



## ***Manjit Nijjar's Story***

- My parents came to England in the 1960s. My Dad came here having served in the British Indian Army. He was the most fearless man I ever knew.
- Dad and I had an incredibly close relationship; in fact I'd say he was my best friend growing up. When I was 15 or 16 years old the spectre of marriage was on the horizon and my friends were all getting engaged. Instead of encouraging me to follow suit Dad pulled me to one side and said
- "Manji, I think it's about time you ran away from home!"
- In late 2004 it became glaringly obvious something was wrong. Mum and I had gradually adjusted our lives to accommodate Dad's changing needs without even realising it. Dad had gone to bed and suddenly started shouting and banging saying he wanted to get out but he couldn't find the door. Dad had become afraid of the dark. He never slept in his bedroom again.
- 2005 followed in the same vein. In February Mum was diagnosed with terminal cancer and given less than 6 months to live. In May Dad was given a preliminary diagnosis of Alzheimer's and vascular dementia. In June Mum died.
- None of my Dad's friends would accept that he was ill. They would cross the street to avoid him causing more distress and anxiety, as he did not understand their behaviour. As far as they were concerned he was cursed and had bad karma.
- The fact that he had been an active member of the community for over 40 years became irrelevant and all the support he needed after Mum's death evaporated.
- On one hand I couldn't really blame Dad's friends as they didn't understand what dementia was. You see there is no word for dementia in the Asian languages. So the word mostly commonly used to describe dementia is the same word for insanity. As far as they were concerned Dad had become infected with madness and it is not only contagious but also could be hereditary.
- It did not, however, stop people from giving me remedies to cure him including rubbing his head with almond oil, putting almond oil in his tea, and putting turmeric in warm milk for him to drink.

- I have to admit that I had special prayers said for him both in India and in a local Gurdwara, partly in hope of a cure and partly because of our faith. He was Dad and I needed him especially as Mum had just died.
- Dad had always been a religious man so I would take him to our local Gurdwara. He needed assistance with eating so I would feed him Prasad, which is the Sikh equivalent of the Holy Communion.
- On one particular occasion the congregation had left but I was still feeding Dad. The priest came and turned off the lights.
- So there we were, Dad and I sitting in the dark all alone. This summed up for me what it was to be Asian, have dementia and to be a carer. In a flick of a switch we were became invisible and worthless. It was an incredibly lonely and isolating time for us.
- Trying to access day care services for my Dad brought it's own problems. After all don't "Asians take care of their own?"
- There is a perception amongst statutory bodies that Asian communities don't use services because of extended family networks. Well my brother lives in Canada and we have no family living in the U.K. Even if I had family here there is nothing to say that they would have cared for Dad.
- In that sense are we any different than any other community living in the U.K.?
- The reality was that I felt condemned by the perceptions of the Asian community and those of the statutory bodies which meant that I had no one to turn to, no support at a time of great need. To have had someone to listen to me and help me would have allowed me to focus on Dad and support him better.
- Day care became very important to me because I was working full time and I was worried about Dad's safety as he wandered around the streets of Wolverhampton. It wasn't until Dad had been beaten up and been hit by a car before I got the full day care provision for him. I could finally breathe knowing that he was safe. I knew Dad better than anyone else and what he needed was to be at home. All Dad and I needed was more support at an earlier stage to avoid the inevitable crisis upon crisis that rained down on us.

- To compound the issue when dad was finally allocated a day care I was asked “Why have you ‘thrown your father away’”? by members of the Asian community who knew him. Even though Dad has now gone I am constantly being told that I have failed him.
- Caring for Dad has changed my personal and professional life. I decided to make a difference by working in a third sector organisation, with the Asian community in Wolverhampton. In my job I am trying to provide the support that Dad and I lacked so desperately. This involves raising awareness of dementia, helping carers by providing support and advice in a culturally appropriate manner. There are no flashy gimmicks or lavish productions here.
  - It’s about opening the hearts and minds of Asian people through information.
  - Breaking down the prejudice and tackling the fear associated with dementia
  - Showing pictures of a healthy brain compared to one with dementia.
  - Emphasising that dementia is a physical illness not a mental health problem or madness.
  - Where appropriate talking to the whole family and not just to a couple of members
  - Providing Caring and Coping with Loss in Dementia for Asian Carers by Asian carers.
  - Trying to reduce the stigma of day care by encouraging older carers to attend day care services with their spouse so it’s a day out instead of an issue of abandonment.
  - Working with Statutory bodies to improve services.
- In this time of austerity when services are being cut and carers find they are fighting for everything, hard to reach communities become harder to reach. The fear of dementia and all that it can mean for a community can lead to greater isolation. The people with dementia and their carers within those communities become more marginalized and less visible.
- There are pockets of really good work being done across the country by statutory and third sector organisations.  
So the questions I would like to ask you are,
  - Who is doing this work in your area?
  - And
  - Can we do this work together and do it better for the people who matter?
  - Maybe this is your opportunity to bring your light in to their darkness.
  - The photo behind me during my talk has been that of my Dad, my brother and me when the only darkness in our lives came when the sun went down.