Dementia, my family, friends and me

Meri Yaadain CiC

Supporting Black Asian Minority Ethnic (BAME) people living with or caring for someone with dementia

Meri Yaadain

Why might talking about dementia be difficult with family and friends?

Dementia is a taboo subject for many people in the BAME communities. Our friends, close family and wider family will have preconceived ideas and also some ignorances or prejudices about it. Not knowing enough about dementia leads to these perspectives.

Some members of the family may see these changes as deliberate, others may see that you are being possessed by jinns, spirits or some kind of witchcraft or magic. This tends to push carers away from seeking medical support. Friends and wider family often don't know how to talk to you about these changes so they may try to avoid you for fear of causing offence or embarrassment.

Having little awareness of dementia means that family and friends can't have conversations like they can when it comes to other medical matters where everyone seems to have an opinion about the best way to getting medical advice.

A lack of support will also mean your family carers may struggle to support you with outside services, instead trying to manage things at home even if you feel you might be being misunderstood at times.

How can you help yourself?

You can help yourself in a number of ways:

YOU YOURSELF
Don't be frightened or worried about changes in your memory, communication or changes in managing everyday tasks. Speak to a GP for an assessment. Talk to family and friends so they feel at ease to talk with you about any worries you have. Be involved in activities that support physical and mental wellbeing.

FAMILY AND FRIENDS
People do not always know how to approach or to talk to someone with dementia because of ignorance or a lack of understanding. If you are involved in activities that support you living with dementia you can also find it easier to talk to family and friends. You may also want to discuss 'lasting power of attorney' and other decisions about longterm care, preferences and about your finances, a will or inheritance.

USING SERVICES
Using services will help commissioners and service providers to hear what works well in helping you. It will break the myth that BAME families 'look after their own'. Using services will help you learn how to involve family or friends in conversation so that they can feel more at ease in talking to you about your dementia.

Meeting and talking to other people living with dementia will give you a safe space within which to raise anxieties as well as learn coping strategies from other people in a similar situation.

REMEMBER

Dementia is a condition that affects people in different ways depending on the type of dementia. There is also a big difference in your ability to talk to family at friends depending on the stage of your dementia. Some people feel they can live well with dementia, coping as well as they can. Others feel they really struggle with it especially if there is little or no support from friends and family. However, if able to do so, you can take steps to raise the concerns or worries to help family and friends feel that it is ok to talk to you without feeling embarrassed or unsure. This leaflet is designed to give a 'start' to this topic, feel free to talk to us to see how we can help you.

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