

## Dementia and day care – supporting the partnership of care

*by Margaret Dangoor*

As Research Involvement Manager for the **MODEM project** in the Personal Social Services Research Unit (PSSRU) at LSE I am responsible for ensuring that people with dementia, their carers and the wider community are involved with MODEM, 'modelling outcome and cost impacts of interventions for dementia', at all stages of the 4 year project. I chair the reference group of users, carers and professionals who work at the front line of dementia care.

Dementia Awareness week having just passed and **Carers Week** being held this week, I am reminded quite how many years I have been travelling with my family members on the 'dementia journey' and how that journey has been helped or hindered. During Carers Week and as a local Ambassador for Carers UK I will be promoting the interests of carers at one of our local health centres and will also be attending a local annual carers' conference.

My journey as a carer has been rich in the friends and experience I have gained as a member of the dementia and carer community; much has been positive although there have been tough times, particularly more recently as my husband, Eddie, has moved into the advanced Alzheimer's stage and my sleep is somewhat curtailed by attending to Eddie's needs and his endless 'mantra' of repetitive phrases which can go on well into the night and even into the early hours of the next day.

Eddie first started to develop signs of Alzheimer's around 2006, when I was still driving regularly up and down the M4 from Richmond upon Thames, visiting my mother living at her Bath nursing home; she also had Alzheimer's Disease. She was in her mid 80s when she first showed signs of memory loss and she eventually died in the nursing home aged 102. It was her choice to move into residential care when she was no longer able to live on her own after my father died. She had wanted to stay in the town where they had lived and where she could keep in touch with the community and her friends for as long as possible. We were very fortunate that the nursing home management was excellent, the staff very caring to the end of her life. For my mother, residential care was her choice and it was right for her.



Margaret and Eddie

Eddie developed his memory loss at a younger age, in his mid 70's; he is now 84. His dementia journey has been more rapid than my mother's with a steady decline mentally and physically following formal diagnosis in 2008. While my mother retained her strong personality and her need to feel she was in control well into her dementia journey, Eddie quickly became passive and dependent. There is a book written by Oliver James called 'Contented Dementia' and certainly, for the majority of the time, as long as Eddie feels safe and secure within a familiar environment he appears very contented within himself.

We live in the outer London Borough of Richmond upon Thames and since the introduction of the National Dementia Strategy in 2009 the borough has been active in working to implement the objectives of the strategy. In spite of diminishing financial resources the borough has been innovative in its support for the development of **change**

of services and activities for people with dementia and their carers and is working to develop a dementia friendly community.

Adelina Comas-Herrera, Research Fellow within PSSRU at LSE and Academic Project Manager of the **MODEM project** has described in her **blog** a recent visit she made to **Memory and Company**, 'a fantastic "Alzheimer's Health Club" in Ontario (Canada)'. Although not so innovative and more in line with the traditional model, we have in Richmond an excellent intensive day centre for individuals with moderate or advanced dementia. Over the last few years the centre has benefitted from extensive refurbishment and it provides a comprehensive range of activities. There is also an increasing two-way connection with the wider community. Our borough is divided by the River Thames and recently a new smaller centre, specifically designed for people with dementia has been opened. This centre run by a local charity has improved accessibility for people living the other side of the borough.

Within the provision of local services and activities for people with dementia and their carers and influenced by my first hand experience, I am a firm supporter of a dementia care community day facility being available and accessible for individuals to attend if appropriate to their needs. A day care facility is particularly important for those people with dementia living on their own. They can enjoy the stimulus of being within a community environment and participating in different activities. As with all the individuals attending the centre, their general health and wellbeing, nutrition and hygiene can be discreetly observed or attended to. Even for individuals with carer support at home, a community facility can be life enhancing for both the cared for individual and the carer.

Eddie became quite passive fairly early on in his dementia journey. As he became increasingly dependent it became difficult to find activities that motivated and interested him. He eventually started attending the day centre, increasing the days as time went on. His regular attendance at the day centre has very much enhanced his quality of life and he has always been actively encouraged to participate in a range of activities by the staff. My experience is that people with dementia require continuity in their day-to-day life and need people around them who through familiarity, understand their individual needs. When Eddie was more articulate he used to talk about feeling safe, either with me or at the centre, his way of expressing that he was content within the environment in which he found himself. As his condition has deteriorated, the staff are able to assess his day-to-day requirements, an assessment built on their experience of caring for him and an understanding of Eddie's personality. Now, at an advanced stage of dementia, with much reduced ability to communicate his needs, with mobility problems, sometimes incontinent and generally frail, he still appears content within his world. He no longer knows who I am, or the individual staff at the centre but we are somehow familiar to him. He quite frequently still expresses his feelings by looking seriously at the individual caring for him and saying with quite an expressive gaze for him 'I like you'. I used to ask him why he liked me and he said 'You are a nice person and you know what to do' or alternatively 'You are a nice person and you look after me'. Quite enduring, and the expressions of content make the caring responsibilities much more rewarding than if one receives no response or where the individual with dementia resists care. I am not the only person to whom he has made the same comment, including staff at the centre!

How much better it has been for Eddie over the years to be able to benefit from a community environment in which he feels secure and can participate in regular activities, than trying to organise stimulating activities on a daily basis at home. How great it would be if the type of centre that Adelina visited in Canada was to influence the future provision of day care in England. Such a centre would help to 'normalise' the dementia journey and could bridge the gap between health promoting preventative services for older people and services that provide more intensive supportive care for those who need it. At our centre there is hairdressing, chiropody, physiotherapy and occupational therapy, apart from all the leisure facilities. Coordinated, integrated care is the model of the moment. Why not be truly innovative and break down the artificial barriers between the normal process of ageing and increased frailty and the elderly with intensive care needs?



What I have learnt from being with people with dementia and their carers is the obvious but sometimes forgotten fact that we are all different with different needs and expectations. However there are some common 'themes'. The dementia journey is progressive and the carer will inevitably take on increasing responsibilities as time goes on. There is no denying that it is not an easy journey but it can be smoothed out to some extent, given the right support.

I am a Dementia Friend and a Dementia Champion. This national initiative has helped to improve awareness of dementia in the community generally. Also, the constant press focus on the demographics of an increasingly elderly population and the likely incidence of dementia has made people more aware that they will come into contact with people with dementia in their day-to-day lives. The Dementia Action Alliance initiative, where organisations are asked to make a commitment and sign up to becoming dementia friendly communities is another positive step but there is still a long way to go before someone caring for a person with dementia can really see a difference in day-to-day life.

In this blog I have concentrated on my experience of day care but this is only one example of activities for people with dementia and their carers that I have been involved with. I facilitate an 'experts by experience group' for carers of people with dementia at each of our two local Caring Cafés and the enormous benefit we enjoy from sharing our experiences with our peers is often said by individual carers to be the most important aspect of any carer support they receive. The Caring Cafés are run by the local branch of Crossroads Care with input from the Alzheimer's Society. There is so much benefit gained from sharing experiences and sometimes gently nudging a carer to let go a bit and share their individual caring responsibilities with others when they are able. We can exchange useful information and ideas about how to cope with different issues as they arise. More than one carer has said that attending the peer support group 'has changed my life'. None of us choose to become carers and we don't always like to admit we are carers. Some do not find the caring role at all easy and can find it very difficult to cope. At least sharing one's experiences makes one feel one is not alone. Dementia can be such a long and lonely journey.

I could write much more about all the activities that can enable people with dementia and their carers to feel that people do care out there in the community. As an Alzheimer's Society volunteer I regularly accompany a group of people with dementia and their carers to a monthly 'In Mind' session for people with dementia held at the Royal Academy. How much pleasure it gives to the participants to attend a session together where they can share a tailor-made experience run by the RA in-house artists for people with dementia. Travelling by mini-bus makes this a possible experience for those with both mobility and cognitive limitations. For individuals who find the trip to the RA just a step too far, art classes and broader art experiences are now held at Orleans House Gallery in Richmond.

My experience of being a carer, not only for my husband but my mother before him and my sharing of that experience with many others, including my experience in my role as an Ambassador for Carers UK, motivates me to raise awareness of the enormous value to the community of informal and family carers. This army of carers underpins any health or social care support that people with dementia might receive along their journey. My view is that people with dementia and their carers are a partnership on a difficult and often long journey and they need to be seen as such as they are dependent one on the other. I am dependent on Eddie because my life is affected by his needs. My life is affected physically, mentally and socially, both positively and negatively. Eddie is dependant of me to support his needs and to ensure the best day to day quality of life that I can, given his limitations.

Many carers of people with dementia are elderly and not in the best of health. I am constantly humbled by the care that people give to their partners in very difficult circumstances, coping with their own significant health issues and their other responsibilities outside the caring role. The provision of support for one partner is also supportive to the other. Community services which enhance the lives of people with dementia and their carers do not necessarily demand significant resourcing. Among a variety of support services for people with dementia it is possible that in the



future imaginative community day care facilities may come back into fashion as an economic option, providing quality experiences for people with dementia in a safe environment; I do hope so.

### About the author

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