

Mirah's story

- Mirah cares for her husband, Akeem, who has dementia
- Akeem has memory lapses and moments of confusion
- Mirah is trying very hard to take Akeem out as much as possible as she feels it is not good for them being stuck at home all day
- Mirah has noticed that she and other carers of people with different health conditions face a lack of understanding when they are out in the community.

You would think people nowadays would have a better understanding of people with dementia. Just the other day, I went with Akeem to the supermarket and due to the huge queues at the check-out, I suggested it would be better if he sat down and waited for me to clear the check out. You can imagine my panic when I later found he had vanished from the waiting area.

Anxiously asking anyone I came across to see if they had seen him to no avail but a couple suggested checking with the security guard who was totally unhelpful – saying I should ask the customer services to make an announcement for him to come to the desk. He was not even prepared to listen to my explanation that in his state he would not have a clue where the customer services desk was, let alone paying attention to the announcement! I felt so embarrassed with everyone looking at me, particularly as it's my local shop.

I went to the local library last week to see if I could find some information about dementia and any support groups – I'm looking for all women's Muslim group – I couldn't find anything except a leaflet about social services which I didn't really understand very well. When I was there, I saw this mother with a 14 year old son in a wheelchair who had learning disabilities and was being quite noisy and difficult. The mother was trying to gently explain to him how he should behave inside the library. The librarian started asking the mother whether the son was all right and seemed a bit annoyed that he was making a noise. In spite of the mother explaining it was best to talk to her son direct, the librarian leant forward to the son and started speaking to him in a very loud voice as if he was deaf and he just became even more distressed!

Akeem did go along a few times to the local day centre but I ended up taking in his meals with me because he would get upset by the food they served there. In the end I decided it was more trouble than it was worth and gave up on it.

Sometimes I feel society would rather have us carers and the people we care for all cooped up inside the home and not try to lead a normal life.

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questions:

1. why does Mirah feel so embarrassed when she goes into the supermarket?

2. what could the staff have done differently to avoid distress to Mirah?

3. how could the library have met Mirah's information needs more adequately?

4. how could the library have supported the parent carer more effectively?

5. what might we be able to do differently to meet the needs of specific groups of carers, and particularly black, asian and ethnic minority carers?
