Alzheimer's Society
Leading the fight against dementia

Living with dementia magazine June 2010

46-year-old Michael Tuton has been caring for his mum, Molly, for the last eight years. Last month, he was crowned Dementia Carer of the Year in the Daily Mail's Carer of the Year Awards 2010.

In 1998, while on a visit home from Canada to see his family, Michael Tuton went shopping with his mum, Molly. They were in a clothes shop when Molly turned to Michael and said, 'Hello! How lovely to see you!'

It was the first indication that something was wrong. It soon became apparent from conversations with his family that Molly had been showing signs of forgetfulness for some time, but his father had been covering up the problems.

Four years later, Michael left his job as a promotions manager in Toronto to return to Hull to care for Molly, who had by then been diagnosed with Alzheimer's disease. The youngest of six siblings, Michael said,

> 'There wasn't a lot I could do in Canada. I was relying on other family members to help Mum and everyone had such busy lives.'

In 2001, Michael's father, Wilf, died. That was when he decided to move home. He said,

> 'I was going to work in London and offer financial support, but my sister Sue was at breaking point and I just said to myself, "Right, I'm moving in." I made the decision in about half an hour. Little did I know that eight years later, I'd still be doing it!'

Sue

Michael's sister, Sue, nominated Michael when she read about the awards in the paper. She says,

> 'Michael looks after mum wonderfully well and I wanted him to be recognised for the great job he's doing. He really is our unsung hero.
>
> He's taught himself all there is to know about dementia and he does everything he can to make mum's life pleasant. I think mum knows he's doing all he does for her because she smiles away when he comes into the room. I'm always praising him, but he'll just say, "Well, she's my mum."

Challenges

Among the things Michael has found difficult over the years is the way people react to him being a carer. He says,

> 'There was a lot of suspicion from people when I started to look after mum. People seemed to be questioning my motives and I was quite offended. It didn't seem a strange thing to do at all to me. Mum was a nurse all her life, and I think I've inherited her caring side. I get a lot of pleasure from seeing her happy and knowing she's comfortable.'

Michael's approach to caring for Molly is pragmatic. He says,

> 'I've treated caring for mum like anything in life, as another challenge. I've adapted as changes have happened. I've had to learn how to change her continence pads and buy her clothes and her underwear. You can't be embarrassed, you've just got to get on and do it. That's the way I look at it.'

Dealing with the crises

Michael says,

> 'A big crisis point was the time when mum got stuck in the middle of the stairs. She just couldn't move. I looked into what we could do and found out we could have a stair lift put in. When she lost mobility, we had a walk-in shower and a hoist fitted.'

Another crisis point was in 2004 when Molly caught pneumonia and lost the ability to swallow. Her weight plummeted to four and a half stone, and the family thought they would lose her. After six weeks in hospital, she was back at home. Michael was trained to use a nasal gastric tube. Six months later, a PEG tube was inserted into Molly's stomach and Michael now feeds her this way. Again, he took this development in his stride.

Each night, he gets up every few hours to turn Molly in bed so she doesn't get bedsores, and pats her back to clear her throat.

Communicating

Michael says,

> 'The thing I miss most about mum is her voice, but we have our ways of communicating. Mum's always been a touchy feely type. The little finger sticks out on one of her hands, and sometimes when I'm helping she holds my finger with that little finger and squeezes it so tight. It's the only thing she has control of now and I think it's her way of connecting with me.'

Michael was presented with his Dementia Carer Year award by TV Presenter and Society Ambassador Ruth Langsford at an awards ceremony in London on 11 May. He said,

> 'Caring is like a job that never ends, but you just adapt. No one does this for the adoration or the money. People do it for love.

Family ties

When Ian Brady developed dementia aged 56, his family didn't know which way to turn. For the last three years, his sons, sister and nephew have been muddling through to ensure Ian is well cared for and happy, though it hasn't been easy.

John, 32, eldest son

'The first year we found out about dad's dementia was incredibly difficult. I'd get frustrated when he wasn't doing things he'd always do, and no one knew what was going on.

It was such a relief when we found out the diagnosis. But finding support has been hard. Dementia isn't just something you get when you're 85, and services for younger people with dementia are virtually non-existent.

I've tried to take responsibility for finding out the financial side of things and benefits, but there are still lots of things we haven't found out.

Everyone is doing what they can but we all have commitments. I'm married with two children and work full-time, but we see a lot of dad at weekends and involve him in everything we do.

Sometimes you forget how he used to be, but we still have him, and you just want to make the most of what you've got when you've got it.'

Martin, 30, middle son

'I didn't used to have a very good relationship with dad, so I wasn't involved at first in helping out, but eventually I just bit the bullet and got on with it.

I think what I've found most difficult about the situation is the feeling of the unknown, of trying to prepare for tomorrow but not knowing what tomorrow's going to bring. In the last two years there's been quite a rapid deterioration from dad being socially interactive to no longer being able to join in conversations.

Fortunately, we all live close by and everyone muscles in. We used to have a rota, but as dad's dementia has progressed and personal hygiene became an issue, we decided to

get a live-in carer, Val, who moved in last month. We're not admitting defeat but we need more support than we're able to offer ourselves now.

One of the positives that have come out of this is that we all spend a lot of time together now. Dad's massively into sport so we take him out at weekends as much as possible and watch sport together. We've never been closer.'

Stuart, 28, youngest son

'I moved in with dad in 2009 but had to move back to London recently to finish my studies. When we lived together, I'd dress and undress him, put him to bed, and then get him up before I went to college. We had a routine and all took it in turns to cook in the evening.

I find getting the balance right difficult in terms of having time to yourself and doing enough for dad. I'm studying for a law conversion course and want to become a barrister which is a very difficult thing to do. All the time I was working on the computer I was aware dad needed occupying and I didn't have time to be as accommodating as I wanted to be.

Moving to London was a difficult decision to make because you feel selfish, but we had Val in the pipeline thankfully and it's been a big relief having him on board. The big worry is the situation changing again, so we've had a look at some care homes locally just to be prepared.'

Eileen, 56, Ian's sister

'It's been very hard coming to terms with the situation. I changed my hours at work so I could come in and shower and shave Ian and get him dressed and give him his medication, but we found him eating raw sausages one day and things like that obviously cause us to worry.

I worry about the future as I don't know what it will hold. The most important thing for us all is ensuring he's happy.'

Patrick, 17, Ian's nephew

'Thursday is my day with Ian. I only live over the road so I'll go round to his house and we'll go into Hertford and buy something for dinner. He knows a lot of people from playing sport and he still recognises people.

When we're walking through town every second person says, 'Hi'. Sometimes he forgets his keys and he'll ring me and I'll let him in or he'll come back to my house, so it helps that we live close by.

Making inroads

By Caroline Graty

The Society in Hackney is working with local organisations to develop peer support networks for the borough's minority ethnic communities.
Hackney is one of the most culturally diverse boroughs in London. People from all over the world have made it their home, and more than 100 languages are spoken in the area.

This rich mix of cultures has created a challenge for Alzheimer's Society - how to encourage people in black and minority ethnic (BME) communities to use dementia services.

Julian Lloyd is the Society's locality manager for North East London. Julian says,

> 'There are some communities we have never been able to access, and we know they are under-represented interms of the numbers of people with dementiagetting a diagnosis and support.'

Working closely with local health and social care service commissioners, Julian and his colleagues put together a proposal to the Department of Health. They received funding to establish culturally appropriate peer support networks for people with dementia and carers from different countries and cultures. The project is one of 40 pilot sites (known as demonstrator sites) set up following recommendations in the National Dementia Strategy for England.

Barriers to support

There are several reasons why people with dementia and carers from BME communities often don't receive the help they need. Some communities have no concept of dementia, or believe it is an inevitable part of ageing rather than a disease. Often dementia carries a stigma that deters people from seeking help. And for those who do seek help, language is often a barrier.

In addition, some communities have a strong tradition of looking after older people within extended families. Families will cope with the care of a relative with dementia, often only looking for support when a crisis occurs.

The project's peer support group facilitator Amy Claringbold is working hard to break down some of these barriers. Her approach is to build relationships with local organisations that already provide

services within the different communities. Amy says,

> 'We bring the dementia expertise, they bring the language skills and knowledge of their individual community.'

Ways of working

The backing of key community figures is vital for the project's success. One example of this is within the Muslim community. Amy says,

> 'I was advised to write a script for the Imam to read out in the mosque, explaining that we wanted to hear from people with memory problems. With the Imam's blessing, it becomes more acceptable for people to come forward.'

Because many people within BME communities know little about dementia, much of Amy's initial work has focused on raising awareness of the illness through talks and workshops. As some languages don't have a word for dementia, or the words they do have carry very negative connotations, Amy is careful to talk about memory loss rather than dementia.

Although still in the early stages, the project is showing the value of tapping into existing networks and tailoring services so that they are sensitive to different cultures.

So far, so good

- The project has formed a Caribbean Memory Group in partnership with the Hackney Caribbean Elderly Organisation, which advised Amy about suitable activities. Amy says,

  > 'People love talking about the islands where they grew up, so we do a lot of reminiscence and memory exercises and quizzes with a Caribbean theme.'

- In partnership with the North London Muslim Community Centre, Amy is setting up a support group for Asian men. Single sex groups are appropriate for the cultural traditions of the community. In the longer term, Amy aims to establish another group for Asian women.
- Amy has been working with Hackney's Turkish and Kurdish community in partnership with the Alevi Cultural Centre. 'We are setting up a group for people who are worried about their memory to try to encourage them to access the memory clinic. We want to get people on the right track towards diagnosis, treatment and support.'

- Amy is beginning to build relationships with the Orthodox Jewish community, traditionally a very self-contained community, with a view to co-facilitating a group.

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