

## Living with Dementia May 2008



For our members and supporters living with dementia, the need for money to support the work of Alzheimer's Society is obvious.

Volunteers frequently say to me that if only there was more money available, we could support so many more people.

Of course, more money also means more research into dementia, leading to greater hope for the future. But as competition for funds becomes ever more challenging, our need to win hearts and minds for our cause is as pressing as ever.

The Society needs to seize every opportunity it can to educate people about the prevalence of dementia and its financial and social impact in a way that will inspire people to donate. Our new brand is an important first step in making us stand out and stating our ambition for the future.

Our income grew by 12 per cent in 2006/07, but the number of people contacting us for support grew by 21 per cent. Ongoing funding is absolutely crucial to ensure we can continue to reach our goals.

Thank you for your support.

*Jo Swinhoe, Director of Fundraising and Marketing*

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Elaine Moody and Jo Cashell were among 290 runners who took part in the London Marathon on 13 April.

Elaine, (pictured here on the far right next to Jo Cashell), is the first person with dementia to run the Marathon on behalf of the Society.

She was accompanied throughout the race by Jo Cashell, who agreed to run with Elaine as she was feeling a little concerned about the starting point. The pair completed the Marathon in five-and-a-half hours.

Elaine, 55, who has Alzheimer's disease, started running just two years ago. She has taken part in a half marathon in Newark, but this was her first London Marathon. She said,

There were so many people shouting 'Go on you can do it!' The kids along the way wanted to do 'high-fives' so it was really good fun. I couldn't have done it without Jo.

Mick Moody, Elaine's husband, said,

I watched them both jogging down the Embankment with big smiles on their faces. When they finished I thought, Any minute now Elaine's going to cramp up but she still had a spring in her step. She was absolutely bubbling which was marvelous.

In all, 290 runners took part in the Marathon for the Society, and we are hoping to raise £260,000.

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You might expect medical students and trainee psychologists to have a thorough grounding in dementia. In fact, despite five years of medical study, just a few hours are spent on dementia training

Training in dementia care is sorely lacking in the UK. Medical and psychology students may have some training in the physiology and biology of dementia, but the human side of the disease is largely neglected.



One carer and early member of Alzheimer's Society, Margaret Butterworth, decided to do something about this lack of training and many years ago established a group of carers to talk to medical, psychology and nursing students.

The group is known as CRAC Dementia (Council of Relatives to Assist in the Care of Dementia). Through her contacts at University College London (UCL), Margaret was invited to run carer training sessions for second-year post graduate clinical psychologists. Margaret ran the sessions for 15 years until her death five years ago.

## Success

The training module proved so successful it is now in its twentieth year. In 1995, the group was invited to extend the sessions to medical students. Former carer Shirley Nurock now chairs CRAC Dementia. Shirley first met Margaret when her husband was diagnosed with dementia almost 20 years ago. Shirley says, 'I was given Margaret's name as my local contact by Alzheimer's Society. She passionately believed that carers were the people to advise on the kind of support they needed, and felt that they should be involved in the commissioning of services.'

These sessions are now an official part of the students' curriculum at the Royal Free & University College Medical Schools in London. The sessions for medical students take place in a lecture theatre each term, and psychology trainees have a half-day session once a year. Their aim is to demonstrate how families deal with dementia in real life, outside a clinical environment.

## Carers' stories

For example, one carer speaks about his experience of caring for his wife at home until she died, another about how she had to overcome bureaucratic obstacles to find the support she needed to look after her husband, who had fronto-temporal lobe dementia. One woman describes the effect of dementia on her family when her husband developed Alzheimer's in his fifties; their three children then in their early teens. One of the aims of the training sessions to medical students is to emphasise how doctors can be more supportive.

The presentations to clinical psychology trainees are followed by small group discussions, each led by a different carer. Shirley says, 'These group discussions allow us to reflect on our roles and the questions from the trainees bring into focus the problems we encounter and how we deal with them. Some students do find the sessions difficult to deal with and for some, it is the first time they have encountered close up the effects of dementia.'

## Feedback

Feedback is an essential part of the training. Students and trainees complete evaluation forms following each session. One trainee wrote, 'The lecture left me feeling upset. But we are training to be psychologists. In our daily work, we will be dealing with upsetting stories and issues.' Another student questioned why the carers seemed so negative about their roles.

Shirley responds, 'It is overwhelming, having to care for a loved one with dementia. We tell the students how it is. Should we be putting a gloss on it and telling others how rewarding carers find it? We don't think so. For many of us, caring is, or has been, a traumatic experience and left us with psychological and physical scars. This is often reflected in what we say. Hearing these accounts may well be an introduction to harsh reality for students.'

Shirley says that while some carers find these sessions emotionally cathartic, others find them quite upsetting. 'For ex-carers, especially, it can bring back memories that they would rather forget. But we feel the students should hear our stories and we see this as one of the most worthwhile activities we undertake.'

Dr Joshua Stott is Course Administrator at UCL, and believes the programme has the potential to change clinical practice. He says, 'The students do hear from carers in their clinical settings, but in the training sessions it is from a different position. The carers can talk about their experiences not from a position of seeking help, but from a position of being educators.'

CRAC Dementia is looking to attract more carers in London by linking up with other carer networks. The group would like to see the concept of carers as educators and trainers rolled out in university medical schools across the country. Anyone interested in finding out more can email the group at

[crac.dementia@hotmail.co.uk](mailto:crac.dementia@hotmail.co.uk)

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Sisters Deirdre and Bernadette decided they would both look after their mother, who has Alzheimer's, when their father died. The arrangement has led to some positive results.

When her husband died three years ago, Bridget Kelly lived alone in her Colchester bungalow. Bridget, 84, has always been an independent woman, but her family began to worry about her coping alone due to Alzheimer's disease. Bridget has four children; two sons in London and two daughters; Deirdre in Leigh-on-Sea in Essex, and Bernadette in Bristol.

Deidre said,

Mum lived alone in her bungalow for about a year after dad died, and she wasn't really looking after herself. I would visit her with my brother at the weekend and a lot of the visit would be taken up doing jobs. She was telling us she was eating but she was losing weight, and we were very concerned when we'd find her fully dressed in bed. One day, for the first time in her life when we were leaving she asked, 'When are you coming back?'

On one occasion when Bridget was under the weather, she went to stay with Deirdre and her family. Deirdre said,

There was no hurry for her to go back home. It felt easier having her with me than having to juggle work, children and rushing down to Colchester to check she was okay. But she was always independent and it didn't sit comfortably with her to depend on us; this never featured in her life plan.

Deirdre said the decision for Bridget not to go back home evolved rather than ever being formally decided. Bernadette and Deirdre decided it would be best for both of them to share her care. While they were a little concerned about the effect on their mother of moving between two homes, Deirdre says this a small price to pay for what has become a good solution.

She says,

I think there was a deep-seated feeling inside that she shouldn't be living with us or intruding on the families. But in all the time she's been with us - and my sister - she's been very thoughtful and asks how it fits in with us.

Now, Bridget lives with Deirdre and her husband Ian and two sons, Patrick and Callum, for around eight weeks, and then goes to live with her other daughter, Bernadette, husband Peter and their three children, Louise, Julian and Maddie, in Bristol. The families are delighted that although the move can unsettle Bridget initially, she soon settles down once she has arrived. They believe the fact she is surrounded by family and keeping active has had a positive effect on her condition.

Deirdre says,

I envisaged her getting slowly worse but she has picked up mentally and physically. She walks more now, she's put weight on and her memory has definitely improved, and I think it has to be the stimulation. She comes from the West of Ireland so she is used to a big family. She adores her grandchildren and is very tolerant of them. I sometimes worry about the screaming that goes on but she'll just say, "That's what life's all about".

It's interesting as there's lots of support for carers in my area, but very little support for people with dementia. My sister has a lot more going on for mum in her area, so she goes to Singing for the Brain classes which are really stimulating for her, there are lots of nursing homes which offer day care. When she lives with me she sees people at church and goes to day centres and just fits in with us.

Going to church is a big part of her life. Her faith has been a tremendous support to her and I think church is the one place where she feels 100 per cent comfortable as she knows all the prayers and songs and can recite them word perfectly.

Deidre also says having their grandmother at home has enhanced her relationship with her sons. '

The boys love having her here and they find the things she does quite funny. I had to hide the sugar bowl because she has sugar cravings and they think this is hilarious, I'll buy biscuits and she'll devour the lot in a day. But they are very respectful. One will brush her teeth, another brings her tea or Ovaltine at night and they take her for walks and help her to remember. And she's always on their side.

I admire the way mum's dealing with the situation as I know her confidence has taken a knock. But she fits in happily with us. I think we've made the best of a difficult situation.

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Lead researcher of the Seattle-based team Dr Suman Jayadev says,

We decided to assess the strength of genetic risk factors because enough people came to us asking, "Both my parents have Alzheimer's disease, so what's my risk?"

The 111 couples studied had 297 children who survived to adulthood. Of these, 22.6 per cent developed Alzheimer's disease compared to a rate of between six and 13 per cent in the general population. According to Dr Jayadev,

The implication is that we all have risk factors for Alzheimer's which are probably very small individually. But if you carry multiple small changes you increase your risk to a discernible difference.

The team will continue to monitor the group as the offspring get older, as some of the group have yet to reach 70.

## So what is a risk factor?

A genetic risk factor is an inherited susceptibility or tendency towards developing a condition, rather than a guarantee that a condition will develop. Other factors, such as decisions about how we live our lives, will interact with this susceptibility in determining our future health.

It is possible that someone who has inherited a genetic risk factor for Alzheimer's disease can avoid triggering it. For example, we know that being overweight or having high blood pressure increase chances of developing Alzheimer's disease. But if someone with a certain genetic risk factor exercises regularly and maintains a healthy blood pressure, the inherited weakness might not be exposed and the disease may not develop.

Genetic risk factors can be likened to slightly faulty parts in a machine: if they are not put under too much pressure, the faulty parts may not change and the person will stay healthy.

## Identifying the genes

Pinning down exactly which genes are behind these risk factors will provide an important new framework for understanding Alzheimer's disease. In the UK, Professor Julie Williams at Cardiff University is co-ordinating the largest study of the genetics of Alzheimer's disease in the world.



She says,

We could spend the next 100 years researching which theories about the cause of this disease are correct, but finding the genes which are involved points us in the right direction now.

Professor Williams' team will analyse the genes from 6,000 people with Alzheimer's disease and contrast them with 10,000 control subjects who do not have the disease. Technological developments are making important differences to the possibilities of research in this area.

As Professor Williams explains,

We now have tiny chips which literally have a million mini-experiments on them. We can analyse the genes of a person for just £200, when a couple of years ago this would have cost hundreds of thousands of pounds. There is now great optimism amongst geneticists that we are going to pin down the genes that make people susceptible to Alzheimer's disease. We are on the verge of establishing very important new information about the genetic risk factors for this condition.

Professor Williams' team expect to have the first wave of their results by the end of the year.

Commenting on the role of genetics and dementia, the Society's Head of Research Dr Susanne Sorensen said,

The role of genetics in the development of dementia is still not fully understood. It is clear that genes do play a role but the largest risk factor remains your age. As one in three people who live to over 65 will die with dementia it is vital that more research is carried out to fight this devastating condition.

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Alzheimer's disease (AD) is often (but mistakenly) defined as simply a memory or cognitive disorder, but the true picture is more complicated.

Alzheimer's disease is more accurately described as a visual-perceptual-cognitive disorder. Failing to understand the complexities of the illness can lead to many misunderstandings about the difficulties that people with dementia can face.

## Looking but not seeing

Seeing and perceiving is more than just taking in images in focus. Vision is seeing with the eyes. Perceiving is making sense of what eyes and the other senses are receiving. It requires the ability to co-ordinate all the components of the visual system with the brain's ability to process that information. It is a complex process, and requires the co-ordination of every aspect of our ability to manage and make sense of information.

## Revising the expectation that 'hallucinations are frequent in Alzheimer's disease'

Hallucinations are where people see something although there is no stimulus to see it. This is not the same as seeing something inaccurately- in a distorted, unclear way, or not recognising what is being seen, or, not being able to 'problem solve' that something is a visual illusion. When there is damage to the visual system, people with dementia may not know they are seeing inaccurately. Also, limitations in language ability may make descriptions of what they've seen unclear to listeners.

Hallucinations in people with Alzheimer's disease are reported at between 13 and 73 per cent, with an average of 40 per cent. This suggests they are a common, and even expected, occurrence. Two studies looking at case notes have found that many events classified by GPs as 'hallucinations' were actually more accurately categorised as illusions, misperceptions, misidentifications or naming errors. The studies found that only about 3 per cent of people with AD had "possible visual hallucinations".

Visual and other types of sensory hallucinations were found more frequently in groups of people with other sorts of dementia and illness- especially those with infections.

## Why do so many people with Alzheimer's disease appear to be seeing things incorrectly?

We need to take into consideration several factors:

- Normal deterioration in sight due to ageing.
- The possibility of illness affecting vision - such as cataracts, glaucoma, macular degeneration.
- Damage to the visual system as part of the damage to the brain caused by Alzheimer's disease.
- The interaction between mistakes in seeing and mistakes in thinking.

## **Mistakes in seeing and thinking**

People with Alzheimer's disease appear to experience a combination of 'visual mistakes' and 'thinking mistakes', leading to a combined 'visuo-perceptual-cognitive' illness.

Some of the errors commonly made include:

- Mistaking reflections in shiny surfaces and mirrors.
- Misinterpreting patterns (and water and dirt marks).
- Anxiety about stepping over carpet rods, thinking they signify a change of level.
- Refusing to get into an empty lift if it appears full of people because of their own reflection (s) in multiple mirrors.
- Commenting on 'little people in the corner of the room' (people on television).

## **Minimising visual-perceptual problems**

The single biggest thing that can help vision is to improve lighting levels. Better lighting can also help prevent falls, and has also been reported to reduce genuine visual hallucinations.

More tips are available in a forthcoming Society factsheet by neuropsychologist Dr Gemma Jones and colleagues, where this information comes from. Details of the factsheet will be provided once it is available.

## Living with Dementia May 2008

Dementia research has long been the Cinderella of medical research, losing out to cancer and heart disease in the competition for attention and resources. Whilst everyone wants to find a cure, this is a very long-term objective. Important questions about how best to help people with dementia and carers here and now have been neglected for too long. But this situation is changing.

Dementia is moving up the research agenda and funds are appearing not only for basic sciences research but also for social and organisational studies. In England there is an increasingly integrated research and development process.



The National Institute of Health and Clinical Excellence (NICE) has made a strong case for more research in dementia care, although this has been overshadowed by the controversy of the cholinesterase inhibitor medicines.

The government has funded a research network for dementias and neurodegenerative diseases (DeNDRoN), and this now covers half the country, with a similar network being formed in Wales. There is, at last, substantial funding for programmes of dementia research coming from the National Institute of Health Research (NIHR). Several programmes of dementia research, each worth £2 million and lasting five years, have already started.

One of these programmes is EVIDEM - Evidence based Interventions for Dementia. The programme is aimed at developing and testing interventions which improve patient, carer and service outcomes throughout the dementia journey, from early signs of dementia to end-of-life care. EVIDEM is run from Central and North West London Mental Health Trust (CNWL), and the work will be carried out by a multi-disciplinary research team based across five universities.

Five separate projects are being run within the programme (see below). EVIDEM will bring together the expertise of GPs, nurses, social workers, old age psychiatrists, economists, research scientists and people with dementia and carers to provide an important mix of skills.

EVIDEM is currently recruiting people who wish to contribute to this dementia research to change the way in which services work. It is an ambitious programme, as we hope to recruit 2,000 people over the five year period. People with dementia and their families who join EVIDEM will be offered the opportunity to take part in one or more of five projects.

These are:

- Improving the ability of GPs and practice nurses to recognize the early signs of dementia and offer help.
- Testing the effect of exercise as a treatment for anxiety, agitation, depression and other psychological symptoms and behaviour changes in dementia.
- Working out ways to reduce the impact of incontinence on quality of life.
- Ensuring that people with dementia get the best possible care at the end of their lives.
- Studying exactly how the Mental Capacity Act 2005 is being applied, and how this helps people with dementia and their families and supporters.

The fruit of all this effort will not just be learned articles in scientific journals. We are running annual summer schools for NHS and social care staff, and will produce toolkits for practitioners to apply in their everyday work, as well as computer systems to help with diagnosis and systematic, continuing care.

These projects focus on complex and often sensitive topics, but we believe they are important and need attention now. The government agreed with us. If you live in the North Thames area and feel that this research is practical and important, we would welcome your help.

To join the research programme, you can either write to me, Steve Iliffe, at Department of Primary Care, UCL, Royal Free Campus, Rowland Hill St., London NW3 2PF, send me an email at [s.iliffe@pcps.ucl.ac.uk](mailto:s.iliffe@pcps.ucl.ac.uk) or call Trish on 020 7830 2338 or Kalpa 0207 830 2392.

The Researchers and their Universities

Professor Steve Iliffe (University College London) is responsible for the overall management of the EVIDEM programme and the project on GP education.

Dr James Warner (CNWL NHS Foundation Trust) will test exercise as a therapy for psychological symptoms.

Professor Vari Drennan (St. George's & Kingston University) is running the project on incontinence.

Professor Claire Goodman (University of Hertfordshire) is responsible for improving the quality of care at the end of life.

Professor Jill Manthorpe (Kings College London) will be measuring the impact of the Mental Capacity Act 2005.

Professor Martin Knapp (London School of Economics) is responsible for economic evaluation.

Mark Griffin (University College London) is responsible for research design and statistical analyses.

Dr. Greta Rait (University College London) is responsible for assembling the research cohort of 2,000 people.