

## PLANNING FOR THE FUTURE

Now it has run several courses on dementia for South Asian families, the Alzheimer's Society is thinking about plans for the future. Quite a few of the areas where the Course has run already are keen to offer it again. The Alzheimer's Society, the local partner organisations and the people who went on the Course all agree that there is also a real need for more information and awareness about dementia within South Asian communities, and are thinking about how this could happen.

- Should local workers put more effort into raising awareness about dementia before they try and run another course for carers, or should they try and do both at the same time?
- Should the Course be just for carers, with other opportunities provided for non-carers to learn about dementia, or should the Course be open to both carers and non-carers who want to learn about dementia?
- Could local community partner organisations learn to run the Course by themselves, or does it work best as a partnership with the Alzheimer's Society?

*"People even said on the last session, 'oh, it's such a shame that this is finishing.' They wanted more, they wanted more information."*  
**Local Community Partner**

The Alzheimer's Society is also thinking about how best to support carers after they have been on the Course. The Society runs carer support groups and dementia cafés, which many carers find a good way of keeping in touch with the people they met on the Course. However, we found from talking to the people who had been on the Course for South Asian carers that most didn't get

involved in these groups. It may be that the Alzheimer's Society and other organisations who run groups like this need to think about how to make them more welcoming and friendly for South Asian carers too, or consider setting up a group just for South Asian carers.



## Introduction

The Alzheimer's Society has developed an Information Programme for South Asian Families (IPSAF). There are 4 sessions in the Course. It covers information about dementia, financial and legal issues, services, looking after someone with dementia, and looking after yourself (as a person caring for someone with dementia). Between November 2014 and February 2015 the Course ran in 9 towns and cities. In each place, the Alzheimer's Society ran the Course with a local South Asian organisation.

*"Honestly, I really can't even describe how important that course was, you know, how much it's helped us, how much information it's given me"*  
**Carer participant**

The Society asked the Bradford School of Dementia Studies to find out what people who went on the Course thought of it, whether it made a difference to their lives and the lives of their families, including the person living with dementia, and how well the partnerships with community organisations worked. Our aim was to help the Alzheimer's Society make the Course as useful as possible for the people who attend.

## Who we talked to

We visited 7 of the Courses which ran in 2014. We invited the people attending the Course to stay behind after the last session, and talk to us in confidence about how useful they had found it. We spoke to a total of 42 people in this way. We also visited 7 people at their homes, and spoke with them and their families about any differences the Course had made. We visited 3 of these families a few months later to find out if they were still finding what they had learned on the Course useful. We also spoke to 9 Alzheimer's Society staff who ran the Course, people from 5 of the community organisations who had worked with the Society, and 2 people who designed the Course. We also ran a 'before and after' knowledge quiz, which helped us understand what people had learned about dementia and support for living with dementia.



We would like to thank all of the people who gave up their time to help us learn about the dementia Course. This leaflet describes some of what we learnt from all these conversations.

## Finding Out More and Contact Details

This leaflet is a summary of a longer report that we have written for the Alzheimer's Society. If you would like a copy of this, please get in touch with either Jan Oyeboode or Jane Mallinson, at the Bradford School of Dementia Studies:

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## What we learned about the IPSAF course

### WHY PEOPLE WENT ON THE COURSE

Between 6 and 17 people went on each Course. Although intended for people who care for someone living with dementia, the people who went were a mix of carers and others who were interested in learning about dementia. The carers liked being able to talk to people in a similar situation, but were also glad that more people were able to learn about dementia. Some of the facilitators running the Course agreed, but others found leading mixed groups difficult, and felt the carers would have got more out of the Course if it had been carers only.

The local community organisations were very important in encouraging people to go on the Course. Often people already trusted these organisations. Staff spent time talking with people they thought would benefit, about how the Course could help them. In some places, it helped that transport and activities for the person with dementia were provided.

*"Until you go and spend some time with a family, see the person with dementia, show them the benefits of what it can bring, it's very difficult to expect people to just turn up"*  
**Alzheimer's Society Facilitator**

## THE DESIGN OF THE COURSE

The Course was specifically for South Asian families only. The people who attended very much appreciated being able to go there with people who understood their particular circumstances. They also liked that the Course was translated, and the materials showed South Asian families as case studies. A small number of those who attended would have liked the option



of attending a mixed group, due to concerns about confidentiality within their close-knit community.

Participants really appreciated the extra knowledge provided by staff from the local organisations. They

understood the culture, and were aware of the ways in which things might be different for South Asian carers, compared to White British families. Many of the facilitators thought it would be helpful to include issues such as the loss of English as a second language, cultural food habits, and prayer practices in the Course materials.

The people who went on the Course were very, very positive about what they learned, though some found the legal and financial information a lot to take in during one session. They would have liked more opportunities to share experiences as well as learn new information. They particularly appreciated talking to and hearing from other carers. The facilitators were also positive about the content, though many would have liked a bit more time to respond to the needs of the group during the sessions. Many participants would have liked more sessions, and were sorry when the course came to an end.

## THE DIFFERENCE THE COURSE MADE TO CARERS' LIVES



The people who went on the Course told us they learned a lot about dementia. Some non-carers felt more able to recognise the signs of dementia as a result. Carers felt they understood the person with dementia better, for example, why they did things such as not eating, or repeatedly walking to and fro.

*"If you don't realise they have an illness, you think they're doing it on purpose. By gaining an understanding of the illness, you feel better, as you realise this person is ill, they can't help it."*  
Carer Participant

Carers also learned a lot about legal and financial matters, and services they could get help from. Not everyone used these immediately, but they were glad to know about them for the future. Carers tended to focus on help with practical issues such as power of attorney and carers' assessments, rather than social support such as dementia cafés. Time is an issue, but it may be that

providing more social support specifically for South Asian families would help.



*"When you experience something which devastates you emotionally, big time, it's so important to find people in the same boat as you."*  
Carer Participant

Through meeting other people in a similar situation, many carers also came to realise that they were 'not on their own'. The Course provided a supportive place where carers were able to talk about their emotions and experiences and learn from one another. This helped some carers feel less stressed.

*"It's valuable for our community and it's helpful that the Alzheimer's Society thought about the South Asian community, and that they picked up that they need that extra guidance; so it's very helpful"*  
Carer Participant

*"There was lots of things, as soon as they said it, everybody just looked and smiled or laughed" ... "oh, you're having a joke, that's not going to happen, but they knew, in the way that they said, yeah, we know that this happens, but you still need to get everyone together. They understood how it happened, didn't they?"*  
Carer participant

## HOW THE COURSE HELPED PARTICIPANTS' FAMILIES

Because carers gained a better understanding of the person with dementia's condition, they were able to change how they cared for their relative. They talked about finding it easier to keep calm because they

*"You speak slower, you use shorter words, like she wanted to go to the bathroom ... and she was like 'How far is it, is it far, is there any steps?' and I'm like 'No it's not far, we've just got a couple of steps, it's just there'; but it's just cutting out, instead of a long sentence, just using the main words, just to give them a bit of reassurance"*  
Carer Participant

could communicate better with their relative, planning a more organised routine, and the importance of helping the person with dementia remain independent. One carer told us how she and her husband had felt able to take her mother-in-law on holiday as a result of the Course, which they had all enjoyed.



Many participants shared what they learned with their families,



which made a difference to their roles as carers too, though family members understandably felt they would have learned more if they had been able to go on the Course themselves.

*"Whenever me and my Mum come back we always tell my Dad straight away everything we've learned. Then when my brothers and sisters come back, we tell them as well ... They think it's quite shocking because they never knew about that, and they think it's coming from you. You go to this session and you tell us. It's really helpful."*  
Carer Participant

## PARTNERSHIPS BETWEEN THE ALZHEIMER'S SOCIETY AND LOCAL ORGANISATIONS

The Alzheimer's Society decided to work with local South Asian organisations to make sure the Course met the needs of the local community, and to make better links with the communities for all their services. These organisations included South Asian health and carers' support organisations and community centres, plus one GP surgery and one mosque. The partnerships worked best where the Course matched the existing work of the local organisation. Where it didn't, the local partner was supportive but less actively involved. As a result, the people who went on the Course in those areas missed out on the community knowledge which other local partners brought.

*"They have taught me stuff and I have taught them stuff, so it has been really good in that way."*  
Alzheimer's Society facilitator

The partnerships worked very well in almost every case. Local partners appreciated that the Alzheimer's Society was trying to meet the needs of South Asian families, and felt that working with a large, well-known organisation was good for their organisation. The Alzheimer's Society got a lot



of help with spreading the word about the Course, and learned a lot about South Asian communities and how to work with them. The partnerships worked well when the staff from both organisations took the time to talk about what they wanted to achieve, and shared their knowledge freely. Good communication, respect for each other's knowledge and skills, and working together on preparation all helped. The training provided by the Alzheimer's Society was appreciated, though it might help to offer facilitation training for less experienced facilitators and some training on dementia for local partners.

In all the towns and cities, the Alzheimer's Society and the local organisations had practical ideas or plans for carrying on working together.

*"Something we're looking at is to hold a few open days here, and try and get people on board, as carers."*  
Local Community Partner