the relevant support and services being at a local and national level.

Alzheimer’s UK Dementia Action Alliance Launch Event
22nd May 2014

Healthwatch North Lincolnshire received a recognition award for joining the Dementia Action Alliance and signing up to an action plan that outlines steps for our organisation to become more accessible to those living with a dementia diagnosis or those supporting someone who has a diagnosis.
What has Healthwatch focused on so far?

Dementia Friend
Healthwatch staff members and volunteers attended a Dementia Friend session held in May 2014. Becoming a Dementia Friend gives us a better understanding of dementia and the small things we can do that can make a difference to people living with dementia - from helping someone find the right bus to spreading the word about dementia. Healthwatch North Lincolnshire are continuing to encourage people to sign up as Dementia Friends and holding a further session in October 2014.

Local Alliance/Regional Alliance
Healthwatch Directors are representatives at the Dementia Local Alliance and Regional Alliance meetings.

The Current Picture

Local Population
- There are approximately 2,260 residents of North Lincolnshire living with dementia, with an estimated 608 people developing the condition each year.
- Late onset dementia affects approximately 7% of the North Lincolnshire population aged 65+.
- Early onset dementia is relatively rare, affecting an estimated 2.2% of people with dementia, or an estimated 50 people under the age of 65 years in North Lincolnshire.

Ethnicity
Locally there are estimated to be just 16 people from BME communities that have been diagnosed with dementia living in North Lincolnshire, one of whom with early onset dementia. The proportion with early onset dementia (6%) is higher than it is for the White population, due to the much younger age profile of these communities. As this population ages, we should expect the numbers of people from BME communities living with the disease to grow.¹

¹ Source – Public Health Intelligence Team, North Lincolnshire JSNA, 2014
Purpose of Report
Healthwatch has a responsibility to work with communities, talking, listening and enabling people to share their views, and as such has worked jointly with Alzheimer’s Society to hold a dementia engagement event with the BME community. The primary focus of this event was to raise awareness of dementia services and gain a better understanding of the Sikh communities’ understanding of dementia services, Memory Cafes and the knowledge of the role of Alzheimer’s Society & Healthwatch.

Methodology
A questionnaire was devised which was used as part of the engagement event at the Sikh Community on the 5th October at the Gurdwara on Frodingham Road. Both Healthwatch Staff and Alzheimer’s Society carried out engagement with members from the Sikh community.
Survey Results

There were 23 responses to the survey at the event. None of these respondents had experienced dementia or knew anyone with dementia. Their responses are therefore not based on close personal experience of living with memory problems.

Do you think there is enough information for BME communities about dementia?

There were 5 respondents who felt there was enough information about dementia, with the remaining 18 either not knowing or saying there was not enough information. A recent research report has highlighted evidence of lower levels of awareness among BME groups of the causes of dementia and how it can affect people’s lives.²

In your community, how comfortable do you feel discussing dementia or memory problems with other people?

Some respondents explained how a diagnosis of dementia was kept within the family and regarded as a symptom of older age.

It was felt there could be a stigma attached to dementia. This was also highlighted in the research cited above, where it was found that levels of stigma may exist among Asian communities, sometimes influenced by religious and cultural beliefs. It was also found that BME families tend to be less likely to consider themselves in the formal role of ‘carer’, but more likely to identify with traditional expectations of care giving within the family.

The following comments were made:
• “Tend to keep it within the family and offer support to cope”
• “Stigma may relate to mental health and old age”
• “Might be kept quiet as it is difficult illness for families to cope with”
• “I don’t know of anyone in our community that has dementia”
• “At the temple I could discuss this but would like the temple to organise this.”
• “Our community doesn’t understand dementia”

² Black and minority ethnic people with dementia and their access to support and services – Social Care Institute for Excellence research briefing 35; March 2014
Do you have a way of describing dementia in your own language?

The Social Care Institute for Excellence research also found that in most South Asian languages there is no work for ‘dementia’. Our survey asked respondents if they had a way of describing dementia in their language. Some used a form of words for ‘memory problems’ whereas some had no word for dementia:

- “Memory problems”
- “No”
- “Not really”
- “Out of this world”
- “Chetha Bouljana” (Meaning Memory Forgotten in Punjabi)

How would you prefer to access information about dementia?

Respondents indicated how they would prefer to access information about dementia should they need it. Most people would use the internet or ask a GP, followed by reading leaflets or going along to group meetings.

![Chart showing preferences for accessing dementia information]
How useful are the following in supporting people living with dementia?

Respondents believed that getting support in the home would be most useful when dealing with dementia, followed by information about benefits and financial help and information about living well with dementia. It was felt less useful to meet other people living with dementia and their carers.

Do you think any of the following are a barrier to accessing support around dementia?

It was felt that language would be the greatest barrier to accessing support concerning dementia, followed by a lack of cultural understanding of the condition. It was believed by 8 respondents that stigma would be a barrier to accessing support with dementia.
Before today, had you heard of Alzheimer’s Society?
There were 50% of respondents who had heard of the Alzheimer’s Society.

If yes, have you used the services of Alzheimer’s Society?
None of the respondents had used the services of the Alzheimer’s Society.

Before today, had you heard of Memory Cafes?
Only one of the respondents had heard of Memory Cafes.

Would you be interested in going along to a Memory Café?
There were 5 respondents who would be interested in going along to a memory café, 12 were not interested. 4 respondents did not know if they would be interested.

Which of the following would be important to you when you think about going along to a memory café?
Respondents were asked to consider what they might like to be able to get from going along to a memory café. The most important was getting access to information about dementia, followed by opportunities to get advice. It was felt less important to meet others with dementia and their carers or find out about other services.

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<th>Important</th>
<th>Access to information about dementia</th>
<th>Opportunities to get advice about dementia</th>
<th>Having a drink and a chat</th>
<th>Finding out about other services that can help</th>
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<td>Having a drink and a chat</td>
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<td>Finding out about other services that can help</td>
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About the Respondents

There were 9 male and 11 female respondents. The ethnic group of these respondents is shown opposite.
It was clear from the engagement event and the research findings that much more information is needed about dementia within the BME communities in North Lincolnshire. Raising awareness about dementia with the BME community is vital to improving their access to supporting services. Healthwatch North Lincolnshire makes the following recommendations:

- Stigma may lead to reluctance to access dementia services or to late diagnosis. Healthwatch North Lincolnshire will work with Alzheimer’s Society and the Dementia Action Alliance to raise awareness within the BME community, developing targeted approaches through outreach work.

- Healthwatch North Lincolnshire to raise awareness within the BME community of the word ‘dementia’ and how recognise the signs of dementia and benefits of earlier diagnosis, such as access to dementia specific services locally.

- Deliver Dementia Friends sessions in the BME community in North Lincolnshire which is culturally acceptable and tailored to the local community.