



The **Impact** of Dementia on Women

How women are disproportionately affected
across their lives and what needs to change

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The Impact of Dementia on Women

Dementia has been the leading cause of death for women for over a decade. Although women have a longer life expectancy than men, it is not yet fully understood why they are at a greater risk of dementia. Biological and lifestyle factors both contribute and research is ongoing,

Women are also more impacted by dementia in other areas of their lives. They are most likely to become caregivers for a family member or loved one with dementia, with further implications for their social lives, financial stability, mental wellbeing and career progression. In dementia research, women make up the majority of the workforce, but are underrepresented in senior roles.

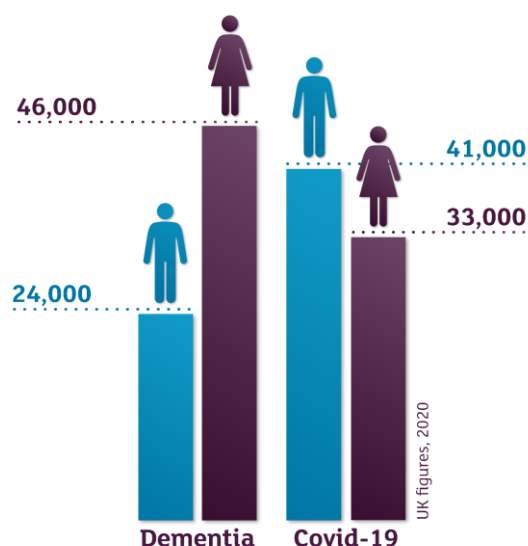
This analysis considers how women are impacted by dementia and what actions are needed to ensure that women have the best chance to benefit from future research and treatments for dementia.

Dementia is the leading cause of death for women

Dementia has been the leading cause of death for women in the UK since 2011¹. Dementia was the third most common cause of death in men in 2020, after COVID-19 and heart disease².

Nearly two thirds (65%) of the estimated 944,000 people living with dementia in the UK are women³. Around 46,000 women died of dementia in 2020, compared to 24,000 men^{1, 2}.

Women over the age of 60 are more than twice as likely to develop Alzheimer's disease than breast cancer for the rest of their lifetime⁴. The lifetime risk of developing dementia for women is one in five, compared to a one in 10 chance for men⁵.



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How do dementia risk factors affect women?

Although women have a longer average life expectancy (83 years) than men (79 years)⁶, this alone does not account for the higher incidence of dementia. Some of the biological and lifestyle risk factors for dementia can affect women and men in different ways. However, it is still not fully understood why dementia is more prevalent in women, which is why ongoing research in this area is so important.

Age and hormonal changes

The largest risk factor for dementia is age: prevalence in the over-65s is one in 14, increasing to one in six for those over the age of 80 years⁷.

More than twice as many women live past the age of 90 years compared to men⁸. However, longer life expectancy does not equate to more years of good health. Older age comes with an increased risk of many conditions, including hearing and sight loss, arthritis, depression and dementia.

People with dementia have increased rates of many other conditions, including cerebrovascular disease, stroke, Parkinson's disease, diabetes, anxiety and depression, and pneumonia⁹.

There is evidence that hormonal changes can impact cognition. After the menopause women have reduced levels of oestrogen, a hormone which has been linked to changes in cognition and an increased risk of developing dementia. Hormone replacement therapy has been trialled as a treatment for dementia, but results are inconclusive¹⁰. Some studies have suggested that starting periods earlier and later onset of menopause are associated with a lower risk of dementia¹¹.

Hypertension and physical activity

High blood pressure is a risk factor for both vascular dementia and Alzheimer's disease¹². Some evidence suggests there is a greater association between high blood pressure and dementia in women than in men, and that women who develop hypertension in their 40s are at a greater risk of dementia later in life¹³.

Low levels of physical activity, particularly in mid-life, have been linked with higher incidence of dementia¹⁴. With increasing age, physical activity tends to decrease for both sexes, however women are more likely to become less physically active than men earlier in life¹⁵.

Women in the UK have one of the lowest physical activity rates in the world¹⁶. The Active Lives Survey found that four in 10 women do not participate in enough activity to experience health benefits and that men take part in more sport and physical activity in almost every age group. There are around 300,000 fewer women than men who are regularly active¹⁵.

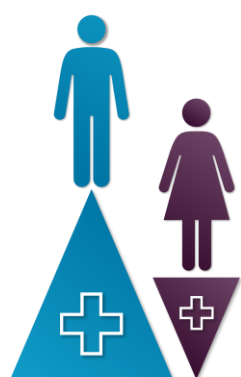
Living alone and loneliness

Social isolation and depression have been identified as two major risk factors for dementia. Higher levels of social contact are associated with better cognitive functioning in later life¹⁷.

Many older people experience loneliness as a result of living alone or following bereavement. Depression often accompanies feelings of loneliness¹⁸. Almost double the number of women over the age of 70 live alone compared to men¹⁹.

Older people who live alone can have more difficulty accessing health services and support. People who attend medical appointments alone are less likely to receive a formal diagnosis of dementia¹⁹.

Women receive worse healthcare than men



Healthcare ranking

Women receive worse healthcare than men in the UK, with the largest gender health gap in the G20 countries

The UK has the largest difference in male and female healthcare experiences in the G20 countries and the 12th largest globally, with women receiving worse healthcare than men. From global rankings of health and wellbeing including 156 countries, men's health is placed at 87th and women's health at 125th. Mexico, Australia and the US have some of the smallest gender health gaps in the G20¹⁶.

Early signs of dementia in women can present differently than in men, which could lead to higher rates of missed diagnosis or misdiagnosis. For example, women are more likely to retain their verbal memory and word recall during mild cognitive impairment and the early stages of dementia, and may therefore score higher on screening tests²⁰.

Individuals living with dementia receive less medical care than those without. Women with dementia receive less health monitoring, fewer GP visits and stay on potentially unsuitable medication longer than men²¹.

Medical research overlooks sex differences

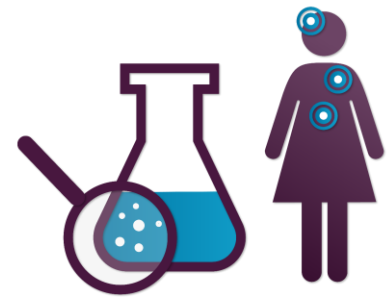
Women experience drug effects differently to men and have a 1.5 times greater risk of negative side effects²². Despite this, 72% of randomised controlled trials reviewed did not report any sex-specific outcomes or any explanation for not doing so²³.

In animal research, male animal models outnumber female models by 5:1. Where female data is used and analysed, it is often disregarded if it does not fit the typical male pattern²⁴.

There are typically fewer research participants from older age groups in studies²⁵. Lower numbers of participants make it harder to analyse by sex differences, reducing the likelihood of this analysis taking place.

Female volunteers for dementia research studies are typically older, and are more likely to have multiple health conditions and take more medication than male volunteers. Due to this, they are more likely to be excluded from opportunities to take part in research²⁶.

Alzheimer's Research UK requires that research we fund has considered equity, inclusion and diversity when determining study populations. The sex of the animals studied must be specified in research proposals, with an expectation that both sexes will be included.



Women are less likely to be included in clinical trials, despite experiencing drug reactions more often than men

Women are more likely to become carers for loved ones with dementia



Around two thirds of unpaid carers of people with dementia are women

Around two thirds of unpaid carers of people with dementia are women^{27, 28}.

In the UK, 81% of unpaid carers experience isolation, depression and anxiety in their role²⁹, all of which are contributing factors for cognitive decline.

Female carers spend more hours in their caregiving role than male carers and are 2.5 times more likely to live with the person they care for⁴. Between the ages of 45-54 years, one in five women will provide unpaid care to an older friend or relative³⁰.

Giving up work or reducing working hours in order to provide care for a loved one impacts on mental wellbeing and financial stability; almost 40% of carers reported that they struggled to make ends meet³⁰.

People providing unpaid care are 2.5 times more likely to experience psychological distress and poor health than non-carers³². More women (62%) than men (50%) are worried about the impact of caregiving responsibilities on their physical and mental health³¹.

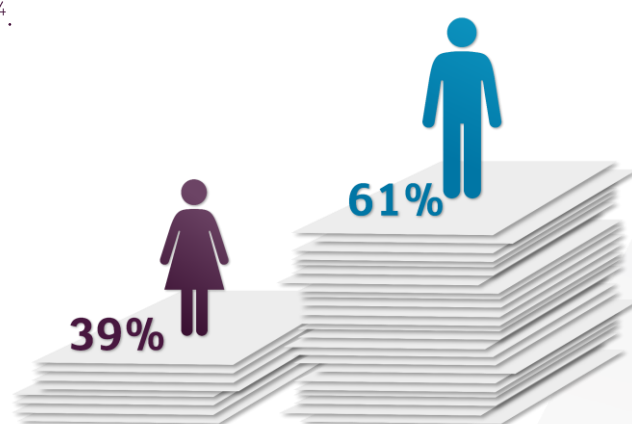
More female carers (56%) are concerned about not being able to cope financially due to caregiving responsibilities than male carers (45%)³². Currently, more than one million unpaid carers live in poverty in the UK³³.

Women are underrepresented in senior research roles

Just 22% of the UK's STEM (science, technology, engineering and mathematics) workforce are women, and only 13% of management roles are held by women³⁴. Female researchers are more likely to leave academia before reaching senior positions³⁵.

During the COVID-19 pandemic, the number of publications from female academics decreased while publications from male researchers increased. A reduction of almost 20% was seen in the number of women as lead or senior authors on research papers³⁶.

The majority of dementia researchers are women (60%), but an increase in junior female researchers has not translated to an equivalent increase in senior female researchers. In 2020, women held 39% of senior research positions³⁵.



Female dementia researchers are less likely to become senior academics

At Alzheimer's Research UK, we have found that 37% of our grant applications are awarded to female researchers. Early career researchers received 64% of grants and senior researchers received 33% of grants³⁵.

As part of our efforts to improve the diversity of researchers working in dementia, Alzheimer's Research UK will trial new ways of reviewing research grant proposals, with applications being anonymised to limit the possibility of bias among reviewers. We are also introducing narrative CVs, allowing applicants to discuss their broader contributions to the field.

“Having seen how dementia affected my mum from a young age and knowing my grandma went through the same, I want to do all I can to change the status quo for women in the future”

Carli Pirie
Research volunteer

Recommendations

This report identifies key areas where women are more likely to experience the impact of dementia than men. Our recommendations call for government, policymakers and other stakeholders to recognise and prioritise dementia as a significant issue for women's health, and to address inequalities in healthcare and research.

Recommendation 1: The UK government's Dementia and Women's Health strategies need to recognise the disproportionate effect of dementia on women, and target this as part of their implementation.

- The Department of Health and Social Care should ensure that there is a unified and strategic approach to addressing the risk of dementia in women across the two strategies.
- Increased funding is needed for dementia research, in line with the government's commitment to the Dementia Moonshot, which includes the prioritisation of risk factors and outcomes for women.
- The concept of Brain Health should be embedded across government departments and policies, with specific emphasis to raise awareness and address dementia risk factors that particularly impact upon women.
- Health Education England, in conjunction with the relevant medical Royal Colleges, should provide training on the difference in clinical presentation of dementia between women and men.

Recommendation 2: Regulators and funding bodies should set out expectations and give clear guidance to reduce the gender data gap and improve the diversity of participants in clinical trials.

- Funding bodies should ensure they have clear recommendations and guidelines in place that include the use of animal models of both sexes; inclusion of both male and female participants in clinical trials; and disaggregation and analysis of data by sex.
- Peer-reviewed academic journals should encourage researchers to report clinical trial results by sex regardless of null results.
- Protocol development should be more flexible to ensure that women are not excluded from dementia trials due to common comorbidities and medications.
- Regulators should signal an ambition to achieve greater diversity within clinical trials and share innovation to ensure that trials adequately represent individuals affected by dementia.

Recommendation 3: Research organisations and funders, including the life sciences industry, NHS, government, academic institutions and charities should have clear plans to "break the bias" and demonstrate that female researchers can participate on an equal basis with male researchers.

- More support should be available for women and early career researchers to progress in academic roles, including mentoring and assistance through absence due to caring, illness or parental leave.
- Evaluation and progression in academic roles should recognise a wider range of work and contribution, including teaching, mentoring, engagement activities and publication history.
- Additional innovative measures should be piloted to reduce bias in the application process, including narrative CVs and anonymisation of grant applications and peer reviews.
- Groups which represent the sector, such as the Association of Medical Research Charities, should facilitate the sharing of best practice.

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