



Paper

# Dementia-friendly workplaces

IES Perspectives on HR 2017

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The ageing of the UK workforce has been one of the immutable features of the labour market since its demographic certainty became clear back in the 1980s. The numbers are familiar. One third of the workforce will be aged 50 or over by 2020. In the UK 2.9 million people aged between 50 and state pension age are out of work. Of these, only 0.7 million see themselves as retired and yet 1.7 million think it is unlikely that they will ever work again. Of the 7.2 million people aged 50-64 who are employed, 42 per cent are living with a health condition or disability. Sometimes these figures leave employers feeling both bemused and resigned.

In this paper I want to focus on two aspects of ageing at work which are already manifesting themselves as consequences of the growing prevalence of dementia. The first, and in some ways the most immediate, is the challenge which many older workers have of caring for someone with dementia. The second, which will become significantly more concerning for employers in the medium-term, is the need to manage dementia and cognitive decline among those still at work.

## Working and caring

Our recent knowledge about the challenges faced by employees who are caring for people with dementia comes from research carried out by organisations such as Alzheimer's Society and Carers UK. What the studies tell us in summary is that:

- About 50 per cent of all the UK's 6.5 million carers are also in paid employment (Carers UK, 2014).
- It is estimated that by 2020, 850,000 employees in the UK will be looking after elderly relatives with dementia (Alzheimer's Society, 2012).
- Compared with other carers, those looking after elderly relatives with dementia are most likely to be working full time (61% according to Carers UK, 2013).
- In general, there seems to be a gap between the support that employers say they offer these carers, and support that the carers report that they can access on the ground (Carers UK, 2014).
- For example, 83 per cent of employers say they offer flexible working hours to carers but only 48 per cent of carers report having such flexibility available (Ibid.).
- Similarly, 64 per cent of employers say that they offer flexible or special leave but only 38 per cent of carers report that this is accessible to them (Ibid.).
- Just over 40 per cent of employers report that they offer remote working to carers whereas only 18 per cent of carers report that this is accessible to them (Ibid.).

- Just over half of these carers report that their work has been affected by their caring responsibilities. Almost a quarter said that they had changed their work patterns, with a fifth having reduced their hours and one in ten taking on a less demanding and lower paid role (Ibid.).
- The area of support which carers said they would value most and would make most difference was 'practical support from care workers trained to work with people with dementia' (Ibid.).

Other areas where carers felt that they would benefit from further support included information; signposting to external resources and support; and access to emotional support from occupational health or Employee Assistance Programme (EAP) providers (Ibid.).

We have known for a long time about the challenges faced by employees with childcare responsibilities and both employment law and organisational practice have, to a large extent, adapted well. The logistical and emotional demands of caring for an elderly relative with dementia are no less onerous for employees. Indeed, in some ways the psychological toll can be greater as many carers have to deal with permanent changes in their relatives' capacity for self-care, their personalities and their wider health as they seek to support them towards the final stages of their lives with dignity and love. The demographic die is cast. Most UK employers over the next 20 or 30 years will encounter employees who need to juggle their work with the compelling need to provide high-quality care to an elderly relative with dementia. The support they need from their employer is most often simple and inexpensive. All they want is for employers to make it easy for them to ask for help and then for it to be given with generosity, compassion and humanity.

## Dementia at work

Another clear priority for action is making sure that the growing number of older workers who also have long-term health conditions are given the help they need to keep working (Taskila et al, 2015). Contrary to popular mythology, older workers do not have significantly more sick days than their younger colleagues, but they sometimes have chronic and fluctuating health conditions which affect their functional capacity at work and increase their risk of having to leave work prematurely.

Despite that fact that the over-65s are the fastest growing segment of the workforce, the numbers leaving work before state pension age – often for health reasons – are still significant. Of course, conditions such as cancer, cardiovascular disease, stroke and arthritis feature prominently among the causes of premature job loss or early retirement. However, it is the spectre of early cognitive decline associated with dementia among working-age adults which is giving increasing cause for concern.

The World Health Organisation (WHO, 2012) estimates that 10 per cent of the 35.6 million people worldwide with dementia are aged under 65. The number of people with dementia in the UK is forecast to increase to over 1 million by 2025 and over 2 million by 2051 (Ibid.). According to the Alzheimer's Society, which has produced an excellent guide for employers<sup>1</sup>, there are currently over 40,000 people with dementia under the age of 65 in the UK and 18 per cent of them continue to work after their dementia is diagnosed (Alzheimer's Society, 2015). This 'time bomb' is likely to have serious social and economic consequences, with impacts on productivity and social inclusion (Frahm-Falkenburg et al, 2016). But the idea that nothing can be done to support people living and working with this condition is being challenged (Ritchie et al, 2015). There are excellent examples of jobs being redesigned around the capabilities of people working with dementia and the adoption of simple adjustments such as allocating mentors or 'buddies', increasing signage and labelling in workplaces to help people find places and resources, creating quiet spaces and soundproofing, and adapting working hours to accommodate fluctuations in symptoms or to help manage the impact of medication.

In knowledge-based organisations the tacit knowledge, skills, experience and know-how of older workers should be a major asset both to employers and the wider economy. While it remains largely an intangible asset to which it is hard to ascribe a financial value, it is clear that extending the productive working lives of older workers makes sense from both an economic and social perspective. Even dementia should not be a barrier to having a full, fulfilling and extended working life. Every organisation has the challenge of capturing and building on the wisdom of its older workers before they retire and 'dementia-friendly' workplaces need to become routine and unremarkable arenas within which we make this possible on a larger scale (STUC and Age Scotland, 2016).

Many people with dementia are, especially in the early years, able to continue working and choose to do so. Additionally, many people, and especially those with early-onset dementia under the age of 65, have financial commitments such as mortgages or dependent children and so are anxious to stay in paid employment for as long as they are able (Robertson, 2013; Evans, 2016). Early assessment and diagnosis is important in preventing problems arising at work and enabling people to continue to work even after a diagnosis. However, currently fewer than half of people with dementia (48%) receive a formal diagnosis. This can be because people are either reluctant to talk to their doctor and seek help, or because health professionals are not confident in making a diagnosis.

Employees with early-onset dementia can often experience delays receiving a diagnosis because, as the condition is relatively rare in people under 65, the symptoms are often

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<sup>1</sup> [https://www.alzheimers.org.uk/info/20116/making\\_organisations\\_more\\_dementia-friendly/357/creating\\_a\\_dementia\\_friendly\\_workplace](https://www.alzheimers.org.uk/info/20116/making_organisations_more_dementia-friendly/357/creating_a_dementia_friendly_workplace)

attributed to stress or depression. As a result, it is likely that there are a significant number of people working with dementia who are unaware of their developing condition.

Coupled with this, in 2013 the Dementia Direct Enhanced Service (DES)<sup>2</sup> was introduced to the GP contract to help tackle the low rates of dementia diagnosis. The DES promotes a case-finding approach where clinicians ask those who are at a higher risk of developing dementia if they are worried about their memory so they can be referred for appropriate tests. As a consequence, people can be diagnosed at an earlier stage, when they may still be functioning well and are able to cope at work with relatively few changes.

Various studies chronicling the experiences of workers living and working with dementia suggest that, prior to getting a diagnosis, they were left questioning why they were struggling to complete routine tasks at work or having difficulty remembering the details of instructions they had been given (Chaplin and Davidson, 2016). In some cases, the employee may notice differences in cognition but ascribe these changes to work pressure, changes in work roles, or changes attributed to the ageing process (eg declining physical strength or stamina, poor eyesight, forgetfulness and hearing loss). As a woman who had been a Nursing Assistant told Chaplin and Davidson (2016):

*'All through my life I had been a good speller and I even got to the point one day when I spelled my own name wrong and at that point I did become concerned.'*

However, once people have a diagnosis of dementia they can start to put the problems they may have experienced at work into context. They can begin to make plans, such as considering how long they want to carry on working, and they can have conversations with their employer about how they can be supported to stay at work. Early diagnosis can also assist employers to provide support and seek specialist advice from services such as occupational health (OH) about how best to support individuals and plan for the future. It should also be recognised that work can, in some circumstances, have therapeutic benefits for workers in the early stages of cognitive decline. A systematic review by McCulloch, Robertson and Kirkpatrick (2016) found evidence for a number of health benefits of continuing to engage in meaningful work. Indeed, previous research among 430,000 self-employed French workers by Dufouil et al (2014) found a potentially preventative impact, with evidence of 'a significant decrease in the risk of developing dementia associated with older age at retirement'. The authors concluded that their evidence lent support to the so-called 'use it or lose it hypothesis' of cognitive decline.

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<sup>2</sup> <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/03/facilitate-tmly-diag-dementia.pdf>

People who develop dementia while working, irrespective of their age, often fear going to their GP to get a diagnosis because they feel that they have everything to lose. Employers can help by having clear and open policies about how the organisation will support people who develop dementia and encourage staff to be aware of the condition. The Alzheimer’s Society runs Dementia Friends<sup>3</sup> information sessions for businesses to help staff learn about dementia and the steps they can take to make a difference to the lives of people with the condition.

The kind of workplace support which employers might consider will depend on the nature, severity and job-relatedness of the cognitive impairment. Sachs and Redd (1993) offer a simple framework which can be adapted to a range of organisational contexts:

**Table 1 Examples of cognitive difficulties and potential workplace accommodations**

Cognitive Difficulty	Potential accommodations
Reduced attention, distractibility	Enhancing signal stimuli through use of headphones, bold print, colours, or illustrations. Reduced distractions from noise by modifications in lighting, workplaces location, sound, and visual barriers.
Short-term memory impairment	Presentation and encoding of information in multiple modalities, such as instruction manuals that use verbal descriptors and illustration. Allowing employee to use memory cues or aids when performing task. Increasing opportunities for repetition and review of task.
Sequencing, planning	Numbering or colour coding aspects of job to enhance sense of order. Providing visible models of completed work to aid in self-monitoring of performance.
Visual spatial confusion	Simplifying diagrams for operation of machinery or completion of tasks. Using verbal cues or captions in diagrams. Providing written instructions to supplement visual instructions.
Verbal communication	Minimising needs for verbal communication through non-verbal monitoring systems such as checklists. Supplementing written instructions or tasks with visual diagrams, illustrations or maps to enhance understanding.
Poor generalisation of skills across situations	Increasing opportunities for repetition of tasks before switching tasks. Enhancing similarity in task components by performing tasks in same location or with same equipment.
Preservation, rigidity	Enhancing differences in task components by performing tasks in different parts of work space, using different styles or types of equipment for different tasks.
Fatigue, reduced speed	Reduce or avoid productivity requirements. Incorporate modifications in scheduling to allow for rests and review. Enhance sense of time passage through use of logs.

*Source: Sachs and Redd, 1993*

<sup>3</sup> <http://www.dementiafriends.org.uk/>

Eventually, it may no longer be possible for employers to make workplace adjustments to keep a person at work – or the individual may be ready to leave by choice. The guide produced by the Alzheimer's Society (2015) recommends employers avoid using capability and disciplinary procedures, but follow instead a 'dignified exit package and strategy'. As a former HGV driver told Chaplin and Davidson (2016), this can be a difficult time and can leave the employee feeling embittered and even betrayed:

*'They said there were no jobs I could do, safety wise, in the depot. The will wasn't there really was it?'*

Dementia frightens people, in part because it is progressive and is currently resisting attempts to prevent or treat it. But as most of us will now be compelled to work much longer before we retire, it is inevitable that more workplaces will need to have policies, adaptations and levels of awareness and compassion to deal with the consequences of a doubling of dementia cases in the UK, either because employees have caring responsibilities for elderly relatives or because they receive a diagnosis themselves while they are still of working age. Sadly, this is not a domain where we have much choice because the demographic and epidemiological trends do not lie. The sooner employers get to grips with developing policies and practices which make them dementia friendly, the better equipped they will be to play their part in making the lives of those affected directly or indirectly by dementia more dignified and less isolated.

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## More on this topic

IES carried out research in 2016 for CIPD investigating how employers can best manage an increasingly older workforce in the context of their health and wellbeing and care responsibilities. The study compared five European countries: the Czech Republic, Denmark, France, Germany and the UK. Read more here: <http://www.employment-studies.co.uk/resource/creating-longer-more-fulfilling-working-lives>

For more information on any of IES's work mentioned in this chapter, or to discuss working with us in these areas, please contact Stephen Bevan, Head of HR Research Development:

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## The dark side of wellbeing: Dementia

**8 June 2017, London**

As the workforce ages, most employers have no plans to accommodate employees with cognitive decline. This event will look at both issues of the increasing rise in cases of dementia and the employer responses and consider examples of innovative practice which are beginning to emerge.

To find out more or book a place, please visit: <http://www.employment-studies.co.uk/events>



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