

REPORTED FEATURE | SOCIAL JUSTICE & PUBLIC HEALTH

The Invisible Workforce

*Dementia, Carers and the Hidden Crisis in Plain Sight —
Who Really Pays the Price, and What Education Could Change*

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The UK has nearly 6 million unpaid carers. Globally, dementia is projected to affect 153 million people by 2050. The people keeping this crisis from complete collapse are largely invisible — unrecognised, underpaid or not paid at all, and quietly sacrificing their own health, income and futures. This is their story.

1. The Scale of What We Are Facing

Dementia is not a future crisis. It is a present one, accelerating in plain sight.

In the United Kingdom, approximately 982,000 people are currently living with dementia — a figure projected to reach 1.4 million by 2040 (Alzheimer's Society, 2024; Wittenberg et al., 2019). Of those, an estimated 71,000 are living with young-onset dementia, diagnosed before the age of 65, many of whom are still working, parenting and engaged in the full spectrum of adult life when symptoms first emerge (Alzheimer's Society, 2023).

Globally, the picture is more staggering still. The WHO estimates that dementia prevalence will rise from 57.4 million cases in 2019 to 152.8 million by 2050 (Global Burden of Disease Study, 2021). A new case of dementia emerges somewhere in the world every four seconds. The annual global cost already exceeds US\$1.3 trillion — a figure projected to reach US\$2.8 trillion by 2030 (World Medical Association, 2024).

In the UK alone, the total cost of dementia reached £42 billion in 2024 and is forecast to nearly double to £90 billion by 2040 (Carnall Farrar for Alzheimer's Society, 2024). Yet the vast majority of this cost — 63% — is borne not by the state, but by individuals and their families.

<p>982,000</p> <p>people in the UK living with dementia</p>	<p>£42bn</p> <p>total UK dementia cost in 2024</p>	<p>153m</p> <p>projected global cases by 2050</p>	<p>63%</p> <p>of costs borne by individuals & families</p>
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2. The Unpaid: The Workforce Nobody Hired

Behind every person living with dementia, there is almost always someone else — a partner, an adult child, a sibling, a friend — quietly absorbing the work that the state does not do.

“I didn't choose to become a carer. I was a wife. Then, slowly, I became something else entirely. I stopped sleeping properly about two years in. I stopped seeing friends. I stopped being able to say how I was, because the honest answer took too long to explain.”

— Composite voice — drawn from documented carer experiences, *Dementia Carers Count, 2024*

There are 5.8 million unpaid carers in the UK (Carers UK, 2024). The economic value of the care they provide in England and Wales alone is estimated at £162 billion per year — 29% more in real terms than in 2011 (Centre for Care, 2022). For dementia specifically, unpaid care represents £21.1 billion of the UK's total annual dementia costs — the single largest component, accounting for 50% of all dementia expenditure (Alzheimer's Society, 2024).

A third of unpaid dementia carers report spending more than 100 hours per week providing care — more than two and a half full-time jobs, without pay, without employment rights, and without a contract (Carnall Farrar, 2024). Meanwhile, only 14% of carers receive any form of respite care.

2.6 million people in the UK have given up work entirely to care, and a further 2 million have reduced their working hours (Carers UK, 2024). The State of Caring 2024 survey found that 40% of all carers had left employment to take on caring responsibilities. More than half of working carers — 56% — said they could not use their statutory right to Carer's Leave because of financial anxiety about taking unpaid time off.

The poverty rate for unpaid carers is 50% higher than for non-carers (Carers UK, 2024). Leaving employment to care does not only affect immediate income — it erodes pension contributions, career progression and long-term financial security, often permanently.

By 2040, the demand for unpaid dementia care is projected to increase by 43%. Without systemic intervention, the gap between what the state provides and what families absorb will only widen.

The unpaid carer workforce is the largest, most exploited labour force in the country — and it operates entirely outside employment law.

3. A Gendered Crisis

Caring is not gender-neutral. Approximately 70% of dementia carers worldwide are women (WHO; Dementia Statistics & Facts, 2024). Globally, 50% of dementia costs are covered by informal care — and that informal care is predominantly provided by women (WHO, 2021). Women also face a higher lifetime risk of developing dementia themselves: the lifetime risk for a woman over 45 of developing Alzheimer's disease is approximately 1 in 5, compared to 1 in 10 for men.

"My career had just started to go somewhere. I'd been promoted twice. Then my mother's diagnosis came, and there was no one else. My brother lives in Australia. My father passed away. So it was me. It's always the daughter."

— Composite voice — drawn from documented carer experiences

The Lancet Commission (2024) identified that despite dementia disproportionately affecting women — both as patients and as carers — 57% of the modifiable risk factors identified in its framework are more prevalent in men. The system that generates dementia risk, and the system that absorbs its care burden, are both shaped by gender inequality. Neither has been adequately addressed by policy.

4. What Caring Does to Those Who Care

The health consequences of unpaid caring are severe, documented, and largely ignored by public health policy.

85% of dementia carers have reached crisis point, according to a 2024 survey by Dementia Carers Count. One in five unpaid carers report neglecting their own health while providing care. More than 50% of caregivers globally report deterioration in their own health as a direct result of caring responsibilities (Dementia Statistics & Facts, 2024).

The psychological burden is equally significant. Nearly 70% of dementia carers globally report high levels of stress. A longitudinal US study found that carers reporting mental or emotional strain had mortality risks 63% higher than non-carers, even after controlling for demographic factors (Carers UK, 2024).

Caring can have a negative impact on physical health, mental health, social relationships, employment and financial security — simultaneously, and over extended periods that often last years. Public Health England has classified caring as a social determinant of health.

"I went to the GP for the first time in three years last month. She asked me how I'd been. I didn't know where to start. My back has gone. I haven't slept properly since 2021. I haven't cried in so long I've forgotten what it feels like."

— Composite voice — drawn from documented carer experiences

36.3% of unpaid dementia carers have caring responsibilities for more than one person simultaneously. And yet the Carer's Assessment — the legal mechanism through which carers are entitled to support — remains poorly understood and underused. 39% of carers who had not received an assessment cited not knowing what it was as the primary barrier (Carers UK, 2024).

5. The Paid: A Workforce in Crisis

For those who choose caring as a profession, the financial reality is stark. Care workers in the UK earn some of the lowest wages in the developed world.

The average care worker wage in the independent sector was £12 per hour in 2024 — below which 80% of all UK jobs are paid (Health Foundation, 2024). Care workers are paid £4.88 per hour less than the average UK wage. A support worker in the NHS starts at £21,730; their equivalent in the independent social care sector averages £16,500 (Community Integrated Care, 2024).

United Kingdom	£12 (independent sector avg, 2024)	Below 80% of all UK jobs
Germany	~£13.70/hr	Strong union representation
Australia	~£13–16/hr	+ penalty rates for nights/weekends
Norway	~£17.50/hr	Extensive social benefits, job protections
United States	£11.80–£14.10/hr	Varies significantly by state

The vacancy rate in adult social care in England is 8.3% — three times the wider economy rate of 2.7%. Annual staff turnover runs at approximately 25%, with care workers leaving for retail, hospitality and other sectors that offer comparable or better wages without the emotional and physical demands of dementia care (Skills for Care, 2024).

82% of care workers surveyed said they had considered leaving the sector in the previous year, citing low pay as the primary factor. The sector is losing experienced staff faster than it can recruit or train replacements. And only around a third of the care workforce in England has received any dementia-specific training (Skills for Care / CQC, 2024).

"I've been doing this for eleven years. I know these residents. I know what they like, what calms them, what frightens them. And I earn less than the person making sandwiches at the supermarket down the road. I'm not bitter. But I notice."

— Composite voice — drawn from documented care worker experiences

The Gangmasters and Labour Abuse Authority reported that 61% of all labour abuse complaints in the first quarter of 2024 concerned the care sector — a sector where exploitation of migrant workers, zero-hours contracts and unpaid travel time between visits remain widespread (Hansard, 2024).

The care workforce is twice as likely to live in poverty as the average UK worker (Health Foundation, 2024). The Employment Rights Bill (2024) proposes a Fair Pay Agreement for adult social care — but the Spending Review did not provide sufficient funding to both meet growing demand and deliver meaningful wage increases simultaneously.

We have built an entire care system on the assumption that some people's time is worth almost nothing. That assumption is not sustainable — and it is not just.

6. The Economy and the Forecasts

The economic implications of the dementia care crisis extend far beyond the immediate costs of care provision.

The total cost of dementia to the UK economy in 2024 stands at £42.5 billion, with 77% attributable to social and unpaid care (Alzheimer's Society / Carnall Farrar, 2024). By 2040, this is projected to reach £90 billion — a figure that does not yet account for the compounding costs of an underfunded care workforce, carer health deterioration, and lost economic productivity from the millions who have left or reduced their employment to care.

The per-person annual cost of dementia care rises from £28,700 for mild dementia to £80,500 for severe dementia — a nearly threefold increase. The costs of social care alone are projected to reach £40.7 billion by 2040. 43% more people are expected to require domiciliary care by then. By 2040, an additional 76,000 people with dementia are projected to be living in residential care, and 30,000 more in nursing homes (Carnall Farrar, 2024).

Globally, the WHO reports that the annual cost of dementia is expected to rise from US\$1.3 trillion in 2019 to US\$2.8 trillion by 2030. Of that global figure, 50% is attributable to informal care — the same unpaid, invisible, largely female workforce described throughout this article.

Despite this, spending on dementia diagnosis and treatment represents only 1.4% of total dementia healthcare costs. The system is investing almost nothing in identifying and treating the condition early — at precisely the point where intervention is most effective and least expensive.

7. Education Is the Most Powerful Intervention We Are Not Scaling

The Lancet Commission on Dementia Prevention, Intervention and Care (Livingston et al., 2020) identified that up to 40% of global dementia cases are attributable to modifiable lifestyle and environmental risk factors. The 2024 update extended this to 14 identified risk factors, suggesting that up to 45% of cases could theoretically be prevented or delayed through targeted intervention.

These risk factors include: low levels of education in early life, social isolation, physical inactivity, smoking, excessive alcohol consumption, obesity, hypertension, diabetes, depression, hearing loss, traumatic brain injury, air pollution, cardiovascular disease, and — critically — poverty and wealth shocks (Livingston et al., 2020; Lancet Commission, 2024).

Education emerges as both a protective factor and a delivery mechanism. Higher levels of education in early and mid-life are associated with greater cognitive reserve — a kind of neurological resilience that delays the onset of dementia symptoms. Public health education that reaches adults aged 25–50 with accurate, accessible information about modifiable risk factors represents one of the highest-return investments available to policymakers.

Yet awareness of dementia risk remains critically low. A significant proportion of the public still believes dementia is an inevitable consequence of ageing — a perception that removes the motivation to act preventatively.

The WHO Global Action Plan on the Public Health Response to Dementia (2017–2025) set a target of 75% of countries providing support and training programmes for carers and families by 2025. Evidence indicates this target has not been met. The WHO's iSupport programme — a structured skills and knowledge training resource for dementia carers — remains severely underfunded and implemented at insufficient scale globally.

<p>SDG 3</p> <p>Good Health & Wellbeing</p> <p>Prevention reduces the number of people who develop dementia. Education about modifiable risk factors — delivered to adults aged 25–50 — represents a measurable, cost-effective public health intervention. Carer health must also be recognised as a health outcome in its own right.</p>	<p>SDG 4</p> <p>Quality Education</p> <p>Education in early and mid-life is a documented protective factor against cognitive decline. Livingston et al. (2020) identified low educational attainment as a primary modifiable dementia risk factor. Equitable access to quality education is therefore a dementia prevention strategy.</p>	<p>SDG 10</p> <p>Reduced Inequalities</p> <p>The dementia care burden falls disproportionately on women, on lower-income families, on migrant workers and on unpaid carers. The poverty rate among carers is 50% higher than the national average. Addressing care inequality is inseparable from addressing economic and gender inequality.</p>
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8. What Must Change: Policy Imperatives

<p>Recognise unpaid carers as a workforce</p>
<p>The state must acknowledge the £21.1 billion in annual care value provided by unpaid dementia carers. This means financial support, pension protection, access to Carer's Assessments, and paid Carer's Leave under the Employment Rights Bill.</p>
<p>Pay care workers a living wage</p>
<p>The Employment Rights Bill's Fair Pay Agreement must be fully funded. Care workers earn £4.88/hour less than the UK average. The poverty rate in the care workforce is twice the national rate. This is a political choice, not an economic inevitability.</p>

Invest in early diagnosis

Only 1.4% of total dementia healthcare costs are spent on diagnosis and treatment. Investment in early diagnosis reduces total costs significantly by extending time in mild stages and delaying the most expensive phases of care.

Scale dementia education nationally

Community-based education programmes targeting adults aged 25–50 — addressing modifiable risk factors including cardiovascular health, education, physical activity and social engagement — represent a measurable prevention strategy aligned with SDG 3 and SDG 4.

Address the gender dimension explicitly

Policy frameworks must explicitly recognise that dementia care is a gendered issue. Women are disproportionately affected both as patients and as carers. Any national carers' strategy that does not address gender inequality is incomplete.

Implement the WHO Global Action Plan targets

The UK must honour its commitments under the WHO Global Action Plan on the Public Health Response to Dementia 2017–2025. The 75% target for carer support programmes has not been met. The iSupport programme must be funded and deployed at scale.

9. Conclusion

Dementia is not a private tragedy. It is a public health emergency, an economic crisis and a social justice issue — and the people bearing most of its weight are the ones least visible in policy, least compensated in the labour market, and least supported in their own health.

The evidence is clear. Prevention is possible. Education works. Caring — when properly supported and fairly compensated — is one of the most valuable things a society can organise. And the current system is failing on every one of these dimensions simultaneously.

We know what needs to happen. We even know what it costs — and what it will cost if we continue to do nothing. The question is no longer one of evidence. It is one of political will.

The invisible workforce has been holding this crisis together for decades. It cannot hold it indefinitely.

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