Caring for carers

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Dementia costs the UK an estimated £26 billion every year, almost half of which is the cost of the army of unpaid carers made up of people’s families and friends.

When calculating the cost of an unpaid carer, it is important to consider not only paying for replacement care, but also the ‘opportunity cost’ – the value of activities they are no longer able to carry out because of their caring commitment.

The enormous service provided by unpaid carers should be recognised and we should support them wherever possible. A recent survey by Alzheimer’s Society found that 90 per cent of carers experienced feeling of stress or anxiety at least several times a week. Many also struggle to talk about their feelings or to find the time to take care of themselves.

To help tackle this, we have launched a trial to test the ability of online therapy support packages to help reduce stress and depression among carers. This trial has been in the pipeline for many years, overcoming several technical challenges to reach this stage.

We are now looking for over 700 people to take part in the study to see if this kind of support could be beneficial to the wider population of carers, see page six for more details.

Ian Le Guillou
Editor
Careandcure
A study of nine people who had had moderate to severe traumatic brain injuries found that clumps called amyloid plaques are still present in the brain over a decade after the injury. The injuries had occurred between 11 months and 17 years prior to the study, many caused by road traffic accidents.

Although they had no physical disabilities from the injury, many still experienced memory and concentration problems. The study participants underwent a brain scan using a technique that allows scientists to view amyloid plaques.

‘Research is increasingly showing that a blow to the head, such as that sustained in a road accident, triggers biological processes in the brain that burn away in the background for years,’ said Dr Gregory Scott, the lead researcher.

‘Although previous research has shown that some head injury patients have these amyloid plaques shortly after the incident, these findings suggest these plaques are still present in the brains of patients over 10 years later. This helps shed light on why brain injury patients seem to be at increased risk of dementia – and may help us develop treatments that reduce this risk.’

Protein clumps associated with Alzheimer’s disease have been discovered in the brains of people who had experienced head injury years earlier.

Serious head injuries are known to raise the risk of developing dementia, but we do not fully understand how this happens. The scientists behind this new research studied amyloid plaques accumulating in people who survived an injury but had not shown symptoms of dementia, giving insight into how it may develop.

‘The effects of a severe head injury can remain hidden for years. More research is needed to understand why it puts you at an increased risk of developing dementia and whether there are ways to reduce that risk once a head injury has occurred.’

Researchers at University College London have also spoken about a study they are running with north London’s Saracens rugby club to investigate changes in samples taken from players after matches. They hope to identify molecular markers that are linked to head injuries, to determine the level of injury and recommend how long a player should stop playing in order to recover.

Dr Clare Walton, Research Communications Manager at Alzheimer’s Society, said, ‘It is important to note that the protein clumps seen after brain injury were much fewer and located in different regions than the clumps seen in the brains of people with Alzheimer’s disease. This means it is not a simple case of head injury triggering the same brain changes that occur as dementia develops.'
Dementia can affect spatial awareness and balance, and each year 60 to 80 per cent of people with dementia experience a fall. These falls can accelerate decline in physical and mental health, so are important to address.

Researchers hope that the PrAISED (Promoting Activity, Independence and Stability in Early Dementia) trial will help reduce the number of falls and fractures among people with dementia. This could reduce and delay disability, distress and the cost of the disease’s progression. The intervention could form an addition to treatments offered after a diagnosis of dementia.

The study’s targets include ‘dual-task’ activities that involve doing two things at once, a particular problem from the earliest stages of dementia which might be improved with training. The aim is to set back the impact of the disease by a year or two, to help people live well with dementia for longer.

Professor Rowan Harwood from Nottingham University Hospitals NHS Trust, who is leading the study, said, ‘Nearly half of broken hips occur in a person with dementia and attempts to prevent these falls to date have been largely ineffective, so our new study aims to rectify that.

‘We started by looking at ways of preventing falls, but interviews with patients, carers and professionals suggested that we should focus on promoting activity, independence and wellbeing rather than emphasising the falls themselves.’

**Exercise therapy in early dementia**

A major £2.8 million study is being launched into therapy that aims to maintain activity, independence and balance among people living with the early stages of dementia.

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**Omega-3 may boost Vitamin B**

New research suggests that vitamin B supplements could help to improve learning and memory for some older people who have high levels of omega-3 in their blood.

Researchers studied over 250 older people with mild cognitive impairment – memory problems that are not severe enough to be classed as dementia – and gave them either B vitamins or a placebo for two years. Blood levels of several chemicals, including omega-3, were measured before and after the study.

The study found that people who had high levels of omega-3 in their blood and took vitamin B performed better at thinking and memory tests, compared to those who did not take vitamin B or had low omega-3 levels.

Evidence for the role of vitamin B in dementia is not clear. B vitamins are responsible for lowering homocysteine, a chemical often found at high levels in the blood of people with dementia, but some clinical trials have shown that taking B vitamins has no effect on brain function, despite their effect on homocysteine.

Dr Doug Brown, Director of Research and Development at Alzheimer’s Society, commented, ‘These results help us to tease apart who could benefit from taking B vitamins, suggesting that they might only improve cognition in people who have high levels of omega-3 oils in their blood.

‘As this study shows, the relationship between nutrition and brain health is complex. We need to see increased research efforts to help us understand the role that diet and nutrition can play in reducing a person’s risk of dementia.’
A new study shows that a drug originally developed as an antidepressant may work to enhance the brain’s ‘waste disposal’ and slow the progress of Alzheimer’s disease.

Research in mice has shown that proteasomes, the cell’s waste disposal system, may break down during Alzheimer’s disease. The protein tau, which accumulates in the brain in the disease, is thought to clog the system, creating a cycle in which increased levels of damaged proteins become toxic, clog proteasomes and kill neurons.

The study tested the drug rolipram, which enhanced proteasome activity in mice with the early signs of Alzheimer’s disease. It is hoped that this may prevent dementia and reduce damage to the brain.

Rolipram, initially developed as an antidepressant, is not used clinically because it causes nausea as a side effect. Similar drugs have been tested previously for their benefits in helping the brain to create memories, but this discovery demonstrates a new way in which rolipram might help people with dementia.

Dr James Pickett, Head of Research at Alzheimer’s Society, said, ‘This study in mice appears to show that the drug rolipram – which was first developed to treat depression – can restart the waste disposal system in brain cells and flush out the toxic clumps. This prevented memory problems in the mice studied, but only in those that showed signs of the early stages of Alzheimer’s disease.

‘This discovery suggests a new way in which people with dementia could be helped, but it is still very early stages and there are many hurdles to overcome before we know if it’s effective in people.’

‘There are many hurdles to overcome before we know if it’s effective in people.’

Dr Pickett
It is no secret that those who care for people affected by dementia are vital contributors to our health and social care system. Unpaid carers account for £11.6 billion of the economic cost of dementia yet many of them are struggling in silence, often dealing with a myriad of emotions including stress and depression.

An Alzheimer’s Society survey carried out in January 2016 found that 90 per cent of carers experienced feelings of stress or anxiety several times a week or more. Of them, 60 per cent said that they struggled to talk about the impact of caring because they felt guilty for putting their own needs ahead of the person they are caring for.

Testing times
To improve support for carers of people with dementia, Alzheimer’s Society, supported by donations from Nominet Trust and the Stavros Niarchos Foundation, has funded researchers at Oxford Health NHS Foundation Trust to see if online therapy and support packages can be of benefit. We are asking carers to sign up to the trial, called Caring For Me and You, to test these online packages.

Dr Jane Fossey, the lead researcher on the study, said, ‘Carers often feel the profound effect the role can have on their own lifestyle – spending long hours providing care, juggling their own needs with those of the person they are caring for and forfeiting their social time. As a result, carers of people with dementia are more likely to experience stress and depression.

‘This study could have important implications for how carers of people with dementia are supported to manage stress and depression. The results from this trial could open up a whole host of new ways for them to access help and advice. If shown to be effective, Caring For Me and You could pave the way for a national roll-out of this tailored and accessible support.’

Finding the time
Due to the complex, progressive and unpredictable nature of dementia, carers may feel that they cannot spare the time to see their doctor.

Alzheimer’s Society is funding a project to find ways to help carers access much-needed therapy and support so that they may cope better with feelings of stress, anxiety and depression.
Others find it difficult to arrange for replacement care, while some feel uncomfortable about a therapist coming to their house. The researchers believe that delivering the support packages online may help to overcome some of these difficulties, as people can access the packages at any point from their own home.

Dr Doug Brown, Director of Research and Development at Alzheimer’s Society, said, ‘In this country, unpaid dementia carers prop up our health and social care system. This silent army of wives, husbands, sons and daughters spend 1.3 billion hours a year providing care. This can take an enormous toll on their emotional health and wellbeing.

‘Carers tell us that even when they have taken that difficult first step by going to see their GP, accessing any sort of face-to-face therapy presents a whole new challenge – from finding the time to attend and getting care cover to the extremely long waiting times facing many for these treatments. Being able to log on at home to immediately access tried and tested support and coping strategies has the potential to transform the lives of tens of thousands of carers.’

Support packages
The participants will be randomly assigned one of three packages – online cognitive behavioural therapy (CBT) alone, online CBT with additional telephone support, or a specialised carer information and support package. CBT is a psychological intervention that enables carers to develop coping strategies by working through their thoughts, feelings and difficulties. There is evidence for the effectiveness of CBT and it is now established as a first-line approach for the treatment of mental health conditions including depression, anxiety and stress.

Each package consists of 20 online sessions of 20–30 minutes each, which can be completed at any time over a 26-week period. The researchers will analyse the results to find out whether any of the three packages help carers to manage feelings of depression, anxiety or stress.

If this approach is shown to be successful, the findings could be used as evidence to support a potential national roll-out of the scheme.

‘A huge difference’
Michelle is 33 and one of our Research Network volunteers, who use their personal experience of dementia to review research grant applications.

When her dad, Dennis, was diagnosed with early-onset Alzheimer’s, she found herself struggling to cope with her role as his carer. She spoke to us about why she believes that carers need to be able to access support more easily at home.

‘Dad used to live by himself and would call me if there was anything wrong, day or night. If ever he couldn’t get hold of me he would immediately ring the police. I felt permanently on edge, waiting for the phone to ring, and I would find myself waking up in the night because I thought I had heard the phone.

‘I was physically and emotionally exhausted – I stopped seeing my friends and I couldn’t sleep. I was desperate for help, but kept putting off going to the doctor because I just didn’t have the time. If it had been as easy as logging on at home to get support it would have made a huge difference.’

Anyone aged over 18 who is caring for someone with dementia at the moment and not receiving professional mental health support can sign up to see if they are eligible. You will also need access to a desktop or laptop computer that is able to access the internet.

Sign up by visiting www.caringformeandyou.org.uk or call 01865 902833.
My maternal grandmother was diagnosed with dementia when I was in secondary school. At the time, statutory support was minimal and the impact this had on all members of my family was significant.

The experience motivated me to work with people who have dementia and showed me the distress such a diagnosis could cause, both to the individual and their carers. The wish to understand and alleviate such distress was one of the things that led to my career choice as a clinical psychologist.

I have been a clinical psychologist since 2003 and have always worked with people with dementia. Among other things, I have tried to help people with dementia to decrease feelings of depression and anxiety by using a type of talking therapy called cognitive behavioural therapy (CBT). My research sprang from this clinical interest and was developed in collaboration with a group of people with dementia who were peer support workers in the same service as me.

We know that CBT is effective in reducing anxiety and depression for people who don’t have dementia. Based on this, there have been large-scale government initiatives aimed at improving access to such therapies. There is, however, much less evidence as to whether CBT is useful for people with dementia. While there have been two small recent studies, with promising results, there is not agreement about how CBT might be best adapted to take account of the thinking, language, planning and memory problems that people with dementia experience.

My research is focused on understanding how best to adapt CBT for anxiety and depression so that it caters for the needs of people with dementia. There has not been much work in this area so my research is a first step, looking to understand what bits of CBT people with dementia might find difficult.

I will meet around 100 people with dementia in their homes or a clinic and give them tasks that mimic important parts of CBT. I will compare performance to groups of people without dementia to help understand which aspects of therapy are difficult for everyone, and which are difficult just for those with dementia.

Finally, as everyone with dementia is different I will be looking at which aspects of dementia might particularly affect important parts of CBT. In all, this will help me to understand how to adapt and individualise CBT offered to those with dementia.

As my research has just started I don’t yet have results, but even when I do it will just be a step on the way to the end goal of ensuring that people with dementia have good access to effective psychological therapies. In future, I want to use the results to develop innovative psychological therapies for people with dementia who also experience anxiety or depression.

As an Alzheimer’s Society fellow I am also enrolled in the Dementia Research Leaders programme and wish to influence others in research and practice. I am in a good position to do this – I work at University College London as a trainer for clinical psychologists, supervising dementia research, and can directly input results into the teaching of future healthcare professionals. My fellowship research has a number of trainee clinical psychologists involved in subprojects, and I hope this inspires them, as well as others I supervise and teach, to do research with people with dementia in future.
Over the past 20 years, the Netherlands has rolled out 125 Meeting Centres to provide person-centred care for people with mild to moderate dementia and family carers in a community venue. This system is based on the Adaptation-Coping model put forward by Professor Rose-Marie Dröes in 1991, which gives insight into the different ways people deal with their dementia and helps families to understand their behaviour.

The person with dementia is offered individually tailored support to empower them and provide an opportunity to live an active, social, stimulating and meaningful life. Alongside this, carers or families are provided with information and practical, emotional and social support. People with dementia and carers contribute ideas to the list of services and activities available at the Meeting Centre, as well as relevant information to share with other service users.

The benefits of these Meeting Centres were demonstrated in two controlled studies at centres in the Netherlands. Compared to those using regular day care, after seven months of participation in the Meeting Centres, participants with dementia showed fewer behavioural and mood problems, increased activity, less unsocial and depressed behaviour, and a higher self-esteem.

Over the course of the study, only four per cent of the Meeting Centre participants were admitted to a nursing home compared to 30 per cent of usual day care participants. Carers taking part generally felt more competent and less burdened than carers using day care as respite only.

The centres had clear benefits to people in the Netherlands but it remains to be seen if it would be as effective in countries with different cultures and systems of health and social care. Alzheimer’s Society has set up two pilot centres in Droitwich Spa in Worcestershire and Leominster in Herefordshire, which will be evaluated as part of an EU-funded research project called MeetingDEM to see whether this service model can bring the same benefits to people with dementia and their carers living in the UK.

‘Alzheimer’s Society is thrilled to be the implementation partner for the UK’s first Meeting Centres. We will be delivering the Adaptation-Coping model, as used across the Netherlands, to ensure that people with dementia and their carers receive support around all the ways dementia affects life, not just the health of the individual with the condition,’ says Gill Read, Services Manager.

The UK Meeting Centres will be evaluated and monitored by the Association for Dementia Studies at the University of Worcester, in collaboration with University College London and the London School of Economics. The overarching aim is to evaluate the efficacy and cost-effectiveness of Meeting Centres in terms of the behaviour, mood and quality of life of people living with dementia, the sense of competence of their carers, and any delay in moving into residential care. The evaluation is also being carried out with Meeting Centres that are being set up in Poland and Italy.

Dementia is an international problem and research is a global effort. Successful new ways of providing care can be developed anywhere, and it is important that we take note of what has worked well elsewhere so that we may implement it at home.
New research grants funded

Alzheimer’s Society has awarded £2.4 million to new research in the latest round of grants. Here we feature three of the new research projects.

Preventing depression

Dr Vasiliki Orgeta at University College London has been awarded a senior fellowship to develop a therapy to prevent depression in people with early-stage dementia without the need for drugs. People with dementia are at a higher risk of depressive symptoms, sadness and loss of enjoyment of life. This hinders their ability to perform everyday activities, puts them at risk of needing residential care earlier and affects their quality of life.

There are currently no effective treatments, as medications such as antidepressants are ineffective and have significant side effects.

A person with both dementia and depression will be struggling with two lots of difficulties. They may find it even harder to remember things and may be more confused or withdrawn. Depression may also worsen behavioural changes in people with dementia, causing aggression, problems sleeping or refusal to eat.

Dr Orgeta will use existing knowledge about depression in dementia and talk to families and people with dementia to develop an intervention. The therapy will be planned to meet their needs, offering strategies and support to cope with depressive symptoms. The intervention will be trialled by 60 people with dementia and their carers with the support of a psychologist. This study will find out how feasible it is to recruit people with dementia and how many sessions they can complete.

Improving trials

A project grant has been awarded to Professor Nick Fox to help improve the design of secondary prevention trials in Alzheimer’s disease by investigating the role of brain scans. The idea of secondary prevention is to treat people who already have signs of the disease in the brain, but do not show any outward symptoms.

One of the main challenges in designing prevention trials is how to measure whether the drug has worked. Tests of memory and thinking may be affected by temporary improvements in symptoms and so other measures are needed for a clearer result of the potential treatment.

The researchers will make use of a large study called the Dominantly Inherited Alzheimer Network, which follows people who have a genetic link to Alzheimer’s disease and are at higher risk of developing the condition. The researchers will collect brain images from people in this study and use these to determine what to look for when assessing how well a drug works.

This project will help the design of future trials so that the results are a good representation of how a drug works. This will help us to understand whether drugs used in future clinical trials are effective at preventing dementia.
Understanding causes

A PhD student in the lab of Dr James Duce at the University of Leeds will study a biochemical process that increases production of amyloid-beta, a hallmark of Alzheimer’s disease. This is produced when the protein APP is split into smaller pieces. This research group discovered that another protein called lactoferrin, which is produced in response to inflammation, can attach to APP and increase the chance of it being split up.

The student will use various techniques to investigate how lactoferrin can change levels of amyloid-beta as well as understand its significance in Alzheimer’s disease. Experiments will range from studying how each protein attaches to the other, through to how they work in individual cells and within a whole brain.

This research will provide greater understanding about how the inflammation that increases the amount of lactoferrin results in the damage to cells seen in Alzheimer’s disease. By the student identifying the exact part of each protein that makes contact with the other protein, it is hoped that new drugs can be developed to block this interaction. A drug that could stop the attachment of lactoferrin to APP could reduce the production of toxic amyloid-beta.

Going Dutch on research

Alzheimer’s Society and Alzheimer Nederland have awarded seven knowledge exchange fellowships to help share research knowledge and skills between the UK and the Netherlands.

Knowledge of research techniques – often built upon years of experience – is not straightforward for new researchers or groups to pick up. As with the Meeting Centres covered in this issue, great ideas and new ways of working can come from anywhere, and it is important that these are shared widely.

To help this flow of knowledge, Alzheimer’s Society and Alzheimer Nederland are jointly funding seven exchange fellowships for care and biomedical researchers to spend up to a year in the other country to establish and strengthen collaborations between research groups.

Alzheimer’s Society and Alzheimer Nederland are the largest care and research charities in their respective countries. Both organisations have a proud history of funding research and the knowledge exchange fellowships will allow researchers who, on the basis of their scientific excellence, may be expected to make an important contribution to dementia research.

One exchange fellow from the University of Edinburgh, Dr Javier Escudero Rodríguez, will be joining Amsterdam’s VU University Medical Center to study how mild cognitive impairment affects brain circuits that are active in forming short-term memories. He expects to find out how mild cognitive impairment modifies the way in which different areas of the brain interact with each other, which could help to detect Alzheimer’s disease earlier with reliable, safe and cheap tests.

Dementia Citizens is inviting people living with dementia, their carers and dementia researchers to register and get involved in a new digital ‘citizen science’ community that will help people affected by dementia and researchers to connect online.

Dementia Citizens aims to help people with dementia find meaningful digital activities to enjoy, with their carers, at any time. Participants will be asked to carry out an activity, such as listening to music or creating a digital life story book, and complete wellbeing surveys. The information collected will help researchers to design better care.

For researchers, Dementia Citizens will make it easier to carry out research into dementia care and gather new types of data through digital devices. The platform will provide the technology that researchers need to build apps for research projects, and will connect researchers with people in the community.

To find out more and register your interest in taking part, either as a researcher or a participant, please visit www.dementiacitizens.org

Call to register to take part in online dementia research
About us

Alzheimer’s Society is the leading support and research charity for people with dementia, their families and carers.

Since 1990, Alzheimer’s Society has funded over £35 million of cutting-edge dementia research. We aim to increase our investment in our research programme to around £10 million a year by 2017 and £100 million over the next decade. This money funds important research that will help us to improve the quality of life of people with dementia, by tackling questions related to the causes of dementia, investigating good practice in care and treatment, and pursuing a cure.

Research Network

One distinctive feature of our ground-breaking research programme is the integral involvement of people with dementia and carers.

As part of our Research Network, volunteers with direct experience of living with dementia inform our research priorities.

If you have been a carer for someone with dementia or you have dementia and are interested in joining the Research Network, please contact Anna Grinbergs-Saull, Research Engagement Officer, for an application form or apply online at alzheimers.org.uk/researchnetwork.

Alzheimer’s Society maintains editorial independence over the content of this magazine.

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For general enquiries, email info@alzheimers.org.uk.

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