

Women and Dementia

A Marginalised Majority



**Alzheimer's
Research
UK**

The Power to Defeat Dementia

IT'S TIME TO DEFEAT DEMENTIA

Page 3

DEMENTIA IN THE UK

Page 6

WOMEN AS CARERS

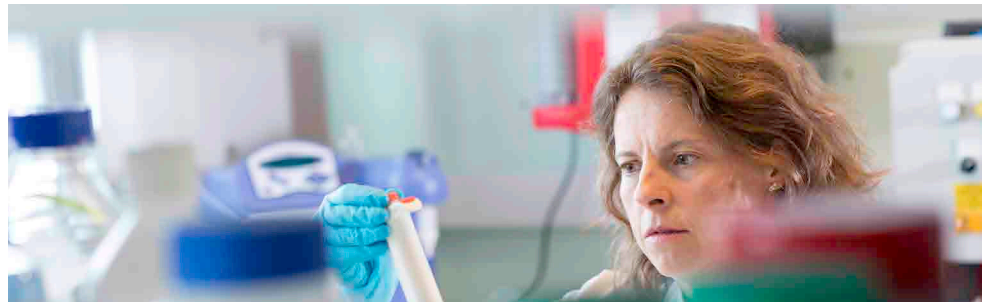
Page 8

WOMEN & WORK

Page 10

WOMEN IN SCIENCE

Page 12



i Dementia is the leading cause of death among women in the UK.

i After the age of 65, the risk of developing Alzheimer's disease doubles approximately every 5 years.

| Age | Risk Level |
|-----|------------|
| 65 | Low |
| 70 | Medium |
| 75 | High |
| 80 | Very High |

i Women over 60 are twice as likely to develop Alzheimer's disease than breast cancer.

ALZHEIMER'S

BREAST CANCER

i Men and women with dementia in the UK.

39%

61%

It's time to Defeat Dementia

Alzheimer's Research UK's
fight against the biggest
killer of women in the UK.



At Alzheimer's Research UK we know:

The effects of dementia are devastating.

The diseases that cause dementia are progressive, meaning they get worse over time, and currently there are no treatments that can slow or stop the damage. The physical and cognitive decline of a person with dementia can occur rapidly, or be drawn out over a decade or more. Ultimately though, dementia is fatal. Dementia weighs on individuals, families and communities, as well as the economy and health care system, and has an impact on everyone. However, in the UK population as a whole dementia hits women the hardest.



Women are more likely than men to have dementia in their lifetimes, and it is the leading cause of death for women in the UK. The chances of developing dementia grow considerably as we age, so while several thousand women in the UK each year are now celebrating their 100th birthday, many more are at risk of losing valuable years to the condition.

It is also predominantly women who take on the role of caring for a loved one with dementia.

Women are more likely to reduce their hours or stop working to care for someone with dementia, and some even feel penalised at work for taking on care responsibilities.

Dementia is one of the greatest medical challenges of our time, and there is an urgent need for a treatment, particularly as the number of people with dementia grows. Our goal is to shed light on the unique impact of dementia on women, including the stress and demands of living with dementia or caring for someone with the condition. All too often, women are carrying the responsibility of care for their loved ones, only later to be living with the condition themselves. Women are dying from dementia, but not before it has taken a considerable toll on minds and bodies.

Women are a force in the fight to defeat dementia as well. Alzheimer's Research UK is leading the world in funding pioneering research that will make a real difference to people's lives – now and in the future. **World-class female scientists play an important role in making the breakthroughs that will take us towards this goal.** A steady increase in focus and funding from government, industry and the charitable sector is vital for us to grow and support the scientists working tirelessly to make a difference for people with dementia and their families.

500,000 women are living with dementia in the UK

Dementia affects over 850,000 people in the UK and 44 million worldwide. It is estimated that 61% of people with dementia are women and 39% are men. This is likely to reflect the fact that women live longer than men and age is the biggest known risk factor for the condition. While some studies have suggested that other factors may affect the number of men and women with dementia, there is no firm evidence that women are more likely than men to develop dementia at any given age. Based on this estimate, there are currently more than half a million women in the UK living with dementia.

Dementia is also the most feared condition for people over the age of 55, more than any other major life-threatening disease, including cancer, stroke, heart disease and diabetes. These concerns are well-grounded, women in their 60s are almost twice as likely to develop Alzheimer's disease over the rest of their lives as they are to develop breast cancer¹. Some may fear the devastating symptoms of dementia, including memory loss, loss of the ability to communicate, mood and personality changes, and eventually declining health and death. Others express fear of becoming a burden to loved ones as the condition progresses because they have first-hand experience of the challenges of caring for someone with dementia.

While the experience of living with dementia varies from person to person, women and men have been shown to express the symptoms of dementia in different ways, indicating the possibility that male and female brains react differently to the diseases that cause it.² Gender can also influence the benefits of activities that may potentially reduce the risk of dementia, such as exercise. In women, exercise has been shown to improve mortality, whereas in men the positive effect of exercise is in cognitive improvement.³





Dementia: the
biggest killer of
women in the UK



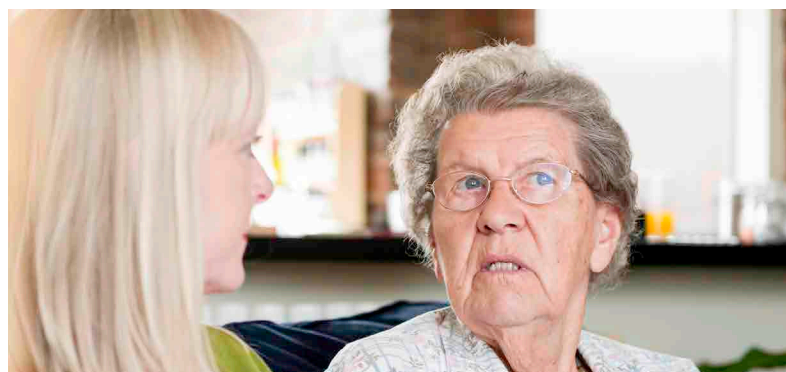
In the UK, dementia is the leading cause of death among all women.

The Office of National Statistics reported that 31,850 deaths of women in the UK in 2013 could be directly attributed to dementia, while even more may have been hastened by the condition.

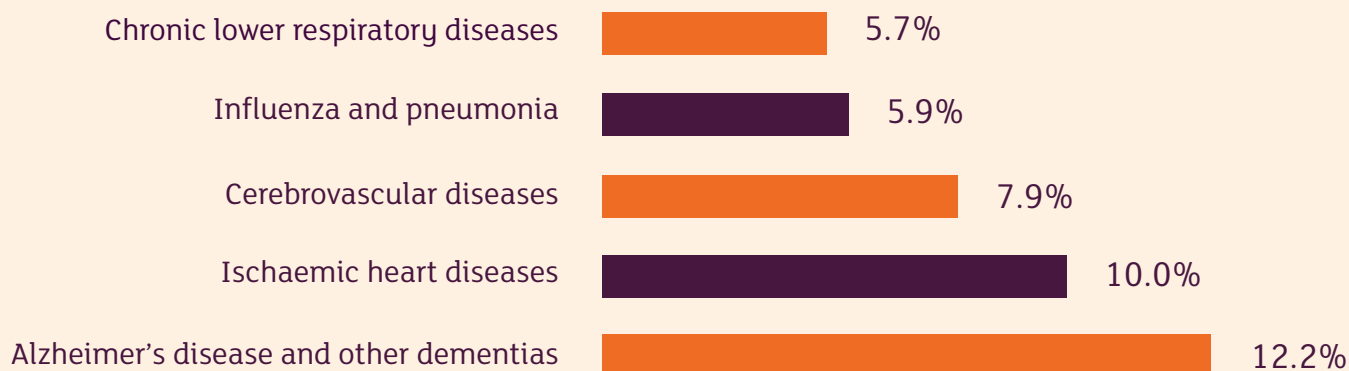
That amounts to 12.2% of all causes of death for women, more than heart disease, stroke or the most common forms of cancer.

Age is the primary risk factor for dementia in the UK and women are living longer than ever. After the age of 65, the risk of developing Alzheimer's disease doubles approximately every five years. According to population data, 72.5% of people aged 90 or over in the UK in 2012 were women. Today, an 85 year old woman has an average further 6.8 years of life remaining.⁵ The unfortunate result of these trends is that many women are living their extra years in ill health.

A dementia diagnosis significantly reduces a person's life expectancy. People with dementia, men and women, live an average of five years after diagnosis, though this can vary widely depending on the individual case. The overall trend indicates that living with dementia shortens a person's life, so that even if dementia is not the direct cause of death, there is a negative impact on the length and quality of someone's life.



The lead causes of death in the UK:



Accurately recording dementia as a factor in death:

i

Deaths recorded with an underlying cause of dementia were also increased by a rule change in 2012 to count aspiration pneumonia as being a consequence of one of a number of other conditions. The total percentage change in deaths attributed to an underlying cause of dementia was 7.1%.

i

A change in 2012 of the coding of chest infections contributed to a reduction of 2.5% in deaths allocated an underlying cause of respiratory disease and an increase of 7.0% in those allocated to the mental and behavioural disorders category, which includes dementia.



Women as Carers

Not only are women more likely to have Alzheimer's disease or another form of dementia, they are also more likely to be caregivers of those with dementia. Generally, a carer is someone providing support on an unpaid basis, and it can be a mentally and physically exhausting task. Most carers do not choose or plan to take on the role, but have it develop out of necessity either from a sudden crisis or over time as a loved one's health and independence deteriorates. **Between 60 and 70% of all unpaid dementia carers are women.**

According to surveys of unpaid carers for people with dementia, there are 2.5 times more women than men who provide intensive, on-duty care for someone 24-hours a day.⁶ Of those women, half found their caring responsibilities to be physically stressful, while even more, 62%, found the experience emotionally stressful.



2.5 times more women than men provide intensive, 24-hour care for people with dementia.

Women are also more likely than men to help with the more personal aspects of care, such as bathing, dressing, using the toilet, and managing incontinence. Among carers, women are 2.3 times more likely than men to have been providing care to someone with dementia for more than five years. The figures show that women make up a large portion of the carers who are supporting someone with advanced dementia, who may be incapable of communicating or be confined to a bed or chair.



62% of female carers said that the experience was emotionally stressful.



Research shows that women who care for people with dementia also feel less supported than their male counterparts.

Wives caring for their husbands with severe dementia reported receiving less support from friends and family than husbands caring for their wives in similar circumstances. Many carers experience feelings of isolation, but for women these feelings are more likely to be linked to depression, which in itself may be a risk factor for dementia.

The number of people acting as carers for their loved ones is projected to increase dramatically as the UK population ages, and the majority of those are likely to be women.

In Europe, there are roughly four people of working age for every one person who is too young to work, or retired. However, the demographics across Europe, including the UK, are set to shift dramatically over the next 50 years, leaving just two people of working age for every one that is dependent on their support.⁷

The UK already has a larger proportion of people over 65 than the EU average, and as the number of older people rises steeply, the need for carers will continue to increase.



Women and Work

According to a recent analysis of the UK workforce by the Office of National Statistics, there are 14.4 million women currently in employment, which is more than ever in history. ⁸ However, either by choice or circumstance, only 57% of those women are working full time, compared to 87% of men. Women also face earning 10% less than their male counterparts for the same job, a pay gap that is even greater in some health care jobs.

Women who work and care for someone with dementia face the significant and very real possibility of negative impacts to their career.

They may not be in a position to choose between their work and caring responsibilities, and so are forced to do both simultaneously.

However, surveys of working women carers indicate that they are not receiving adequate support in either role.

Added to these professional challenges, women taking on caring responsibilities for someone with dementia may experience further disadvantages. According to recent research, nearly 19% of women who care for someone with dementia have had to quit work either to become a carer or because their caregiving duties became a priority. Among working women carers, 20% have gone from working full time to part time, compared with only 3% of working male carers.



20% of women carers have gone from working full time to part time.



17% felt they had been penalised at work because of their caregiving duties.



18% have taken a leave of absence from work.



10% have lost job benefits (in the US).

19% of women who care for someone with dementia have had to quit work.



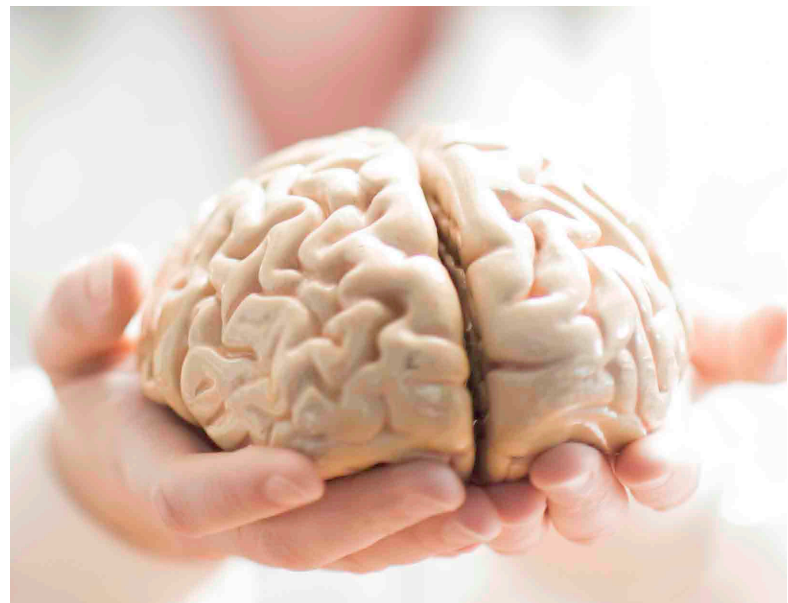


Women In Science

The impact of dementia felt by women is being met by leading researchers – many of whom are also women. These scientists are making advances identifying key proteins involved in dementias, discovering genetic risk factors, and improving brain imaging for better diagnosis. Women, along with their male colleagues, are making important discoveries that are driving the development of new diagnosis and prevention tools, and pushing towards new treatments for dementia. They are leading the fight to defeat dementia.

The UK is a world-leading strength in dementia research and home to established as well as emerging new female scientists. There is a compelling economic case for supporting women in science careers, with the STEM professions (science, technology, engineering and mathematics) adding an estimated £2 billion annually to the UK economy.⁹ However, women are not being retained in the research field: A study which followed the careers of PhD graduates found that in 2009 70% of women continued to be employed in academia compared to 88% of men. By 2012, only 54% of women remained in academia compared to 81% of men.¹⁰

Team diversity boosts productivity and innovation, but research has shown women are exiting academia at a disproportionate rate early in their careers.¹¹



Alzheimer's Research UK has been proud to support the innovative work of female researchers, including:

Prof Maria Spillantini

Prof Maria Grazia Spillantini FMedSci FRS at the University of Cambridge was the first person to identify a key protein in the onset of dementia with Lewy bodies, a disease that is closely related to Parkinson's. **Her work has helped build understanding around the biochemical processes that cause brain cells to die in neurodegenerative diseases.** She also discovered errors in the tau gene in a specific form of familial frontotemporal dementia. Her lab continues to investigate the mechanisms that lead to brain cell death and develop innovative ways to investigate new drug targets. In 2013 she was elected a Fellow of the Royal Society – recognising her as one of the world's most distinguished scientists.

Dr Tara Spires-Jones

Dr Tara Spires-Jones is a Chancellor Fellow and Reader at the University of Edinburgh. **She studies two proteins that occur normally in the brain, tau and amyloid, but that start to behave abnormally in Alzheimer's disease.** This change causes a breakdown of the connections between the cells in the brain, eventually causing the cells to die. She has been able to show that reducing the amount of the two proteins in mice can protect cells, maintaining memory and thinking skills. She hopes to use this knowledge to develop new approaches to protect nerve cells from damage in Alzheimer's.

Dr Jo Barnes

Dr Jo Barnes is searching for biological indicators of Alzheimer's disease in the brain, called 'biomarkers'. She is currently running a long-term study comparing brain scans of people with dementia with changes in proteins in spinal fluid. **The study is revealing links between changes in brain scans and the biological changes happening in the brain in the disease, revealing more about what happens during the disease and how it could be detected at an earlier stage.**



Dr Delphine Boche

Dr Delphine Boche completed her PhD in neuroscience at the Institut Pasteur. She leads a group at the University of Southampton looking at the effects of inflammation and the role of immune cells in neurological disease. **Her important research is shedding light on how the immune system may become activated early in Alzheimer's disease and how this could drive the disease to get worse.** By understanding the molecular changes happening in immune cells in the brain, she is identifying new targets for treatment, as well as highlighting possible risk factors influencing the disease that could be avoided.

Dr Rita Guerreiro

Dr Rita Guerreiro is a geneticist who made the landmark discovery in 2012 that a change in the TREM2 gene increases the risk of developing Alzheimer's disease. **Her work sparked a new avenue of research into the disease focusing on the immune system, where TREM2 plays a role.** She has an Alzheimer's Research UK Fellowship at University College London where she studies the role of genetics in Alzheimer's as well as other rarer dementias. This work is crucial to understand these diseases and highlight new targets for treatment. In 2014, she was awarded European Grand Prix for Young Researcher by the Foundation for Research on Alzheimer Disease in recognition of her contribution to dementia research.

Dr Selina Wray

Dr Selina Wray is a Research Associate in the Institute of Neurology at University College London. Her work is focused on frontotemporal dementia, a form of dementia that can affect people as young as 30, which can dramatically affect a person's personality and behaviour. She is working on a state-of-the-art stem cell technique which allows her to create nerve cells from skin samples donated by people with dementia. **With this technique, she can create cellular models for neurological disease, addressing one of the great challenges of neuroscience.** The brain is the most complicated structure known to man, with a network of over 100 billion neurons, and a working model of the disease can help researchers understand how it develops and test new interventions. Dr Wray was recently awarded almost £1m for a groundbreaking new project, co-funded by Alzheimer's Research UK, to use her innovative technique to screen for potential new drugs.



The time to act is now

Dementia has a disproportionate impact on the lives of women, both for their likelihood of developing dementia, and as carers of someone with dementia. It is the leading cause of death of women in the UK.

However, many of the leading scientists making strides in the fight against dementia are also women. Their success in the future will be based in no small part on the participation of women in research and clinical trials, as well as the growth of the dementia research field in ways that attract and support women.

Thanks to focus and funding, other diseases have seen huge advances in recent years. We must now turn our efforts to dementia in support of the 850,000 people with the condition and the millions more who are partners, daughters, sons, and friends.

Women are marginalised when it comes to dementia. They are more likely to die from the condition than anything else, they bear a disproportionate burden when it comes to caring for people with dementia and we are not making enough of the talent we have in the UK because there are not enough female scientists fighting the diseases.



References:

1. Seshadri, S et al. (2006) The lifetime risk of stroke: Estimates from the Framingham Study. *Stroke*; 37(2):345–50
2. Ott BR, et al. (1996) Gender differences in the behavioral manifestations of Alzheimer's disease. *Journal of the American Geriatrics Society*; 44(5):583-587. <http://europepmc.org/abstract/MED/8617910>
3. Fallah, N et al. (2009) Modeling the impact of sex on how exercise is associated with cognitive changes and death in older Canadians . *Neuroepidemiology*; 33(1):47-54. <http://www.ncbi.nlm.nih.gov/pubmed/19365142>
4. ONS (2014) Deaths Registered in England and Wales (Series DR). DH. http://www.ons.gov.uk/ons/dcp171778_381807.pdf
5. ONS (2013) National Life Tables, United Kingdom, 2010-2012.
6. ONS (2014) National Life Tables, United Kingdom, 2010-2012. <http://www.ons.gov.uk/ons/re/lifetables/national-life-tables/2010---2012/stb-uk-2010-2012.html>
7. Alzheimer's Association (2014) Factsheet: Women and Alzheimer's disease. http://www.alz.org/documents_custom/2014_facts_figures_fact_sheet_women.pdf
8. Creighton, H (2014) Europe's Ageing Demography. ILC. http://www.ilcuk.org.uk/images/uploads/publication-pdfs/Europes_Ageing_Demography.pdf
9. Government Equalities Office (2014) Think, Act, Report: Mending The Gap. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/371077/Think__Act__Report__mending_the_gap.pdf
10. The Royal Society of Edinburgh (2012) Lifting Barriers to Women in Science, Technology, Engineering and Mathematics: A Strategy for Scotland.
11. Wellcome Trust (2013) House of Commons Science and Technology Committee: Women in STEM careers. Wellcome Trust.

Alzheimer's Research UK is the UK's leading dementia research charity. As research experts, we specialise in funding world-class, pioneering projects at leading universities to find preventions, treatments and a cure for dementia.



Alzheimer's Research UK
3 Riverside, Granta Park
Cambridge, CB21 6AD
www.alzheimersresearchuk.org

Registered charity no. 1077089 and SC042474