Open Doors for People with Dementia
By Mike Howorth, Cathy Riley, Gillian Drummond and John Keady

Salford is a city in close proximity to Manchester in the Northwest of the United Kingdom. Salford has a fascinating social, economic and cultural history. For example, it was from observing and being amongst the working class people and environment in Salford in the 1840s that Fredrich Engels and Karl Marx drew inspiration to publish ‘The Communist Manifesto’. In many ways, Salford’s solidly working-class culture continues to this day. Whilst the nature of ‘mill working’ and its relationship to ‘heavy industry’ may have changed over the intervening years, Salford continues to have many socio-economic challenges and higher than national averages for vascular disease, including vascular dementia.

However, Salford also offers a close-knit community and commitment to older people and service development. It was from this commitment that Open Doors was first conceived with a set of values and a vision (see box on page 2). Gill, Cathy, and John were all part of the planning team that developed the Open Doors Network Facilitator’s post, but from the outset we were all clear that we wanted to purposively employ a person with dementia in the National Health Service (NHS) to lead and develop their own network. It was believed at the time, and still is today, that people with dementia should be empowered to lead, develop, and innovate their own services and support networks.

It was in early 2010 that Mike Howorth, a retired NHS orthodontist in his early 80s, stepped forward to take up the part-time post and position of the Open Doors Network Facilitator. Mike was diagnosed with Alzheimer’s disease in 2007 and at the time he was looking for an opportunity to give something back, to contribute to life outside the home he shared with his wife. Being the Open Doors Network Facilitator made this possible whilst also allowing Mike the flexibility he needed to shape services, networks, and information for people with dementia in Salford in an image he wanted to reflect. In his role as (continued on page 2)
Open Doors (continued from page 1)

the Open Doors Network Facilitator, Mike has spent the last two years building networks across the city of Salford and beyond, undertaking a variety of tasks and (self-imposed) duties in this process. Mike has become an ‘expert patient’ and positive role model for people with dementia at the time of their diagnosis, and acts as an inspiration to others attending the local NHS memory assessment and treatment service. Mike has also taken a lead group’ and a ‘post-diagnostic group’, both innovations grounded in peer support, but with the friendship groups situated around the city to enable community access through public transport.

Whilst all of the above initiatives are important, one of the unexpected benefits of Mike’s return to work after 15 years in retirement has been an increase in his overall feelings of well-being and in confronting, and overcoming, some life-long social anxieties and fears, including public speaking. Mike also acknowledges that it was initially a ‘big challenge’ to instil in others with a new diagnosis of dementia a sense of hope and to see that his own contribution to that person’s life was positively framed and of value (Howorth et al. 2012). This validation was borne out in a testimonial to Mike from a lady who had recently been diagnosed with dementia:

“When I was first diagnosed, I was very much in denial about my condition. The Open Doors network has fully supported me and others who attend. Mike, who

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facilitates the group, has brought me out of my shell to discuss openly my fears and concerns. Knowing that Mike, having dementia, is able to understand and empathise with us, means so much.”

From the time of his initial diagnosis, Mike has been determined to find out as much as possible about Alzheimer’s in the hope that he would be able to slow down its progression. This thirst for information has been achieved by reading journal articles and books. He has what he respectfully refers to as ‘the book’ (Snyder, 2010; Living Your Best With Early-Stage Alzheimer’s: An Essential Guide), which is a publication full of advice for those with a recent diagnosis. ‘The book’ was so helpful to Mike at the start of his own journey that within various Open Doors meetings and ventures, Mike will often discuss one or two chapters from ‘the book’ to explore if any attendees have similar problems or issues. It’s part of Mike’s overall belief system that disseminating good quality information to others with the diagnosis is the first step in helping to confront and overcome problems and thereby live well with the condition.

In the NHS and in Salford, Mike has shown himself to be a tremendous service and resource asset. His motivation and energy is infectious. He constantly challenges the professionals around him with his quest to bring an end to the stigma that surrounds the diagnosis and the need for people with dementia to be included in decisions about their lives. It takes a special person to dedicate this precious time of life to the good of others and to the good of people with dementia and their families as a whole. And Mike is a very special person.

For more information about Open Doors, email Cathy Riley at: Cath.Riley@gmw.nhs.uk


British Physician with Alzheimer's Creates Informative Website

Dr. Jennifer Bute was a General Practitioner in the UK, before she had to retire due to developing Alzheimer’s. She had also been a caregiver to her father with Alzheimer’s. Since her own diagnosis, it has become her passion to help people understand dementia, and to reduce the stigma and hurt associated with it. She recently filmed a series of brief teaching videos covering ten different subjects related to dementia including a medical overview and a series of practical tips for managing symptoms. You can view her excellent videos on her website at: http://gloriousopportunity.org/

There she also provides many informative handouts and slide presentations that can be downloaded free of charge.

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Help is a Phone Call Away
Alzheimer's Association
24/7 Helpline

Anyone living with Alzheimer’s, or those who are providing support, know that daily life can often be unpredictable. Questions or concerns about how to manage memory loss or other symptoms can arise at any time of the day or night and don’t always comply with the usual business hours.

The Alzheimer's Association Helpline, 1.800.272.3900, provides a 24-hour a day, seven days a week helpline to provide reliable information and support to people with memory loss, care partners, health care professionals, and all others in need of assistance. Trained and knowledgeable staff answer questions and concerns regarding memory loss, Alzheimer's and related disorders, medications and other treatment options, and general information about aging and brain health. Staff guide individuals on how to provide and find quality care. Callers can also seek help with legal, financial, and living-arrangement decisions in addition to referrals to local community programs, services, and ongoing support.

The Helpline can provide confidential care consultation by master's level clinicians who can help with decision-making support, crisis assistance, and education. A translation service can accommodate calls in 170 languages and dialects.

NEW RESOURCE
Living with Mild Cognitive Impairment
By Nicole Anderson, PhD, Kelly Murphy, PhD, and Angela Troyer, PhD

In recent years there has been greater emphasis on detecting memory loss and other changes in cognition (thinking) at an early stage. A diagnosis of Mild Cognitive Impairment (MCI) is made when problems in cognition are greater than normal for one’s age and education, but not significant enough to interfere with independent daily functioning. Over time, MCI can develop into Alzheimer’s or a related disorder.

Although symptoms may be mild, people living with MCI must make many adjustments. Living with Mild Cognitive Impairment is the first comprehensive resource to address diagnosis, management, and treatment of the condition. Some readers may be overwhelmed by the breadth of the book (over 350 pages), but much of the text is written in a friendly and informative tone that can appeal to both professionals and families. For persons with MCI, sections two and three of the book provide the most helpful chapters on managing symptoms and making lifestyle choices to improve daily living and possibly reduce risk of symptom progression.

Living with Mild Cognitive Impairment is an impressive resource that combines cutting edge science with encouraging practical advice. It will stand the test of time as an invaluable go-to guide for this increasingly important topic.
RESEARCH UPDATES

ADNI 2 Now Underway

The Alzheimer’s Disease Neuroimaging Initiative (ADNI) began in October, 2004 as a landmark study that gathered and analyzed thousands of brain scans, genes, and biomarkers in blood and cerebrospinal fluid (CSF). The original goal was to define biomarkers for use in clinical trials to determine the best way to measure effects of Alzheimer’s disease (AD) treatments. The goal has since been expanded to using biomarkers to identify AD at the earliest stage even before outward symptoms are evident. Brain imaging techniques such as positive emission tomography (PET) and structural MRI are showing scientists how the brain’s structure and function change as AD begins and progresses. Scientists are also looking at levels of beta-amyloid and tau in cerebrospinal fluid. Abnormal amounts of these proteins in the brain are hallmarks of AD. These biomarkers are also revealing other changes that could identify which individuals with Mild Cognitive Impairment will go on to develop AD.

ADNI2 extends the work of ADNI1. The overall goal of ADNI2 is to determine the relationships among the clinical, cognitive (thinking), imaging, genetic, and other biomarker characteristics of AD. This study will look at changes along a spectrum from normal aging through very mild symptoms, to mild cognitive impairment (MCI), to dementia. The study will contribute to increased knowledge about all phases of MCI and AD and the development of better clinical and biomarker methods for early detection and for monitoring symptom progression. This knowledge will also help with facilitation of clinical trials to slow disease progression or ultimately to prevent the onset of AD.

For more information about enrollment in this study and for sites across the United States and Canada, see:


International Report on Stigma

Alzheimer’s Disease International (ADI) recently released a report titled “Overcoming the Stigma of Dementia” that reviews research on the experience of stigma and dementia around the world. To learn more about stigma, ADI carried out an anonymous online survey among people with dementia and their family carers. Over 2,500 responses were received from 54 countries. Nearly two out of three respondents felt that there was little understanding of dementia in their country and that this contributed to misunderstanding or stigma about the condition. The report also discussed concerns people have regarding disclosing the diagnosis to others. Although 66% of survey respondents with dementia said they have made friends who are connected to dementia in some way, many reported experiences with friends or family who have pulled away due to the dementia.

The report also provides ten key recommendations to overcome the stigma of dementia and urges world-wide progress in this area. Read or download this important and illuminating report at:

http://www.alz.co.uk/research/world-report-2012
Walking and Hiking with Early-Stage Memory Loss

By Anita Souza

Recent research suggests that both exercise and socialization are important ingredients in living a quality life with Alzheimer’s or a related disorder. Besides, getting together to walk and talk can be just plain fun! The Western & Central Washington State Chapter of the Alzheimer’s Association has recently begun offering two programs aimed at promoting walking and hiking activities for persons with early-stage memory loss and the initial response has been enthusiastic!

Our hiking programs are geared to younger-onset Alzheimer’s participants who value the chance to meet others under age 60 who are living with memory loss. Two hikes took place over the summer in regional parks and included lunch and socialization after the hike. These hikes were sponsored by Seattle Parks and Recreation. Participants hiked with an accompanying care partner, or those who were unaccompanied were paired with a volunteer who joined in on the walk. We were excited to fill a need in the young onset community. There are just too few programs out there that address their needs. The hikes will be seasonal and we are in the process of scheduling our next outings for this group.

Our walking program takes place in Seattle’s Woodland Park Zoo and is in partnership with Seattle Parks and Recreation and the Greenwood Senior Center. These organizations worked together with our Alzheimer’s Association chapter on all aspects of program development including volunteer recruitment, training, and site coordination. The zoo provides a nice paved path that people can walk on continuously with very few distractions, aside from the beautiful scenery and the interesting animals.

The first session of the walking program provided us with feedback from participants and we learned some important lessons. Participants requested two separate walking groups - one for those who like to do speed walking and another for more moderate-paced walkers. Our generous program volunteers who accompany participants on the walks make this possible. Without them, it would be difficult to meet the varied needs of the group.

The two zoo walking groups meet together at the end of the walk to socialize in the zoo cafe. These walks will go until mid-November and then we plan to take a break until after the New Year. Rainy (and sometimes snowy) weather can pose challenges in our winter months, but our participants are excited to continue meeting, rain or shine. We hope to continue the zoo walks as a standard program. However, it will be time limited to 7-week sessions and then participants can sign up again for another series. This gives staff a chance to address the needs of individuals who may no longer be appropriate for this early-stage program, and help them access others activities.

For more information about these walking programs, contact Anita Souza, Early-Stage Memory Loss Coordinator at 206-529-3868 or asouza@alz.org.
Heading into the New Year with a Positive Outlook

As the year comes to a close and the New Year is ushered in, many people take this time to reflect on what is most important in life. Some will make resolutions for the year ahead, while others may take a moment to consider what they are grateful for so they can bring in the New Year on a positive note.

The following reflections are inspired from participants in the weekly early-stage memory loss group at the UC San Diego Shiley-Marcos Alzheimer’s Disease Research Center. Perhaps their reflections and resolutions can inspire your own!

“Starting out positive means not being as critical of myself and hopefully others won’t be as critical of me, too.”

“I want to take my life back and get organized. I want to know where I’m going and do my own scheduling.”

“I’m going to continue to come to the support group every Wednesday at 10:30am! It’s the best part of my week.”

“If you think about the positive, you will have a better day. I plan to end each day with time to reflect on what is right in my life because sometimes I get too caught up in what is going wrong.”

“Be kind to my caregiver – I want to be helpful by telling her nice things and loving her – remembering to say, ‘thank you’ as much as possible.”

“I’m going to look in the mirror, smile, and like what I see.”

“I want to volunteer more so I can do something helpful for others.”

“Find something to enjoy in each day. It may sound simple, but you really have to own that philosophy and practice it.”

“I intend to reduce my handicap in golf next year!”

“It’s important to look around and recognize that there are a lot of people who are worse off than we are. Focus on what you have and be grateful.”

“My grandson is expecting a baby and we’re looking forward to that positive experience in our lives. I want to visit with my family more.”

“I want to slow down and take more time for reflection and prayer - to sit down and designate a time to talk to God.”

“I don’t have a driver’s license, but I drive my husband crazy! I’m going to try to be easier on him.”

“I want to eat good foods because I know that’s important for your health and I’m not so good at that.”

“Put memory loss to work for you and forget about Alzheimer’s! It doesn’t do any good to dwell on it all of the time. Just get on with doing what you can do.”

“It’s important to get up in the morning and get dressed for the day so you don’t mope around. Having something to do each day keeps me going and feeling more positive about things.”
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