

# Women's unpaid dementia care and the impact on employment



## Research limitations

One of the limitations of the research was only being able to review resources in English. Hopefully the information featured will inspire other countries to adapt the research for their own national context.

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# 1 Introduction

**Dementia is an urgent global health crisis that is only set to worsen<sup>1</sup>, yet, the specific health and care needs of people living with dementia are currently under-resourced by governments worldwide. As a result, dementia care continues to be predominantly provided informally by family and friends, at great social and financial cost to them.**

Unpaid dementia care is not equally shared between women and men. Worldwide, the vast majority is provided by women, typically wives, sisters, daughters and daughters-in-law.<sup>2</sup> Women's roles in providing dementia care support are often provided alongside other caring commitments and paid work. The progressive and long-term nature of providing dementia care can have both short-term and long-term impacts on these women's lives, as they juggle the financial, social and personal impact of caring for someone living with the condition.

With changing social and cultural family structures and women's growing economic equality (as a result of more girls staying in education for longer and more women accessing paid work opportunities outside the home), women are becoming less available as family carers.<sup>3</sup> However, worldwide unpaid dementia care is still primarily seen as the responsibility of female family members and friends. This is even the case in the UK where 63% of dementia care supporters are women.<sup>4</sup>

The UK government's 'Challenge on Dementia 2020' (previously known as the 'Prime Minister's Challenge on Dementia') is committed to improving the lives of people affected by dementia and for the UK to be the best place in the world for people affected by the disease. Whilst significant progress has been made in increasing awareness, diagnosis rates and funding into research, more needs to be done to recognise and support the role of family carers and the disproportionate impact on women.

Our increasingly ageing populations, including in the UK, means more and more family carers (disproportionately women) will be relied upon in the future to provide elder care, not just dementia care. As the UK government looks to extend our working lives to reflect longer life expectancies, supporting carers who want to combine work with caring will become increasingly critical to our economy, to employers, and to families and individuals.<sup>5</sup>

Alzheimer's Society continues to strive to support people affected by dementia and understands the personal, social and financial impact dementia care can create for families. In England, there are currently 5.4 million carers. An estimated 35% of those are caring for someone living with dementia, and a fifth of these people are balancing this with paid work.<sup>6</sup> Pressures to provide dementia care to a family or friend alongside paid work, not only impacts the wellbeing of the person providing the care support, but also the wellbeing of the person living with dementia whom they support.

This research report explores the scale of the disproportionate impact unpaid dementia care is having on women globally and the impact caring can have on their ability to continue paid work. The report then looks at the importance of government-led leave provision available to dementia care supporters, including international examples, before finally looking at the role of progressive business-led practices, with examples from the UK.

Alzheimer's Society recognises men's important role in providing dementia care and does not dismiss their experiences. Instead, we recognise the disproportionate impact and reliance, globally, on women to provide unpaid dementia care. If we ensure women affected by dementia, with their multiple care roles, get the right support to access paid work we will get it right for all employees with care commitments.

## Dementia: what does care support look like?

Dementia is an umbrella term for diseases affecting memory, other cognitive abilities and behaviour that interfere significantly with a person's ability to maintain their activities of daily living.<sup>7</sup> Although age is the strongest known non-modifiable risk factor for developing dementia, it is not a normal part of ageing.<sup>8</sup> As the condition progresses, people can be affected by the condition in different ways: the impact of the disease; the stage of the condition; how other people respond to them; and their environment around them.<sup>9</sup>

Someone living with dementia may need support with everyday activities and personal tasks, such as transportation, managing finances, scheduling appointments, shopping, bathing, dressing, going to the toilet, preparing meals and medication management. Because of the long-term and progressive nature of dementia, these tasks can change and become more acute, time-consuming and physically intensive for the care supporter as the condition progresses.

## 2 Unpaid dementia care disproportionately impacts women

### 2.1 Globally women provide the majority of unpaid dementia care

Globally, an estimated 50 million people live with dementia and because there is currently no cure for the condition, this number is projected to triple to 152 million by 2050. Women contribute around 71% of the global hours of informal dementia care, with the highest proportion in low income countries.<sup>10</sup>

Research carried out by Alzheimer's Disease International and the Karolinska Institutet in 2018 shows the scale at which millions of unpaid female carers are 'propping up' ineffective dementia care systems across the world. The research calculated that the annual global number of informal care hours provided to people with dementia was 82 billion hours, the equivalent of more than 40 million full-time workers (in 2015), with women contributing 58 billion of these hours.<sup>11</sup>

Women cannot (and should not) shoulder the responsibility for providing care for family members with dementia.<sup>12</sup> The unequal distribution of unpaid care is widely recognised in international debates as a barrier to women's economic empowerment and access to paid work opportunities.<sup>13</sup>

Carer's leave benefits and flexible working entitlements not only disproportionately support women to remain in the labour force, but as seen with the provision of both maternity and paternity leave, when these provisions are accessible and aimed at men and women in the workplace, they can also contribute to the redistribution of unpaid care in the home.<sup>14</sup>

Alzheimer's Society, via its international networks, has gathered evidence in 11 countries related to the gender dynamic of unpaid dementia care and has collected the experiences of women in the UK providing dementia care support to family members while balancing paid work and other family commitments.

**'There is understanding of the needs of someone with children and flexible working. But there needs to be greater support and flexible working for employees who are taking care of elderly relatives.'**

Female carer, supporting her father with Alzheimer's Disease

### 2.2 Women face social and cultural expectations to fill the family care role

For many women, pressure to provide dementia care can be a result of a lack of affordable, accessible and high-quality dementia care services in their communities. But for many women it can be a result of social and cultural expectations, where it is often assumed that family members, specifically women, are willing and able to provide care for relatives with dementia.<sup>15</sup> A study by Dr Sahdia Parveen at the University of Bradford found that this is particularly the case when considering south Asian (Pakistani, Indian and Bangladeshi) families in the UK, whereby female family members are considered culturally obligated to provide dementia care at home.<sup>16</sup>

The extent to which this occurs by choice is unclear, though the preference for women to take on the role as a family carer appears to stem from deep rooted gender norms.<sup>17</sup> There is the common assumption that women are better carers,<sup>18</sup> and whilst there are certain personality traits that may support such notions (e.g. nurturance),<sup>19</sup> there is no conclusive evidence that women make better carers than men.<sup>20</sup>

Societal messages often dictate that caring behaviours are linked to being female, and therefore can create the expectation that women should fulfil this role when such a situation arises. These societal messages can also lead to external pressure, making women feel guilty if they choose not to adopt the carer role. Importantly, women are expected to become carers even if they do not have sufficient knowledge, or sufficient preparation to become a carer.<sup>21</sup>

Conversely, there is little societal pressure for men to become carers, in fact, there may be more societal and cultural pressures acting on men not to become carers. Globally there are many examples of the view that men should be masculine (e.g. *machismo* in Latin America), to which nurturing and caring behaviours do not conform.<sup>22</sup>

Women will continue to provide care, whether this is due to societal expectations, or an individual wish to support members of their family and friends living with dementia. The long-term and progressive nature of dementia care, not only creates a barrier to these women's access to financial independence through paid work, but it can impact their own health and wellbeing, as well as their ability to participate in all aspects of social, economic, cultural and political life.<sup>23</sup>

## 2.3 Women fill the gap in accessible, affordable and appropriate dementia care

Despite the World Health Organization's recognition of dementia as a global public health priority,<sup>24</sup> awareness of the condition is low worldwide. For example, Alzheimer's Disease International's global survey (from 2019) of 70,000 people found that almost 62% of healthcare providers worldwide think that dementia is a normal part of aging.<sup>25</sup> For countries where dementia awareness is low, dementia health and care provisions and services are likely to be under-resourced and unavailable to family and friends seeking support. As a result, the support needs of family and friends caring for someone living with dementia are not likely to be met by governments or employers.

Dementia is a long-term and progressive condition, associated with complex needs, that requires a range of health and social care services.<sup>26</sup> However, people with dementia are frequently denied the basic rights and freedoms available to others. To ensure that people with dementia can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity, they need integrated, person-centred, accessible, affordable health and social care, including long-term care.<sup>27</sup> However, in most countries the long-term care is provided by friends and family without additional government-funded support.

In the UK, unpaid dementia carers are providing care to the value of £13.9 billion each year.<sup>28</sup>

Women disproportionately provide 63%<sup>29</sup> of the care, an estimated £8.8 billion per year<sup>30</sup>. For people affected by dementia the alternative to unpaid family care, is a privately run care home which, in the long-term, can create catastrophic care costs. Over the past two decades, the average cost of a nursing home place in the UK has almost doubled and is now nearing £1,000 a week. The typical cost of dementia care is £100,000, resulting in people often spending all of their life savings on care. Due to the complexity of the condition, the cost of dementia care is on average 15% more expensive than other types of social care, often referred to as the 'dementia penalty'.<sup>31</sup>

For the UK, the proportion of older people with dementia who have severe dementia is projected to rise in the next decade.<sup>32</sup> The likelihood of living in a care home increases with severity of dementia, which means that in future a higher proportion of people with dementia are likely to live in care homes, rather than receive care in the community.<sup>33</sup> To meet the growing demand for dementia care as prevalence rises, the Care Quality Commission (England's independent regulator of health and social care) estimates the need for 40,000 additional care home places by 2021 for people with dementia. Current trends suggest only an extra 9,000 beds will be available for everyone by 2022.<sup>34</sup>

Lack of awareness and continued gaps in affordable, accessible and appropriate dementia care, will continue to put pressure on women to fill the care gap, often alongside other care responsibilities and paid work.

### Mrs Javanie's experience of juggling full-time work and her father's 24-hour care

Mrs Javanie works full-time for a private company and lives with her father, who was diagnosed with Alzheimer's Disease nearly four years ago and now needs 24-hour support. Mrs Javanie's family all support, ensuring their father has a rota of round-the-clock care. She says that in their Indian culture they wouldn't even think about putting their father in a care home.

Each day before Mrs Javanie can leave to go to work, one of her sisters arrives at her house to support their father during the day. But if something happens in the morning, Mrs Javanie can be delayed getting to work. **'They do know that I get to work late, they think I'm just sleeping but I'm not, there are a lot of things you've got to do before you leave your home.'**

Mrs Javanie is currently on a short-term contract which means she hasn't had access to flexible working opportunities at the company. Despite telling her employer that she is a carer for her father, they haven't made any changes to support her. She says she feels that they could end her contract at any time. **'Nobody really understands that you are living with somebody 24/7, it's only a person who has lived with someone with Alzheimer's who will understand.'**

When asked what support she would like from her next employer, Mrs Javanie said she would benefit from carer's leave, flexible working, compressed working hours and the opportunity to work from home one day a week.

## 2.4 Taking on dementia care doesn't mean other caring commitments stop

It is important to recognise women's experiences of dementia care, as they can be different to that of men's. Women's dementia care roles can happen alongside other (unpaid) responsibilities in the home, such as; cooking, cleaning and caring for children, disabled, sick or elderly relatives, while also juggling and seeking paid work. The majority of these women are aged between 40 and 70, often referred to as the 'sandwich generation' because they provide care to young children as well as support to older family members.

Prevalence estimates of 'sandwich caring' in the UK vary considerably but studies suggest up to 10% of the population provide sandwich care, 84% of which are women.<sup>35</sup> All caring, 'sandwich caring' in particular, has a detrimental impact on employment, especially on full-time employment.<sup>36</sup>

Support in the workplace from managers, through carer's leave and flexible working, can provide immediate relief for working women with dementia care commitments.

Providing dementia care can be stressful for family carers and have a negative impact on their own wellbeing and quality of life.<sup>37</sup> Alzheimer's Disease International's global survey from 2019 of 70,000 people affected by dementia, found that 75% of carers said they were 'often stressed between caring and meeting other responsibilities'. Even whilst expressing positive sentiments about their caring role, over 50% of carers said their health suffered as a result of their caring responsibilities.<sup>38</sup> Research shows that women who care for people with dementia also feel less supported than their male counterparts. Wives caring for their husbands in the later stages of dementia reported receiving less support from friends and family than husbands caring for their wives in similar circumstances.<sup>39</sup>

### Joanne's experience of juggling her mother's care with work, while bringing up her young son

Joanne has been a care supporter for her mum who has been living with Alzheimer's Disease for over 10 years. When Joanne was in her twenties, she saw her mum care for her grandmother. Now she is doing the same for her mum, while also caring for her own child.

As well as balancing the care needs of her young son and her mum, Joanne also supports her family while juggling her work commitments. Joanne says, **'Over the 10 years I have found the whole experience terribly stressful and lonely. The thing about caring for someone with Alzheimer's is that you feel you're on your own.'**

Joanne has been able to juggle her mum's care commitments by reducing the number of days she worked and by using her annual leave. Before she had her son, Joanne says, **'I had two days off a month and those two days I would spend with my mum because I needed to take her shopping or to the doctors'**. When returning to work after having her son, Joanne worked three or four days a week and dedicated one day to visiting her mum at home, bringing her baby with her.

During the last nine months Joanne's mum lived at home, Joanne organised care for her mum while she was at work. During that time, Joanne spent her work breaks checking up on her mum or answering calls. **'For me I wanted to keep my mum at home for as long as possible because I thought that was the right thing to do [...] We kept her at home until the consultant said she needed 24/7 care.'**

Joanne had one female manager who understood her circumstances because she had also been a carer for a family member living with dementia. When Joanne's mum was due to move into respite care, she was given two days' paid carer's leave to support her mum's move. But for those two days Joanne paid for her son to go into nursery while she supported her mother.

**'She's in a care home now, but it still has its challenges. The whole journey is very different from start to right now.'**

When asked, if anything was possible, what employer support would she have benefitted from, Joanne mentioned, **'It would have been helpful if my manager had said "you're a carer, how can we help and support you?". And to be told how many days a year to take for carer's leave and unpaid leave.'**

During the early stages of her mum's condition, Joanne felt it was practical help, such as filling out forms and knowing where the care centres were, which was really important. But as time goes on, she says she would have benefitted from emotional support. During her experience supporting her mum, Joanne hasn't been offered any additional supportive changes or wellbeing support from her workplace.

**'There has been joy, pleasure and feelings of privilege of being a carer for someone with Alzheimer's amidst the loss and difficulties.'**

Providing care to family and friends with dementia can create cumulative emotional pressures upon employees. Caring does not just have a physical component associated with practical care activities, but also a mental component associated with stress, anxiety and tiredness. Carers UK's survey of employees providing dementia care found that over half of respondents (53%) said that their work had been negatively affected due to their caring responsibilities, as a result of tiredness, anxiety and stress, for example.<sup>40</sup>

The UK's largest study of people's experiences of living well with dementia, the IDEAL research programme led by the University of Exeter,<sup>41</sup> has identified three things that are most important to family carers: the need for a better understanding of dementia; access to psychological support; and the ability to access help when needed.<sup>42</sup> These findings

reinforce the importance of providing support to family carers and helps us to understand what kinds of support may be most helpful to them, including in the workplace.

It is vital to ensure that family carers are supported both emotionally and practically in order to reduce stress levels and increase feelings of competence. The IDEAL research programme's findings show that what a family carer is experiencing is important, not just for their own wellbeing, but also for the wellbeing of the person with dementia for whom they provide care.<sup>43</sup> Employers play an important role in supporting employees with care commitments, in all three areas from: understanding dementia and the employees' commitments, to providing wellbeing support, as well as providing a supportive working environment through carer's leave provisions and flexible working practices.

### Joy's loss of earnings to provide care for her mum

Joy lives in north west London with her mum. Joy worked as a medical secretary before having to stop work three years ago to provide full time care support for her mum living with vascular dementia. While caring for her mum over the years, Joy has also juggled support with her father's illness, her daughter's health needs and her own health, which has deteriorated since her mum's care has become more physical.

When Joy's mum received a diagnosis eight years ago, Joy juggled work alongside support for her mum. **'In the beginning it wasn't too bad because she was able to do things for herself.'** But after her mum's condition progressed, juggling work and support to her mum got more difficult.

Before leaving for work Joy would leave her mum's lunch and medication out, but when she returned from work her food and pills would still be sitting there untouched. **'I started to feel guilty that I was going out to work, leaving her and she wasn't eating.'**

Joy reduced her hours to support her mum's care. During this time, Joy's manager was very supportive and allowed her to work flexible hours and take paid leave to take her mum to appointments. **'I was very lucky, I had a very good manager who was very helpful because she had been through it herself – her father had dementia and lived in a care home.'** Then three years ago Joy had to stop her job completely, to support her mum full-time.

Joy mentions that she doesn't think it would be possible for her to step back into her old job. **'I would have difficulty going back into a job because my age is against me and I've been out of work for three years now.'**

**'I don't fancy putting my mum in a home.'** Growing up in her Caribbean community, Joy said families looked after their elders and relatives and putting them in a care home wasn't something you thought about.

Caring for her mum and having to stop work has had a huge financial and social impact on Joy's life. **'If I want to go to the theatre, I have to pay for a carer but I can't afford it now.'**

**'Just over £200 for Carers Allowance is not a lot when you have to give up your job to care for someone. I'll soon be getting my pension but I have lost nearly £2,000 a month in wages. Now I'm living on just over £200 a month. It's not a fair exchange. Carers are saving the government a lot of money. If they were to take care of that person, it would cost them more than £200 a month. It's ridiculous.'**

## 3 Women's dementia care commitments create barriers to paid work

### 3.1 Women dementia carers often have to make changes to their employment situation

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.<sup>44</sup> Age UK and Carers UK's research shows that the risk of withdrawing from the labour market increases when people start to care, even for as few as five hours per week, and that employees caring for more than 10 hours per week are at marked risk of leaving paid work.<sup>45</sup> Older women are much more likely than men to stop work as a result of their caring responsibilities. This disparity is particularly acute for low-income older women.<sup>46</sup>

As the care support for someone living with dementia increases over time, employees can find it harder to work their contracted hours. Employees with dementia care commitments may need to take time away from work, change their working hours, or leave the workforce entirely, in order to meet the person's care needs and their own. According to the 2018/19 Survey of Adult Carers in England (SACE), 21% of working age carers who support someone with dementia, have had to reduce their work commitments or are having difficulty balancing work and caring.<sup>47</sup> With the support of managers, carers should have the opportunity to remain in work, by adapting their working patterns and hours, including the option to reduce their hours.

Women who took part in this research shared that the most supportive and understanding managers were those who had known or cared for someone living with dementia themselves and understood the nature of the condition and type of care support required. This shows the importance of increased awareness and understanding of dementia as a long-term medical condition with complex, specific and changing care needs.

Reducing or stopping paid work can have both short- and long-term financial impacts for women, including loss of income, challenges to career progression and a reduction in final salary pension. For older women who reduce their hours or stop work completely, they can find themselves depleting savings and ending up in financial hardship, ill prepared for their own retirement and care costs.<sup>48</sup>

Multiple layers of financial pressures and social responsibilities can compound feelings of stress. This can result in carers themselves experiencing health problems, such as exhaustion, stress and a more rapid deterioration in existing physical and mental health conditions. In Carers UK's State of Caring 2017 survey, 40% of carers said they hadn't had a day off for more than a year and 25% of carers said they hadn't had a day off from caring for more than five years.<sup>49</sup> Carers who hadn't taken a break from caring within the last year were also more likely to report that their mental or physical health had suffered as a result of caring.<sup>50</sup>

**'We have only been allowed to have carers coming in for seven hours a week, I requested 11 hours but social services refused. So Arthur spends hours on his own during the day.'**

**Arthur needs more attention, but I can't give up work as we cannot afford to live on the benefits we receive. My health is suffering because of the pressure on me and I find it difficult to sleep because I worry about Arthur constantly when I'm not there.'**

Jennifer talking about her husband Arthur living with Alzheimer's Disease<sup>51</sup>

### 3.2 Women are more likely to take on less flexible care roles

The impact of providing dementia care support on paid work will impact everyone differently. The experience of juggling paid work and care will not only depend on the type of work the person does but will also depend on the type of dementia care support they provide.

European time-use surveys of people providing a caring role for someone living with dementia reveal persistent inequalities between women's and men's care activities. On average, working women in Europe spend 26 hours a week on unpaid caregiving, compared with nine hours for the average working man.<sup>52</sup> As a result, women are more likely than men to reduce their paid work to part-time or stop work completely to provide care, negatively impacting financial income and career progression opportunities.

Some research suggests that more women than men also provide more demanding and intensive forms of daily caring, such as bathing and dressing, continence care and walking. For example, in the UK, women are 2.5 times more likely to provide 24-hour care support to someone living with dementia.<sup>53</sup> These tasks are less time-flexible, and therefore create challenges to women being able to work flexibly, resulting in more women going part-time or leaving the workplace completely.

In the UK, among working women dementia carers, 20% have gone from working full-time to part-time, compared with only 3% of working male carers.<sup>54</sup> Time spent caring increases with disease severity, and 50% of carers of people with late-stage dementia spent more than 10 hours a day caring.<sup>55</sup> The long-term and progressive nature of dementia often results in women leaving the workplace completely.

### 3.3 Juggling care commitments impacts women's career opportunities

As a result of these challenges providing dementia care, many female carers find themselves having to make compromises in their working lives: passing up opportunities for promotion and training; working additional hours; and using annual leave time to care. These pressures of combining work and care mean that many women end up leaving their jobs or reducing hours.<sup>56</sup>

The lack of understanding, and even the stigma that still exists around conditions such as dementia, means that people can often feel uncomfortable about mentioning their caring responsibilities at work, even when they clearly need support.<sup>57</sup> Aviva's research of 1,000 workers in the UK with caring commitments (including older relatives, partners and children with disabilities) found that more than a fifth (22%) hadn't told their employer about their caring commitments. When asked why this was the case, more than a quarter (26%) of these 'hidden' carers said they didn't want others to think they weren't fulfilling their responsibilities at work. Nearly one in 10 (8%) said they were worried that they might lose their job, while the same proportion (8%) were concerned their carer duties would affect their career prospects.<sup>58</sup>

## How will WHO's global action plan and national dementia plans support working carers?

In 2017, the World Health Organization's *global action plan on the public health response to dementia* was approved by the World Health Assembly. The global action plan's vision, set to be delivered by 2025, is to create **'a world in which dementia is prevented and people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality'**.<sup>59</sup>

The global action plan includes seven targets for increased policy, awareness, prevention and diagnosis, research, care and treatment of dementia. It sets out parallel targets for countries to achieve and provides governments with the required framework to develop their own national dementia plans.<sup>60</sup> Countries are expected to establish focal points within government ministries to ensure sustainable funding for dementia.<sup>61</sup> By developing its own plan, each country is capable of addressing dementia in a way tailored to its own unique culture and demographics.<sup>62</sup>

Currently 32 countries and territories have adopted a plan on dementia, including 27 WHO Member States.<sup>63</sup> Meeting the global action plan's targets will require a whole-systems approach to tackle the challenges outlined – through joined-up, cohesive, and financed national dementia plans that will enable governments to best meet the needs of people living with dementia and their families.<sup>64</sup>

Action Area 5 specifically focuses on support for dementia carers with the aim to **'help to meet the needs of carers and prevent a decline in their physical and mental health and social wellbeing.'**<sup>65</sup>

One key recommendation calls for the need to **'build evidence on and articulate the importance**

**of carers in the lives of people with dementia, while raising awareness about the disproportionate effect on women'**.<sup>66</sup>

Female workers balancing dementia care commitments could potentially benefit from two recommendations calling for:

- 1 WHO Member States to **'develop or strengthen protection of carers, such as social and disability benefits, policies and legislation against discrimination, for example in employment, and support them beyond their caregiving role in all settings.'**<sup>67</sup>
- 2 International, regional and national partners to raise awareness of the importance of unpaid carers in supporting people with dementia free from discrimination: **'supporting their ability to continue their caregiving in a gender-sensitive manner, and empowering carers with opportunities to develop self-advocacy skills to be able to meet specific challenges in accessing health and social care, including long-term care services'.**

In 2017, the WHO Global Dementia Observatory was developed to monitor and review data on dementia, including reviewing the progress towards targets of the global action plan<sup>68</sup> and plays a key role in assisting countries in the implementation and providing support with measuring progress. These top-down approaches are desirable, but what is also needed is concerted action on the part of all stakeholders to create a society truly inclusive of all people living with dementia and their family members.<sup>69</sup>

## 4 Role of governments in securing the rights of carers at work

### **Ireland: Two years' unpaid leave available for workers with dementia care commitments**

Ireland's Carer's Leave Act (2001) allows employees (with their employer of 12 months or more) to leave their employment temporarily to provide full-time care for someone in need of full-time care and attention. Employees are entitled to take carer's leave of at least 13 weeks up to a maximum of 104 weeks.<sup>70</sup> This long-term leave from employment is unpaid but the Carer's Leave Act ensures that employees who want to take carer's leave will have their jobs kept open for them.<sup>71</sup>

One in nine people in Ireland are currently balancing paid employment with a family caring role. With an ageing population, this figure is predicted to rise to two in nine workers by 2030.<sup>72</sup> Caring Employers, a programme from Family Carers Ireland, is an initiative providing support and advice to employers.<sup>73</sup>

**'By offering greater flexibility and support to employees juggling paid employment and family caring, employers could significantly reduce costs caused by staff turnover, absenteeism and stress.'**

**Catherine Cox, Head of Communications and Carer Engagement with Family Carers Ireland.<sup>74</sup>**

### **4.1 Increasing trend in carer's leave provision**

Workplace leave entitlements are improving for workers globally. Evidence from around the world suggests that statutory rights to time off work to provide care are becoming increasingly common.<sup>75</sup> However, in most countries there remains greater recognition from governments of the needs of workers with young children and parent carers of disabled children, rather than elder care or long-term care.

Approximately two thirds of OECD (Organisation for Economic and Co-operation Development) countries have workplace support policies in place that allow employees with care commitments to take at least some time off to provide care, other than childcare.<sup>76</sup> Short-term leave of around ten days per year or a few days per month is common, both paid and unpaid. Longer-term leave of several weeks or even years, unpaid, is increasingly common. For example, in Spain and Ireland employees have the right to request two years' unpaid leave to provide care.<sup>77</sup>

In approximately 20 OECD countries (not including the UK) some of the time is offered as paid leave, though this tends to be very short.<sup>78</sup> Belgium provides one of the longest publicly paid leave, for a maximum of 12 months for a seriously ill family member, which can be extended up to 51 months unpaid.<sup>79</sup>

In Japan, paid leave is also long, with employees entitled to take up to 93 days' leave for a seriously ill dependent family member who requires constant care, for 67% of their earnings.<sup>80</sup> Scandinavian countries also tend to pay the most during carer's leave, for example in Norway paid leave is equivalent to 100% of earnings per 60 days per episode and in Sweden 80% for 100 days' leave.<sup>81</sup>

Providing dementia care to a parent or relative you don't live with or someone you're not a direct relation of, can cause barriers to employees needing to access carer's leave. Some countries restrict carer's leave eligibility to people caring for a family member or someone in their household. For example, in Italy and Israel paid leave is only specified for a spouse or parent and in Slovenia paid leave is only available if you care for a family member you live with.<sup>82</sup>

### **Mexico: Pressure of unpaid dementia care keeps women in informal work**

In Mexico, women perform over 75% of unpaid care and household work.<sup>83</sup> Despite being an OECD country, Mexico has no legal provisions for workers to take carer's leave or work flexibly, including for employees with childcare commitments or sick relatives. A lack of leave entitlements is having a disproportionate impact on their female population having access to paid work.

For many women who provide dementia care, the long-term pressures result in either having to 'retire' early and be unable to access their pensions, or women having to move from formal jobs to informal work. Speaking to Rosa Farrés González Saravia, President of the Federation of Mexican Alzheimer's Associations, many women who were dementia carers still need to find work that fits around their care commitments. Some women even set up their own informal businesses, such as baking, cleaning or ironing.

## 4.2 Raising awareness among the workforce is important for uptake of care's leave entitlements

Policies that allow employees with unpaid care commitments to take leave from the workplace or adopt a flexible work schedule can help them stay in formal employment.<sup>84</sup> However, workers often don't know their rights at work as a carer. From speaking with other national Alzheimer associations, employees' awareness of care leave entitlements are low and leave provisions and flexible working is often at the discretion of the employee's manager.

Despite legal protection for working carers in the UK, many carers and people living with dementia are unaware of their rights. There needs to be a concerted effort within all businesses and organisations to raise awareness among managers and employees of the Equality Act, Flexible Working Regulations and the right to time off for family and dependents (see box below 'UK: Legal obligations and flexible working for carers').<sup>85</sup> However, the role of information sharing and raising awareness of the rights of workers falls to civil society organisations, organisations in the UK such as Carers UK, Working Families and Carers Trust.

Even in Ireland, which has arguably one of the most appealing care leave legislations for dementia care supporters in the world, awareness of the entitlements among workers is relatively low. A national survey (carried out by the research company Behaviour & Attitudes for Family Carers Ireland) in January 2019 found that out of the survey respondents with full-time or part-time paid work, only 18% of individuals said they were aware that they are legally entitled to up to two years' unpaid carer's leave and that their employer had to keep their role available to them on return to work.<sup>86</sup>

## 4.3 Growing number of countries recognising the impact of ageing populations on family carers

As our population ages, the challenge of people juggling work and dementia care is only going to become an even bigger challenge. Governments and policy makers will need to plan ahead to ensure that clear dementia policies exist to enable the health and social care economy to cope with increased numbers of people living with dementia and their support needs. Dementia not only affects whole families, it also impacts entire economies.<sup>87</sup> Many governments across the world are increasingly aware of the care and support needs of their ageing populations (see for example, the case study from China on page 14), as well as the lack of funding available for elder care services.

The UK is currently lagging behind other countries when it comes to workplace rights for carers. Carers UK is calling on the UK government and employers to provide longer leave for carers who face changes in the condition of the person they are caring for, as well as more flexible working practices to enable carers to remain in work.<sup>88</sup> Some of the women who took part in this research told us that they would have benefited from longer leave entitlements, to enable them to continue in their roles for longer, or to relieve the financial pressure knowing that they could return to work.

The length of time many family members and friends will spend providing care support to someone with dementia, as well as the high stress of the role, means that those care supporters may sometimes have unique needs that broad-based government policies may not necessarily meet.<sup>89</sup>

### UK: Legal obligation and flexible working for carers

Carers of people with dementia are protected under the Equality Act (2010) through 'discrimination by association', as well as also having the right to request flexible working and time off. This protects people, such as carers, from direct discrimination and harassment because they are associated with someone who has a disability.<sup>90</sup>

As with people working with dementia, the Equality Act (2010) requires employers to avoid discrimination and make reasonable adjustments to ensure carers or family members affected by dementia are not disadvantaged in the workplace.<sup>91</sup> Employers are obliged to consider requests for flexible working from carers under the Flexible Working Regulations (2006). All employees have the legal right to request flexible working, as long as they have worked for the same employer for at least 26 weeks.

As an employee, you are allowed time off to deal with an emergency involving a dependant, for example a spouse, partner, child, grandchild, parent, or someone who depends on you for care. The UK government website states that employees are **'allowed a reasonable amount of time off to deal with the emergency, but there's no set amount of time as it depends on the situation'**.<sup>92</sup> The length of time given off and whether that time is paid, is at the discretion of the employer.

## China: Regional governments provide ‘nursing leave’ for workers with ageing parents

The total number of people with dementia in China is estimated to be 14.1 million (in 2020) and to reach 23.3 million by 2030.<sup>93</sup> Traditionally the care and support of the elderly or a sick relative is seen as the family’s responsibility, mostly wives caring for their husbands, and daughters (and daughters-in-laws) caring for their mothers and sisters. Admission to facilities for the care of the elderly is highly stigmatised<sup>94</sup> and as a result informal dementia care provided by family members accounts for more than 80% of the total dementia cost in China.<sup>95</sup> This is higher than the global average.

At the end of 2017, nearly a fifth of China’s population was aged 60 and over (241 million people, of the total population of 1.38 billion). The pressure of parental care and old-age care for only-children is becoming more apparent.<sup>96</sup> To help cope with an ageing population, local governments in recent years have issued policies and regulations on ‘only-child care leave’. In 19 provinces local governments have issued specific regulations to support workers take paid ‘nursing leave’ to care for their parents over the age of 60 years.<sup>97</sup> However, ‘nursing leave’ requirements vary across provinces and there is no national level legislation.

In some provinces, such as Hubei, Sichuan and Ningxia, ‘non-single children’ are also eligible for paid ‘nursing leave’. According to the regulations on the Protection of the Rights and Interests of the Elderly in Ningxia Hui Autonomous Region: **‘during the hospitalization of the elderly, children can enjoy paid accompanying leave [...] the only child accumulates no more than 15 days per year, and the non-single child accumulates no more than 7 days per year’.**<sup>98</sup>

However, despite China recognising the need for children of elderly relatives to take time off work to take on care responsibilities, the ‘nursing leave’ comes with tight stipulations and is arguably too short-term in nature to support employees with long-term dementia care responsibilities. Employees have reported challenges accessing the leave provision, that the detailed rules are not clear, and many companies have reported not knowing how to approve the paid leave. The cost of the leave is also taken on by businesses as employment costs, resulting in many companies refusing to implement the ‘nursing leave’ allowance for their employees.<sup>99</sup>

## 5 Employers must provide immediate support to staff with dementia care commitments

### 5.1 Retaining employees with care commitments has economic advantages for businesses

With over 800,000 people estimated to be living with dementia in England, it is almost inevitable that businesses will face cost implications from the condition.<sup>100</sup> Where employers don't provide support, low morale, absenteeism, presenteeism and high staff turnover can impact on their business costs.

Research commissioned by Alzheimer's Society in 2019 looked at the financial cost implications for businesses, from the cost of the working time foregone by workers caring for friends and relatives living with dementia. The financial cost of working time lost to employees caring for people living with dementia, leaving the workforce or having to miss work due to their dementia care responsibilities for 2019, was £3.2 billion to English businesses.<sup>101</sup>

For most women dementia care responsibilities come about when they are in their 40s, 50s and 60s, a time in their working lives when they have skills and experience built up over many years of working. For older women, re-entering the workforce after prolonged leave can also be a challenge. With little action from employers to retain the skills and knowledge these employees have amassed over years or even decades, businesses face significant loss from their withdrawal from the workforce.

### 5.2 Supportive workplace practices will have a direct impact on employees' health and wellbeing

There is an increasing number of international and UK businesses that are retaining and supporting their employees through carer's leave and flexible working practices, not just because it's the right thing to do but also because it makes good business sense.

Employees with dementia care commitments can experience exhaustion, an exacerbation of existing problems and increased stress, impacting their mental health and wellbeing.<sup>102</sup> This can have a direct impact on their ability to care and meet work commitments. As a result, businesses can face the problem of presenteeism, which is when an employee is present at work but has other matters on their mind and is not as focused on their tasks as they should be, leading to a fall in productivity.

The cost to English businesses of loss of output from carers supporting a person with dementia who said that they felt tired, stressed or depressed, had disturbed sleep, developed their own health conditions, or saw a deterioration in an existing condition, was equal to over £64.4 million in 2019.

Centrica (an international energy company responsible for British Gas and Direct Energy) recently estimated that their paid leave policies have contributed to saving millions to their bottom line by improving carers' health and wellbeing at work, their workers' ability to manage care and work and as a result, reducing the number of employees leaving.<sup>103</sup>

**'Proactively supporting our carer colleagues has saved our business £3.1 million in absenteeism, presenteeism and retention. Like any societal challenge, ignoring the problem is often a more expensive approach than investing time to find a workable solution.'**

**For those people who must juggle the demands of full-time employment and being a carer, it is inevitable they will face unplanned absenteeism, including stress-related absences, all of which are costs to organisations.'**

Centrica<sup>104</sup>

## Aviva recognises 1 in 7 employees have care responsibility

In 2017, the insurance firm Aviva, announced it was giving its 16,000 UK workers the same entitlement to carer's leave as for parental leave.<sup>105</sup> Aviva conducted a six-month pilot of the emergency leave with 100 carers in the first half of 2017. After feedback from participants, the organisation added planned leave to the initiative.<sup>106</sup> Aviva now offers up to eight weeks' unpaid leave for carers a year, as well as 35 hours' paid leave a year for planned events, such as hospital appointments and another 35 hours' paid leave for emergencies.<sup>107</sup> On average, the organisation's working carers take 10 hours a year of paid carer's leave.

**'We know that the financial consequences of leaving work for caring responsibilities can be quite severe. It doesn't just affect their income while they are a carer, it also affects their ability to re-enter the workforce and has a long-term, knock-on effect on income and financial security.'**

**Mary Bright, Inclusion and External Affairs Lead for Chief Executive Officer, UK Insurance at Aviva.**

One in seven of Aviva's employees has at least one form of caring responsibility. According to Aviva in addition to the policy itself, one of the main benefits they found was that employees felt they could be open about their caring responsibilities and feel reassured that others understand that being a carer doesn't mean they're not committed to their job. **'We really want to support carers in the short-term, but also support them in the long-term so that people aren't faced with that awful choice: do they care for somebody they love or do they give up the job that they need?'** says Bright.

### 5.3 Employers need to involve people affected by dementia in workplace changes

Surveys of working women carers indicate that they are not receiving adequate support in either the workplace or their caring role.<sup>108</sup> As this paper has explored extensively so far, since the majority of carers are women, employers must recognise the gender-based inequalities they impose on their employees by not providing care leave policies and flexible working practices.

Changes in workplace entitlements for workers will only come about successfully by involving people affected by dementia in the design of solutions. Opportunities to participate in workplace discussions need to fit around care commitments and be made available to female carers from diverse, cultural and socio-economic groups. Ensuring carer's leave policies and practices meet the needs of employees providing dementia care, ultimately provides better working practices for *all workers* with care responsibilities, now and for future generations.

## 6 Conclusion

Dementia has a profound impact on the lives of those close to the person living with dementia, particularly family carers, the majority of which are women worldwide. Due to variation of cultural and societal norms and access to paid care, pressures of unpaid dementia on women differs between countries. For most, the nature of women's unpaid care support is more likely to be less flexible than that of men's, making it harder to balance care commitments with their paid jobs. As a result, women are more likely to reduce their working hours and stop work completely.

Governments' care leave entitlements and business-led practices are failing to recognise the impact of dementia care commitments, including long-term and elder care in general, on their economies and businesses through loss of workers. While changes in legislation to improve the rights of workers with any type of long-term care commitments is likely to be slow progress, business-led approaches play a vital role in providing immediate support to the workforce with dementia care commitments now, not just for future generations.

Through this research and speaking to women providing dementia care while juggling paid work, we have heard that an increased knowledge of dementia from managers, flexible working practices and paid carer's leave (including long-term leave entitlements) can relieve the pressures of caring and work responsibilities. Without workplace changes and support from managers, female carers are disproportionately likely to face poorer physical and mental health. As the condition of the person living with dementia progresses, requiring more time and less flexible support, women workers may have to stop employment completely. This can have a drastic financial, social and emotional impact on their lives as care supporters, especially if they have multiple care responsibilities and no additional income.

Governments and businesses must improve the provision of long-term carer's leave and flexible working practices in the workplace. This will not just support carers of people living with dementia stay in work for as long as possible, it will support all employees with care commitments.

### Resources for carers and employers in the UK

**Dementia Friendly Business Guide:** Alzheimer's Society's dementia friendly business guidelines outline how changes can make business as dementia-friendly as possible. The approach provides changes for employers to make workplaces more inclusive for people living with dementia and people providing care to someone living with the condition.

Visit: [www.alzheimers.org.uk/dementia-friendly-resources](http://www.alzheimers.org.uk/dementia-friendly-resources)

**Employers for Carers:** Carers UK employers' forum, Employers for Carers, is a membership network of over 115 organisations from a wide range of sectors and a reach of over 1.5 million employees. The forum provides tools and advice for employers, as well as promotes best practice of how to support carers in the workplace.

Visit: [www.employersforcarers.org](http://www.employersforcarers.org)

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