



## THE WORKPLACE RESPONSE TO NEUROLOGICAL CONDITIONS

A focus on migraine, multiple sclerosis  
and Alzheimer's disease

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## About this report

*The Workplace response to neurological conditions—a focus on migraine, multiple sclerosis and Alzheimer's disease* is an Economist Intelligence Unit report, sponsored by Novartis, a pharmaceutical company. It looks at the impact of three neurological conditions on both patients and carers in the workplace and how employers can support them.

The findings of the report are based on desk research and eight interviews with physicians, health experts, business leaders and policymakers. Our thanks are due to the following for their time and insights (listed alphabetically):

- Simi Dubb, director of diversity and inclusion, Centrica, UK
- Una Farrell, communications manager, The Migraine Trust, UK
- Peter Goadsby, professor of neurology, King's College London, and head, King's College Headache Group, UK
- Richard Heron, chief medical officer, BP, and co-chair, the International Occupational Medical Society Collaborative, UK
- Jason Karlawish, physician and author, and professor of medicine, medical ethics and health policy and neurology, the University of Pennsylvania, US
- Dawn Langdon, cognitive psychologist and professor of neuropsychology, Royal Holloway University, UK
- Stefan Tromel, senior disability specialist, International Labor Organisation, Switzerland
- Donna Walsh, executive director, European Federation of Neurological Associations, Ireland

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## Executive summary

This report looks at how three neurological conditions—migraine, multiple sclerosis (MS) and Alzheimer's disease (AD)—affect people in the workplace. We examine the impact on employees living with the conditions, on the employees acting as their carers and the impact on both these groups' employers.

These three conditions are important for several reasons. First, they have a significant impact on people's working lives. AD and MS are progressive while migraine is generally episodic; each will affect working-age populations,<sup>1</sup> but in different ways. MS, a progressive disease, and migraine, a transient and episodic condition, affect people when they are still active members of the workforce, often in their prime working years. In addition, some people with MS and migraine and most of those diagnosed with AD will, at some stage, rely on carers, many of whom are forced to alter their own employment patterns and/or status to provide care. Finally, growth in the number of cases of MS and AD reflect increasing demographic change. As many developed countries, (eg, the US, Japan and the UK) and even emerging-market countries (eg, China) have ageing populations, their citizens are more likely to be affected by AD, as this is a disease primarily prevalent among older people.<sup>2</sup> In addition, people are working longer due to extended retirement ages, as well as the need to save more for retirement. This means that employers are likely to face higher numbers of employees undertaking unpaid carer roles in addition to their regular employment alongside greater levels of AD among their workforce.

Employers should consider how they adjust to the needs of employees living with these conditions as well as those undertaking unpaid carer roles in addition to their paid work. If employers want to build more diversified workforces, they need to take note that these conditions can have a larger impact on women, as there is a higher prevalence of women living with the conditions and acting as carers. At the same time, companies that are able to formulate strategies to address these conditions at work can benefit through the creation of a more diverse and productive workplace, which in turn is likely to lead to stronger employee morale, improve their reputation as a good employer, and make it easier to retain workers. Such workplace strategies have already been piloted in other diseases, such as cancer.<sup>3</sup>

Globally, the prevalence of these conditions means that employers will inevitably come across people living with them, or their carers. According to latest global figures, dating from 2017,<sup>4</sup> migraine affects around 1.3bn people, representing a substantial prevalence rate of 16,828 people per 100,000 population (or 16.8%). AD and other dementias affect around 45m people—some 605 people per 100,000 population (0.6%). For MS, around 1.8m people live with the condition—this means that 22 people per 100,000 population are affected (0.02%).

Based on the results of qualitative interviews and research conducted, it is clear there are a number of significant challenges that employees, employers and governments need

<sup>1</sup> We are using the OECD definition of working age as being 15-64 years.

<sup>2</sup> Older populations are defined here as aged 65 years or greater.

<sup>3</sup> See <http://cancersurvivorship.eiu.com/briefing-paper/>.

<sup>4</sup> Global Burden of Disease Study 2017, Institute for Health Metrics and Evaluation at the University of Washington. Personal communication, January 2019.

to address to improve outcomes for those living with these conditions and those caring for them.

### Key findings:

- **“Presenteeism”, where employees remain in the workplace but are working at less than full productivity, is a bigger problem than absenteeism for employers.**

In all three conditions, symptoms can be “invisible” but affect an employee’s performance. However, greater flexibility in workloads and working hours that allows for episodes of disease (in the case of MS and migraine) may help reduce presenteeism.

- **These three neurological conditions may negatively affect the productivity, participation, and current and future earning potential of employees living with the conditions in the workforce.**

Employees with these conditions are more likely to withdraw from the workforce and/or fear being stigmatised in their current roles, preventing or delaying career progression. This may also affect future retirement benefits. Failure by businesses and governments to understand the impact of these conditions will exacerbate the economic impact on employees with these conditions as well as on society overall.

- **Education and awareness around these diseases in the workplace is crucial.**

A closer collaboration between HR, occupational health, line managers and employees may help in anticipating the problems associated with these conditions for affected employees and for those employees in carer roles. Accommodations can be made at what is often a minimal cost. A 2016 US study found that 58% of employers reported that requested

accommodations for disabilities cost nothing, and where there was a cost, it was typically around US\$500.<sup>5</sup> In particular, better awareness in the workplace of the symptoms, including physical and cognitive ones, associated with AD and MS may support employees living with these conditions and keep them as productive workers for longer.

- **To help retain staff and keep them motivated and productive, better accommodations for employees with migraine, MS or early AD, and for those who are carers, are needed.** Carers, predominantly women at the peak of their careers, often have to depend on the flexibility of employers. These unpaid carers may experience a negative career impact, as they may be viewed as not being as committed to their career or their employer. Given the high cost related to recruitment, it may be beneficial to employers to develop policies that will help retain employees who are also unpaid carers. Supporting female employees who act as carers would also help in building diversity in the workforce. One UK company, Centrica, has saved an estimated £1.8m (US\$2.4m) a year by providing paid leave and peer support to help workers with caring responsibilities.
- **People who suspect that they may have a neurological condition should undergo medical consultations as early as possible since an early diagnosis can help them stay at work.** Improving collaboration between HR, employees, and occupational health experts may help in identifying the extent of disability and in determining the accommodations needed to allow those living with neurological conditions to remain at work.

<sup>5</sup> Beth Loy, Job Accommodation Network, “Workplace accommodations: Low cost, high impact”, updated January 2016, <http://www.leadcenter.org/resources/report-brief/workplace-accommodations-low-cost-high-impact>

- **There is a need to bridge the gap between legislation and practice to help keep employees in work.** There are also differences between countries, with some allowing people to do some work and still keep social benefits while registered as disabled. Although most developed countries have varying degrees of disability legislation, there are gaps in the protections offered by countries to those registered

disabled. Quite often people who are registered disabled are discouraged from working, as they would lose any disability payment while being employed. Employers need to be aware of existing limitations and should seek to work with governments to develop better and more flexible policies that will encourage people to remain in the workforce.

## Introduction

This report focuses on two progressive neurological conditions: Alzheimer's disease (AD), which is primarily diagnosed in older people; and multiple sclerosis (MS), which is primarily diagnosed in younger people.<sup>6</sup> We also consider migraine, a non-progressive neurological condition, as its burden is generally underestimated due to its transient nature.<sup>7</sup>

Employers need to be aware that, globally, neurological conditions have been ranked as the leading cause of disability-adjusted life years (DALYs), a leading measure of overall disease burden expressed as the number of years of productive life lost due to ill-health, disability or early death.<sup>8</sup> Migraine and AD and other dementias are the second and fourth largest contributors, respectively, of DALYs among neurological conditions globally.<sup>9</sup> We are therefore examining these conditions to better understand their impact in the workplace. We will seek to assess how they impact employees affected by these conditions, carers of those affected, and both these groups' employers.

We will also consider the different ways in which companies can provide effective support to their employees living with the conditions, as well as carers, so that these two groups are able to continue working.

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<sup>6</sup> Younger people are defined as those below 35 years.

<sup>7</sup> U Reuter, "GBD 2016: still no improvement in the burden of migraine", *Lancet Neurol*, 2018 Nov;17(11):929-930, [https://www.thelancet.com/journals/lanneur/article/PIIS1474-4422\(18\)30360-0/fulltext](https://www.thelancet.com/journals/lanneur/article/PIIS1474-4422(18)30360-0/fulltext)

<sup>8</sup> Global Burden of Disease Study 2017, Institute for Health Metrics and Evaluation at the University of Washington. Personal communication, January 2019. See WHO for DALY definition: [https://www.who.int/mental\\_health/management/depression/daly/en/](https://www.who.int/mental_health/management/depression/daly/en/)

<sup>9</sup> GBD 2015 Neurological Disorders Collaborator Group, "Global, regional, and national burden of neurological disorders during 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015", *Lancet Neurol* 2017; 16: 877–97, <https://www.thelancet.com/action/showPdf?pii=S1474-4422%2817%2930299-5>

## Chapter 1 Prevalence of AD, MS and migraine

### Key takeaways:

- **The worldwide prevalence of AD is expected to double every 20 years.**
- **MS affects people during their prime working years.**
- **Migraine is the leading cause of disability among all neurological disorders.**

Mental and neurological (nervous system) disorders, including AD, MS and migraine, affect more than a quarter of people at some point in their lives.<sup>10</sup>

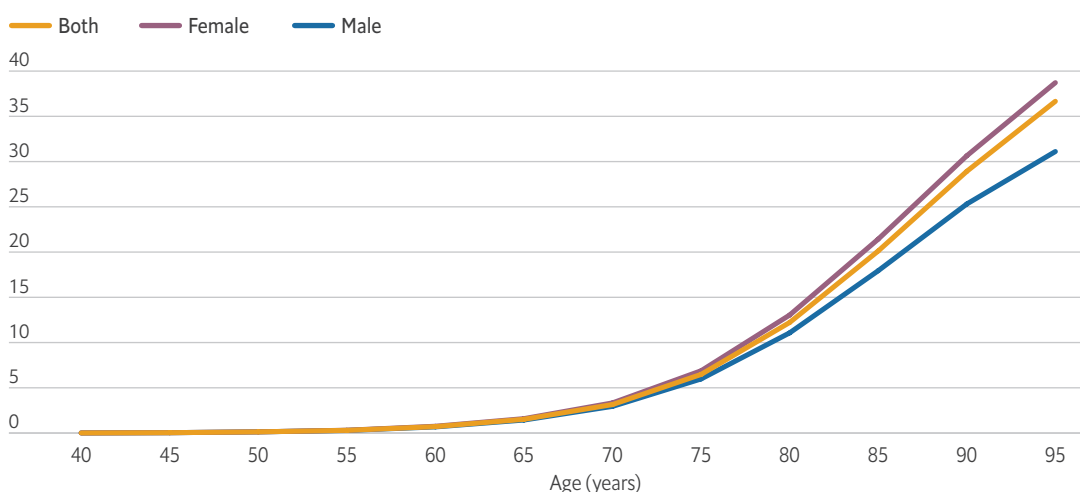
AD is possibly one of the better-known progressive diseases. Someone in the world develops dementia every three seconds, according to Alzheimer's Disease International,

and AD makes up around 50-60% of all dementia cases. As nerve cells die in certain parts of the brain, people living with the condition experience memory and cognitive loss as well as personality and mood changes.<sup>11</sup>

Globally, the number of people living with AD and other forms of dementia was 45m in 2017, more than double the 20.2m with the condition in 1990.<sup>12</sup> This means around 605 people per 100,000 population live with these dementias (a prevalence of 0.6%). See the Appendix for the prevalence and number of individuals with AD and other dementias in selected countries. There is also a gender imbalance, as more women live with the disease than men (see Figure 1).<sup>13</sup>

**Figure 1: Global prevalence of Alzheimer's disease and other dementias**

%; 40-95+ years of age, 2017



Source: Global Burden of Disease Study 2017, Institute for Health Metrics and Evaluation at the University of Washington.

<sup>10</sup> Available at: [https://www.who.int/whr/2001/media\\_centre/press\\_release/en/](https://www.who.int/whr/2001/media_centre/press_release/en/)

<sup>11</sup> Available at: <https://www.alz.co.uk/about-dementia>

<sup>12</sup> Global Burden of Disease Study 2017, Institute for Health Metrics and Evaluation at the University of Washington. Personal communication, January 2019, and GBD 2016 Dementia Collaborators, "Global, regional and national burden of Alzheimer's disease and other dementias, 1990-2016: a systemic analysis for the Global Burden of Disease Study 2016", *Lancet Neurol*, 2019;18:88-106. [https://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(18\)30403-4/fulltext](https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(18)30403-4/fulltext)

<sup>13</sup> Global Burden of Disease Study 2017, Institute for Health Metrics and Evaluation at the University of Washington. Confirmed through personal communication, January 2019.



The worldwide prevalence is expected to nearly double every 20 years, reaching 75m by 2030, with the largest increase expected to be in developing countries, where 58% of those with dementia already live. The fastest growth in elderly populations is taking place in China, India, South Asia and the western Pacific regions.<sup>14</sup>

MS is also a progressive disease, where damage occurs to myelin, a fatty substance that insulates nerves. As there is a loss of myelin in those living with MS, this means there is a disruption in the ability of the nerves to conduct electrical impulses, thereby causing physical disability and other symptoms such as fatigue, weak limbs and blurred vision, and minor cognitive impairment affecting memory and organisation.<sup>15</sup> Diagnosis is generally between 20 and 40 years of age, although onset may be earlier, and the condition can often have an unpredictable nature with remissions and relapses.<sup>16</sup>

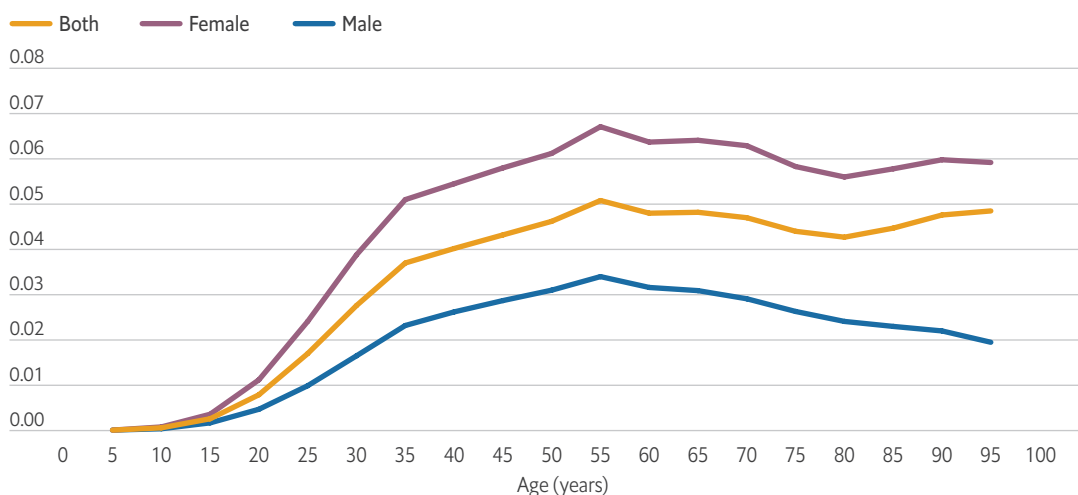
The prevalence of MS is much lower, at 1.8m globally, meaning 22 people per 100,000 population are affected (a prevalence of 0.02%).<sup>17</sup> See Appendix for prevalence and number of individuals with MS in selected countries. Twice as many women as men live with MS (Figure 2). The prevalence of MS is highest in North America and Europe at 140 and 108 per 100,000, respectively, and lowest in sub-Saharan Africa and East Asia at 2.1 and 2.2, per 100,000, respectively.<sup>18</sup>

Migraine is an episodic condition with a variety of symptoms, including sensitivity to light and sound, and feeling sick, but the main feature is a painful headache.<sup>19</sup> Migraine attacks can last from 4 to 72 hours. In around 2% of cases, it can be a chronic condition, where sufferers experience migraine for more than 15 days of the month.<sup>20</sup>

Migraine affected around 1.3bn individuals globally in 2017, representing a substantial

**Figure 2: Global prevalence of multiple sclerosis**

%; by age group, 2017



Source: Global Burden of Disease Study 2017, Institute for Health Metrics and Evaluation at the University of Washington.

<sup>14</sup> Data available at <https://www.alz.co.uk/research/statistics>

<sup>15</sup> Available at: <https://www.msif.org/about-ms/what-is-ms/>

<sup>16</sup> Ibid

<sup>17</sup> Global Burden of Disease Study 2017, Institute for Health Metrics and Evaluation at the University of Washington. Personal communication, January 2019.

<sup>18</sup> <https://www.msif.org/wp-content/uploads/2014/09/Atlas-of-MS.pdf>

<sup>19</sup> The Migraine Trust, <https://www.migrainetrust.org/about-migraine/migraine-what-is-it/more-than-just-a-headache/>

<sup>20</sup> The Migraine Trust, <https://www.migrainetrust.org/about-migraine/migraine-what-is-it/facts-figures/>

prevalence rate of 16,828 people per 100,000 population (a prevalence of 16.8%).<sup>21</sup> Migraine also represents 2.9% of years of life lost to disability, making it the leading cause of disability among all neurological disorders.<sup>22</sup> See Appendix for prevalence and number of individuals with migraine in selected countries. It is the third most common disease in the world,<sup>23</sup> and women are more likely to suffer from migraines than men, with studies suggesting that female sex hormones play a part in triggering them<sup>24</sup> (see Figure 3).

Given the prevalence of these conditions globally, the cost to employees affected by these diseases, to employed carers taking on unpaid caring duties and to employers is significant. In Europe, costs related to brain disorders, which include diseases such as dementia, headache, MS, anxiety, psychotic disorders and Parkinson's disease, are an

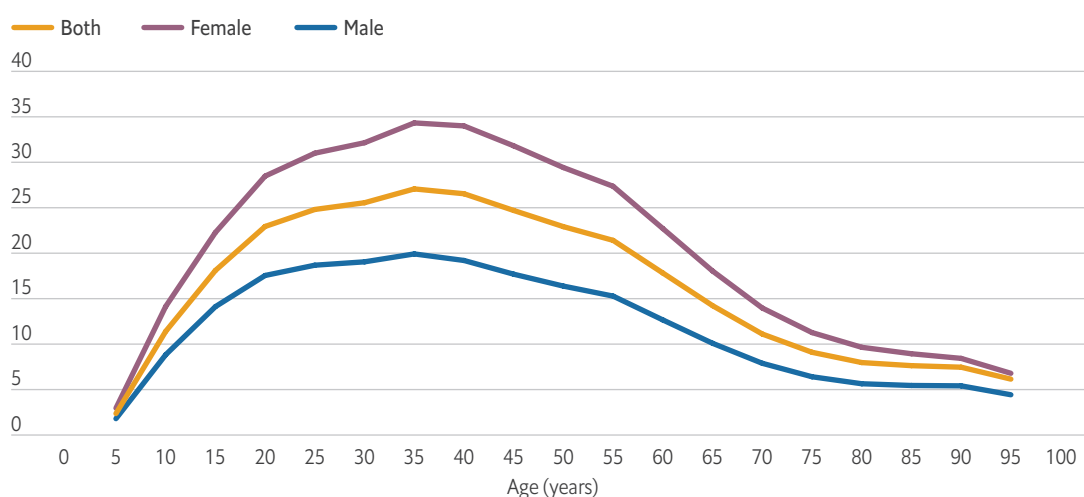
estimated €800bn a year, with some 60% of that related to direct medical and non-medical costs and 40% of that related to indirect costs such as lower productivity, according to Donna Walsh, executive director of the European Federation of Neurological Associations (EFNA), which represents European patient support organisations for people with neurological conditions.

"In terms of migraine and MS, there are more similarities than differences," she observes. "The challenge with neurological conditions is that they are chronic but fluctuating in nature. People can be fine for a long time, then have episodes where they can't come to work or aren't as productive at work."

In the next chapter we will review each of the diseases and the particular burden it has on the three groups in the workplace.

**Figure 3: Global prevalence of migraine**

%; by age group, 2017



Source: Global Burden of Disease Study 2017, Institute for Health Metrics and Evaluation at the University of Washington.

<sup>21</sup> Global Burden of Disease Study 2017, Institute for Health Metrics and Evaluation at the University of Washington. Personal communication, January 2019.

<sup>22</sup> The Migraine Trust, <https://www.migrainetrust.org/about-migraine/migraine-what-is-it/facts-figures/>

<sup>23</sup> GBD 2016 Headache Collaborators. "Global, regional, and national burden of migraine and tension-type headache, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016", *Lancet Neurol*, 2018; 17: 954-76; and <https://www.migrainetrust.org/about-migraine/migraine-what-is-it/facts-figures/>

<sup>24</sup> The Migraine Trust, <https://www.migrainetrust.org/about-migraine/migraine-what-is-it/facts-figures/>

## Chapter 2 Impact on the workplace

### Key takeaways:

- **As people work longer, neurological conditions will increase the burden on employers.**
- **All three conditions reduce employee productivity at work, and employment rates of those with the conditions often fall over time.**
- **The main impact of AD in the workforce is its burden on employees who are also unpaid carers.**
- **Carers' employment prospects are particularly affected: one in four women and one in six men are carers between the ages of 50 and 64.**
- **Those living with the conditions are frequently reluctant to be open about their conditions due to fear of stigma or job loss.**

The nature of these conditions and their different symptoms and progression create different challenges for employers in terms of being able to meet the needs of employees living with the disease and employees acting as carers to those with the disease. They require better awareness between employee and employer, yet many employees are reluctant to discuss their conditions with their employers for fear of stigma and pressure to give up work.

### Understanding costs and how the workplace is affected

#### AD

As life expectancies increase and national populations age, people will be working longer

due to rises in official state retirement ages as well as the need to save more for a longer retirement period. By 2050 some 2.1bn people are expected to be over the age of 60 and still be in work.<sup>25</sup> However, older people are more likely to be affected by chronic conditions, including AD (see Figure 1). This means that employers are likely to see greater levels of this neurological disease among their employees, as well as higher numbers of employees undertaking unpaid carer roles in addition to their regular employment. Moreover, some 18% of those diagnosed with dementia under the age of 65 continue to work after their diagnosis, according to the Alzheimer's Society. Employers therefore need to consider how they accommodate the needs of this ageing workforce, continue to access their key skills, and help them remain as productive as they can be for as long as possible.

"As an ageing workforce works longer, the impact of these and other chronic health conditions on employers will increase," says Richard Heron, chief medical officer for BP, past president of the UK Faculty of Occupational Medicine and co-chair of the International Occupational Medical Society Collaborative. "Employers will face more questions about fitness for tasks in connection with chronic conditions. Equality legislation in Europe and the USA already make it unlawful to discriminate against anyone on grounds of age, and therefore essential to get professional occupational health guidance in this population when a chronic condition impacts their work."

The global cost of AD and dementia is estimated at more than £1trn (US\$1.3trn), with 40% related to informal care.<sup>26</sup> The main

<sup>25</sup> Available at: <http://www.un.org/en/sections/issues-depth/ageing/>

<sup>26</sup> A Wimo et al, "Global Estimates of Informal Care", Alzheimer's Disease International and Karolinska Institute, July 2018, <https://www.alz.co.uk/adi/pdf/global-estimates-of-informal-care.pdf>

impact of AD in the workforce is its burden on employees who are also unpaid carers.

The annual global number of informal care hours provided to people with dementia living at home was estimated to be around 82bn hours in 2015, or the equivalent of more than 40m full-time workers in that year, a number that will rise to 65m workers in 2030.<sup>27</sup> Although 87% of total AD costs occurred in high-income countries, informal care had a heavier burden on poorer countries.<sup>28</sup> Women contributed 71% of the global hours of informal care, with the largest proportion in low-income countries.<sup>29</sup>

And many of these female carers are likely to be still looking after children. "What we are seeing is a 'sandwich generation' of employees with caring responsibilities for both children

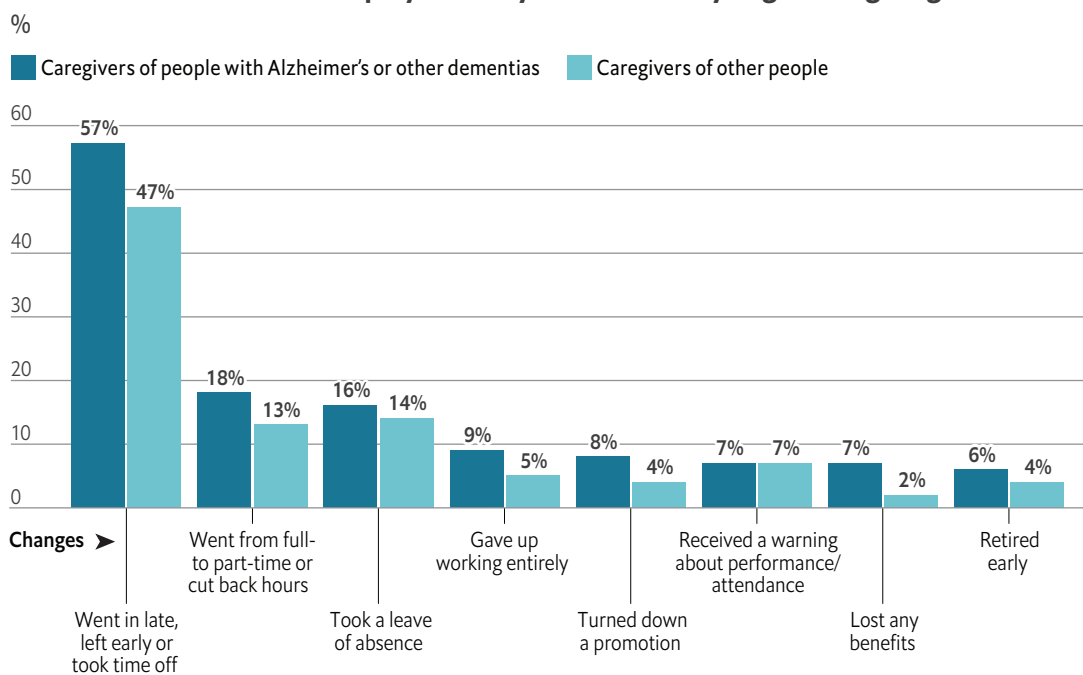
and their parents. Between the ages of 50 and 64, one in four women and one in six men are carers," says Dr Heron. "They may have to reduce their hours, take part-time roles or be absent from work to meet their caring responsibilities," he adds.

According to the Alzheimer's Association, in 2017 in the US caregivers of people with AD or other dementias provided an estimated 18.4bn hours of informal (ie, unpaid) assistance.<sup>30</sup> See Figure 4 for work-related changes among caregivers.

### Migraine

Migraine is perhaps one of the most difficult of the three conditions to be understood by employers. Although it is the only one of the three not to be a progressive condition, it

**Figure 4: Work-related changes among caregivers of people with Alzheimer's or other dementias who had been employed at any time since they began caregiving**



Source: Alzheimer's Association. 2018 Alzheimer's Disease Facts and Figures. *Alzheimers Dement* 2018;14(3):367-429.

<sup>27</sup> A Wimo et al, "Global Estimates of Informal Care", Alzheimer's Disease International and Karolinska Institute, July 2018, <https://www.alz.co.uk/adi/pdf/global-estimates-of-informal-care.pdf>

<sup>28</sup> Ibid.

<sup>29</sup> Ibid.

<sup>30</sup> Available at: <https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf>

manifests in unpredictable ways, contributing to the stigma that those living with the disease are unreliable employees. Many people living with migraine report finding it difficult to receive a diagnosis, as well as feeling isolated and stigmatised as a result of the condition.<sup>31</sup> People who live with migraine can have severe head pain as well as other symptoms that can last anywhere from four hours to three days.<sup>32</sup>

A survey of around 370 people living with migraine highlighted the reduced quality of life and significant impact of the condition on patients' daily lives, with women and those with chronic migraine reporting higher levels of disability.<sup>33</sup> A larger industry-funded study of 11,000 people in 31 countries found that 60% of employed people with severe migraine miss, on average, a week of work per month.<sup>34</sup> The study estimated that migraine costs up to US\$22bn per year in the US; the costs relate to impact on quality of life, work and overall productivity.

Migraine first affects people earlier, but it comes at the peak of their working age, according to Dr Heron, with 5-20% of those in their 20s to 50s affected by the condition. In the UK, the Migraine Trust estimates that 25m lost work and school days a year can be attributed to migraine, and that absenteeism from migraine alone costs £2.25bn (US\$2.87bn) a year.<sup>35</sup>

And a separate report by the Work Foundation, funded by Novartis, found that migraine

costs the UK economy £8.8bn a year in lost productivity.<sup>36</sup>

A separate study found that patients with migraine experience an average of 8.9 more missed days of work a year, compared with colleagues who don't suffer from the condition.<sup>37</sup>

## MS

People living with MS are active members of the workforce. A 2016 survey by the MS International Federation found that 61% of respondents with MS were still in employment.<sup>38</sup> Of these, 68% worked full time, while 26% worked part time.

The survey did find that the proportion of people with MS in full-time work fell with age: 73% of people aged 19 to 30 years were working full time compared with only 49% of those over 60.

The ability to consistently work to full productivity also affects those with MS. A longitudinal study of cognition in people living with MS found that 41% of them had cognitive impairment at the start of the study. This increased to 59% 18 years later, with declines worse in the initially unimpaired group than the impaired group. Impairment included declines in information processing speed, auditory attention, memory and episodic learning.<sup>39</sup> People living with MS were also more likely to report cognitive fatigue the longer they

<sup>31</sup> Ibid.

<sup>32</sup> Available at: <https://www.migrainetrust.org/about-migraine/migraine-what-is-it/more-than-just-a-headache/>

<sup>33</sup> A Raggi et al, "Validation of a self-reported instrument to assess work-related difficulties in patients with migraine: the HEADWORK questionnaire", *The Journal of Headache and Pain*, 2018: 19;85.

<sup>34</sup> P Marteletti, T J Scwedt et al, "My Migraine Voice Survey: a global study of disease burden among individuals with migraine for whom preventive treatments have failed," *The Journal of Headache and Pain*, (2018) 19:115.

Study funded by Novartis. <https://thejournalofheadacheandpain.biomedcentral.com/track/pdf/10.1186/s10194-018-0946-z>

<sup>35</sup> Available at: <https://www.migrainetrust.org/about-migraine/migraine-what-is-it/facts-figures/>

<sup>36</sup> The Work Foundation, "Society's headache: the socioeconomic impact of migraine", April 2018. Report funded by Novartis.

<sup>37</sup> M Bonafede, S Sapra et al, "Direct and Indirect Healthcare Resource Utilization and Costs Among Migraine Patients in the United States", *Journal of Head and Face Pain*, February 15th 2018. <https://americanheadachesociety.org/news/from-the-journal-direct-indirect-costs-migraine/>

<sup>38</sup> Global MS Employment Report 2016, MS International Federation, <https://www.msif.org/wp-content/uploads/2016/05/Global-MS-Employment-Report-2016.pdf>

<sup>39</sup> L B Strober et al, "Cognitive impairment in multiple sclerosis: An 18-year follow-up study", *Multiple Sclerosis and Related Disorders*, April 13th 2014

were engaged in a cognitive task, according to research.<sup>40</sup>

The reason MS is particularly pernicious in the workplace is that some of the aspects of MS are either invisible or not obvious to people in casual conversation, said Professor Dawn Langdon, a cognitive psychologist at Royal Holloway University. "Language is pretty intact, but processing and reasoning and memory [are] affected, so it's kind of a masked symptom." By contrast, she notes, those with early AD can have more apparent language deficits.

Like AD and migraine, the need for additional time off work is a significant factor for employees with MS. Patients newly diagnosed with MS will visit the doctor an average of eight times annually, around three times as often as an individual without the disease, according to a US study.<sup>41</sup>

Although cognitive impairment is a significant issue for employees living with MS and AD, even at relatively early stages of the illness, it does not mean that steps cannot be taken that will keep those affected with these diseases in the workplace longer. The steps that can be taken, beginning with early diagnosis, will be discussed in the next section.

## Early support and stigma

Workplaces can have employees that do not always know they have a condition. A lack of diagnosis means that neither employees nor their employers are able to explain or prepare for any disruptions to work that may be associated with these diseases. According to Alzheimer's Disease International, studies suggest that three-quarters of those with

dementia have not received a diagnosis, and therefore lack access to treatment, care and organised support.<sup>42</sup> This implies that they will also lack provision in the workplace to accommodate the impact of AD. The early symptoms and signs of MS can also be so non-specific that diagnosis can be difficult. The early signs of MS that are often present prior to diagnosis—fatigue, poor concentration and vision problems—can take a toll on a person's ability to perform tasks involving complex reasoning, processing and memory.<sup>43</sup> As a result, Ms Langdon said, half of those with even a minor physical disability due to MS are more likely to leave the workforce and become unemployed.

Given the problems of delayed diagnosis for AD, it is particularly important that employers encourage early occupational health assessments, says Dr Heron. Employees with possible early symptoms need specialist referral, perhaps to a memory clinic, Dr Heron says. He adds: "People's capabilities do not change overnight once a diagnosis is made—a specialist assessment is important both to confirm the diagnosis and identify aspects of a role where the employee may need assistance."



**A key reason for patients not to seek out diagnosis for neurological conditions is the fear that they will be pressured to give up work.**

*Stefan Tromel, senior disability specialist,  
International Labour Organisation*

<sup>40</sup> J Sandry et al, "Subjective cognitive fatigue in multiple sclerosis depends on task length", *Frontiers of Neurology*, October 27th 2014, <https://www.frontiersin.org/articles/10.3389/fneur.2014.00214/full>

<sup>41</sup> G Owens, "Economic Burden of Multiple Sclerosis and the role of Managed Care Organizations in Multiple Sclerosis Management", *American Journal of Managed Care*, May 31st 2016, <https://www.ajmc.com/journals/supplement/2016/cost-effectiveness-multiple-sclerosis/cost-effectiveness-multiple-sclerosis-economic-burden>

<sup>42</sup> Available at: <https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/employment>. Global estimate of undiagnosed extrapolated from Indian study showing 90% of dementia cases remained undiagnosed.

<sup>43</sup> M Cavallo, "Early Signs and Symptoms of MS", *MS Focus Magazine*, <https://www.msfocusmagazine.org/Magazine/Magazine-Items/Early-Signs-and-Symptoms-of-MS>

A key reason for patients not to seek out diagnosis for neurological conditions is the fear that they will be pressured to give up work, says Stefan Tromel, senior disability specialist for the International Labour Organisation, a UN organisation based in Geneva, Switzerland, which brings together governments, employers and workers' organisations to set labour standards and devise policies and programmes. He notes that many employees will use holiday leave to cover medical appointments.

However, another reason why employees may not seek out diagnosis could be the stigma associated with the disease.<sup>44</sup> Actual or perceived stigma can leave those diagnosed with the disease at increased risk of depression and isolation in the workplace. For instance, a 2017 study found that stigma makes depression more likely, and that the perception of stigma on its own contributed to 39% of the factors having an impact on depression.<sup>45</sup> Others with MS worry about colleagues being awkward or unsure of how to respond to the news of their condition.<sup>46</sup>

Peter Goadsby, professor of neurology at King's College London and head of the King's College Headache Group, compares common beliefs about migraine to earlier perceptions by society towards depression, where people did not consider it that serious. Just as depression represents more than just simple unhappiness, migraine is more than just a serious headache, he noted.

In addition, says Dr Heron, some employees with migraine might be underdiagnosed, and therefore undertreated. Earlier diagnosis can provide opportunities to teach those with the condition to avoid triggers and stay at work, he notes. Furthermore, he says, optimising



**Just as depression represents more than just simple unhappiness, migraine is more than just a serious headache.**

*Peter Goadsby, professor of neurology, King's College London*

their medication—for example, by use of triptans—can reduce the severity of an attack and also help migraine sufferers maintain their productivity at work.

Jason Karlawish, professor of medicine, medical ethics and health policy and neurology at the University of Pennsylvania, thinks there may be less stigma towards people recently diagnosed with AD, as there is a greater understanding on the part of the public that there isn't a huge gulf between normal ageing and dementia.

"Previously, by the time we saw these patients, they would be quite disabled and their history would include how they stopped work," he said. "More often than not, now they have milder symptoms [of AD] and people are still at work [as they were diagnosed earlier]."

If the stigma around these diseases are reduced by education within the workplace, it is more likely that an early diagnosis may be possible, thus allowing employers the ability to provide accommodations that can keep workers in the workplace for longer (see Chapter 3).

"Unless we have early diagnosis and associated treatment, it doesn't matter how much social legislation we have in place," says Ms Walsh.

We will now look at the impact of lost productivity in the workplace.

<sup>44</sup> See <https://www.mstrust.org.uk/research/research-updates/180409-stigma-contributes-depression>, <https://migraine.com/expert/three-reasons-stigma-migraine/> and <https://www.alz.org/help-support/i-have-alz/overcoming-stigma>

<sup>45</sup> Available at: <https://multiplesclerosisnewstoday.com/2017/05/26/study-reports-multiple-sclerosis-patients-who-feel-stigmatized-likelier-to-be-depressed/>

<sup>46</sup> Available at: <https://www.mstrust.org.uk/life-ms/your-finances/working-life>

## The cost of lost productivity and lost work

A large cost to employers is lost productivity. For those with these neurological diseases, this lost productivity is often due to the employee being physically present but experiencing, often temporary, declines in cognitive capacity (especially with MS and AD). This lost productivity, known as presenteeism, has a much larger impact on overall productivity than lost workdays, or absenteeism.

### Migraine

In a survey, noted earlier, the researchers found that for each lost workday due to migraine, patients with episodic migraine and chronic migraine work three to four days with reduced productivity.<sup>47</sup> In addition, the survey found that the degree of impact on work depended on three factors: headache severity, the kind of activities in the patient's job profile and the environment in which their job was carried out. This can include flickering lights or excessive noise, both of which can be migraine triggers, according to Mr Goadsby.

Another global study, which included nearly 2,700 migraine patients, found that migraine patients said that they were only 46% as effective at work when experiencing migraine symptoms.<sup>48</sup> This seems to indicate that although the employee may be physically present at work, the level of presenteeism means that employers and employees are losing out.

An extrapolation of these results found that patients with migraine (in the context

of a clinical trial) lost around 19.5 workdays annually, 8.3 days due to absenteeism and 11.2 days due to presenteeism. In the US, the annual employer cost of this work loss was estimated to be US\$3,309 per person with migraine,<sup>49</sup> while another study found that migraine costs to the UK economy were the equivalent to 86m lost workdays.<sup>50</sup>

### MS

For those living with MS, the cost of lost work can be substantial. A 2018 study in Sweden found that people who live with MS on average lost €5,130 of income per year after diagnosis compared with a control group. Losses ranged from €2,430 in the first year to as much as €9,010 after 11 years.<sup>51</sup> An Australian study of 740 employees with MS found that 56% had experienced productivity loss in the previous four weeks, contributing to total costs of A\$6,767 (US\$4,985) per person annually.<sup>52</sup>

A separate US survey found that the employment rate for those living with MS declines from 90% employed pre-diagnosis to a range of 20% to 30% remaining employed within five years of diagnosis, according to research from the Kessler Foundation, a US organisation that supports people with physical and cognitive disabilities caused by MS and other neurological and musculoskeletal conditions.<sup>53</sup>

### AD

The economic burden of AD can be heavily felt by those employees who are also engaged in unpaid carer roles for those living with AD. Although unpaid carers can save governments, families and friends significant amounts, they

<sup>47</sup> A Raggi et al, "Validation of a self-reported instrument to assess work-related difficulties in patients with migraine: the HEADWORK questionnaire," *The Journal of Headache and Pain*, 2018: 19;85.

<sup>48</sup> W C Gerth et al, "The Multinational Impact of Migraine Symptoms on Healthcare Utilisation and Work Loss", *Pharmacoeconomics*, 19 (2) 197-206, February 2001

<sup>49</sup> Ibid.

<sup>50</sup> The Work Foundation, "Society's headache: the socioeconomic impact of migraine", April 2018.

<sup>51</sup> E Landfelt et al, "Personal Income Before and After Diagnosis of Multiple Sclerosis", *Value in Health*, May 2018: 21 (5):590-595, <https://www.sciencedirect.com/science/article/pii/S1098301517335659>

<sup>52</sup> J Chen, B Taylor et al, "Estimating MS-related work productivity loss and factors associated with work productivity loss in a representative Australian sample of people with multiple sclerosis," *Multiple Sclerosis Journal*, June 18th 2018

<sup>53</sup> Y Goverover et al, "Factors that Moderate Activity Limitation and Participation Restriction in People with Multiple Sclerosis", *American Journal of Occupational Therapy*, Vol. 69, February 2015.



can often do so to the detriment of their own jobs and career prospects.

For example, a 2015 study from charity Carers UK found that unpaid carers save the country £132bn a year, which they note is equivalent to the cost of a second National Health Service.<sup>54</sup> A separate study quoted that the public expenditure costs of unpaid carers leaving employment in England were around £2.9bn a year, taking into account the cost of Carer's Allowance and lost tax revenue.<sup>55</sup> The report noted that greater investment in social care could help to reverse these losses to both government and carers.

The impact of caring responsibilities is becoming a key social issue globally. A survey of 1,181 dementia carers in five countries—France, Germany, Poland, Scotland and Spain—found that half were caring for a person with dementia for more than 10 hours per day, and only 17% considered the level of care for the elderly in their country to be good.<sup>56</sup> In the US, unpaid carers provide an estimated 18.4bn hours of care, valued at more than US\$232bn,

according to the Alzheimer's Association.<sup>57</sup> In Australia, the impact was also severe, with total costs in 2016 of foregone earnings by carers totalling A\$3.2bn (US\$2.3bn), or 59% of indirect costs, and the potential loss of income from people with dementia withdrawing from the workforce totalling A\$2.3bn (41% of indirect costs). By 2036 the total indirect cost of dementia is expected to increase to A\$9.1bn.<sup>58</sup>

Dr Karlawish notes that many carers are resigned to withdrawing from the workplace despite the economic toll it takes on them and their families.

"A lot of carers sadly think of it as a normal duty, but they are walking away from social insurance and social payments that come with working," he added.

For this reason we shall next consider what employers are doing and can do to help keep their employees who are also unpaid carers in the workplace as well as those employees who have these neurological conditions.

<sup>54</sup> Available at: <https://www.carersuk.org/news-and-campaigns/news/unpaid-carers-save-the-uk-132-billion-a-year-the-cost-of-a-second-nhs>

<sup>55</sup> L Pickard et al, "Public Expenditure costs of carers leaving employment in England, 2015/2016", *Health and Social Care in the Community*, January 2018, Vol. 26, Issue 1.

<sup>56</sup> "Who Cares? The State of Dementia Care in Europe," Alzheimer's Europe, <https://www.alzheimer-europe.org/Media/Images/9.-Publications/AE-survey-who-cares-The-state-of-dementia-care-in-Europe>

<sup>57</sup> Alzheimer's Association, <https://www.alz.org/alzheimers-dementia/facts-figures>

<sup>58</sup> E Hasnata and H Anh La, "Economic Cost of Dementia in Australia 2016-2056", report prepared for Alzheimer's Australia, <https://www.dementia.org.au/files/NATIONAL/documents/The-economic-cost-of-dementia-in-Australia-2016-to-2056.pdf>

## Chapter 3 Workplace response: what is taking place and what more can be done?

### Key takeaways:

- **Education and awareness in the workplace are vital to helping employees living with neurological conditions feel supported.**
- **Accommodations exist and needn't put excessive financial burden on employers.**
- **Benefits to employers from making accommodations include supporting a diverse workforce and boosting workforce morale.**
- **Workplace accommodations for people living with migraine could include a quiet room where they can rest, adjustments to lighting, and flexible working hours.**
- **Accommodations for people living with MS could include moving a workstation away from sources of heat and scheduling duties around time to take medicines.**
- **Some of the adjustments for people living with AD can include installing sound barriers to minimise distractions and planning dementia friendly meeting spaces.**
- **More can be done to help carers at work and could include offering a carer's leave policy.**

Employers can respond in a combination of ways, including the provision of education and accommodation. Education involves increasing awareness and understanding around neurological conditions in the workplace so

there is a supportive environment. The term "accommodation" refers to the obligation (legal or voluntary) of employers to make necessary adjustments to the workplace for a person with a disability to do their job.

### The importance of education and awareness

Better public education about neurological conditions can help to increase awareness in workplaces and, potentially, reduce stigma, those interviewed say. And the experience of having colleagues with one of the three conditions discussed here can help highlight areas for improvement. Indeed, many employers have offered lifestyle and wellbeing programmes as a perk for employees, and could model awareness campaigns on these programmes.

Switch.ms, an online community for people with MS, has put together a film about the difficulty of being honest about this condition in the workplace,<sup>59</sup> which could be a good resource for employers and their HR departments. Indeed, Ms Langdon says, setting up support websites or social media platforms and online forums are a good way for employers to provide information for patients and carers alike. StayingSMART.org.uk provides information about some of the cognitive difficulties associated with MS and can be useful for employers. And a powerful film called "Out of my head" can similarly help to educate employers and co-workers of the "hidden suffering" experienced by those living with migraine.<sup>60</sup>

<sup>59</sup> Available at: <https://shift.ms/circle-of-truth>

<sup>60</sup> Available at: <https://outofmyheadfilm.com/>

"The important thing is putting in place a system that is fit for purpose in 10-20 years' time," says Ms Walsh. "But, for now, we need to start creating a workplace culture whereby people feel optimistic that they can overcome these conditions in partnership with understanding and amenable employers."

"The general recommendation to employers is to have a proactive strategy to show to employees, showing that they are working in a stigma-free environment and will not meet disclosure with discrimination," says Mr Tromel. "Companies don't need to become experts on all of the individual conditions. There are a lot of commonalities as to what employers can do for staff or family members."

Ideally, occupational health programmes will need to have more specialist knowledge about all three of these conditions, as they can manifest themselves differently, depending on the individual.

"With any chronic and relapsing condition like MS, there is a need for regular advice for employers around fitness for work and safety and accommodations," he adds. "But the biggest improvement for all workers would be a focus on capability, rather than what people are not capable of. What helps is talking more



**Executives talking about health issues they may have, including chronic conditions, is an important way of creating a more diverse and open workplace.**

*Richard Heron, chief medical officer, BP*

openly about these conditions that people were once nervous to talk about."

In terms of education, more "good news" stories about people with the illnesses overcoming their impairments in the workplace would help change public perceptions, Ms Langdon said. Executives talking about health issues they may have, including chronic conditions, is an important way of creating a more diverse and open workplace, Dr Heron points out.

One of the key points interviewees emphasised is the need for earlier assessment of employees with these conditions so that appropriate occupational health referrals can be made and accommodations or adjustments put in place. Each condition requires particular approaches. In the case of MS, for example, employers may need more regular updates from affected employees, Dr Heron notes.

## **Workplace adjustments**

Employers need to consider how they accommodate employees with these conditions so that they can continue working for as long as possible. They also need to consider employees who are also unpaid carers and may struggle to meet their own job requirements.

Accommodations make business sense. A study by DePaul University of 16 large employers in the US found numerous benefits to employers from hiring and supporting people with disabilities, including greater loyalty and reliability, as well as diversification of the workforce.<sup>61</sup>

And the cost is rarely prohibitive, as long as employers are prepared to be flexible and work around the individual needs of the employee.

<sup>61</sup> See "Exploring the Bottom Line: A Study of the Costs and Benefits of Workers with Disabilities," DePaul University and Illinois Department of Commerce and Economic Opportunity, October 2007.

The Job Accommodation Network, a body in the US that provides free and confidential guidance on workplace accommodations and disability employment issues, conducted research in 2016, finding that 58% of employers reported that requested accommodations for disabilities cost nothing, and where there was a cost, it was typically around US\$500.<sup>62</sup>

“Many regulations requiring improved workplace access by employers have improved over recent years to accommodate a range of physical needs,” says Dr Heron. “But with increasing technologies, where you work is becoming less of a primary concern compared with what you are capable of contributing.”

Even industry organisations are making noise in this area. A 2018 report<sup>63</sup> by the Confederation of British Industry says there is a strong business case for workplace health and wellbeing, as companies perform better when their staff are happier, healthier and more engaged. “UK firms that have invested in this say they can see the benefits of lower absence rates, greater company performance and productivity, and are better able to attract the people and skills their business needs. There’s also a powerful moral case for action, which, at a time when a company’s reputation determines their success, should not be underestimated,” the report says. One of its recommendations includes providing line managers with suitable training so they can confidently support their team’s health and wellbeing.

We will now briefly look at some workplace accommodations for the three conditions included in this report.

## Migraine

“The screen is not right, the light is flickering, the colour is off, the light is too bright—visual things are quite punishing for the migraneur,” says Mr Goadsby. “It’s about how the work environment interacts with the misperception of sensation that the migraine brain has.”

Workplace accommodations for those with migraine can include providing a dark and quiet room where they can rest, making adjustments to lighting, and providing flexible or reduced working hours, frequent breaks and allowing employees to work from home.

The London Metropolitan Police are one organisation that has taken the condition seriously, according to Una Farrell, communications manager at The Migraine Trust.

“They are building awareness and education around migraine in the workforce so better adjustments can be made,” she said. “This is commendable, and hopefully other employers will follow in their footsteps. Supporting employees with migraine not only helps retain them; it helps them maximise their effectiveness in their roles.”

Being honest to employers about the condition is key. At a 2016 presentation to the European Neurological and Chronic Pain Disorders at Work Meeting,<sup>64</sup> Jane Whelan, who was living with severe migraine, noted the importance of disclosing her condition to her boss before she was able to benefit from workplace modifications such as flexible working hours and extra breaks. Yet, she pointed out that despite knowledge of her diagnosis, some colleagues were still sceptical about her condition.<sup>65</sup>

<sup>62</sup> Beth Loy, “Workplace accommodations: Low cost, high impact,” Job Accommodation Network, updated January 2016, <http://www.leadcenter.org/resources/report-brief/workplace-accommodations-low-cost-high-impact>

<sup>63</sup> Available at: <http://www.cbi.org.uk/front-of-mind/home.html>

<sup>64</sup> See the European Neurological and Chronic Pain Disorders at Work Meeting Report, February 24th 2016, Brussels. <http://www.brainmindpain.eu/neurological-and-chronic-pain-disorders-at-work-meeting-report/>

<sup>65</sup> Ibid.

Workplace adjustments for migraine should take into account the role of stress in bringing on migraines. Accommodations can include counselling, a more flexible schedule, "white noise" sound machines to mask loud environmental noise such as copier machines, and apps for anxiety and stress.<sup>66</sup>

## MS

Accommodating employees with MS has slightly different challenges, those interviewed say. Most people with MS are initially diagnosed with relapsing remitting MS that becomes secondary progressive MS over the course of the illness, says Ms Langdon.

"Sometimes small things, such as moving [those with MS] to a corner in a busy office can make a difference, certainly in the early stages," Ms Langdon says. "Types of lights might affect visual function during visual impairment. If fellow co-workers speak slowly, that will make [those living with MS] pick up on more information." This reiterates the importance of awareness in the workplace.

Employers may also consider the provision of a chair or stool and moving a workstation away from sources of heat or closer to a bathroom, or, in some cases, offer the option of remote working.<sup>67</sup>

Sue Heller, a bookkeeper at UK legal software firm Quill Pinpoint, said her company told her to take off "as much time as she needed" to come to terms with her initial diagnosis, and has continued to be extremely supportive since.

"When we were looking to move offices, Quill Pinpoint was quick to involve me in the

selection process. They asked for my feedback and to recommend a space I thought best," she said. "However, we were quick to realise that the toilets in the office I selected were too far from the desks. Instead of asking me to pick a different space, they offered to buy me an electric wheelchair to use around the new office."

Staff of the company, which was named Employer of the Year at the MS Society's 2016 Awards, raised more than £13,000 (US\$17,100) for the Society. Ms Heller said her employer has provided more than just the financial benefits of staying in work. "The support provided by my company has meant that getting up in the morning and going to work has given me a reason to carry on," she added.

Leeds Teaching Hospitals Trust's provision of flexible hours also allowed one of its HR managers, Imelda Webster, to cope with managing symptoms and treatment, as well as raising awareness of the condition across the organisation.

Meanwhile, another case study presented at the European Neurological and Chronic Pain Disorders at Work Meeting recounted the experience of an Italian company, Biogen. After hiring an employee with MS as part of



**One employee with MS was able to continue working as usual just by reducing the amount of overtime she did.**

*MS Trust*

<sup>66</sup> Available at: <https://askjan.org/disabilities/Migraines.cfm>

<sup>67</sup> Available at: <https://www.mssociety.org.uk/care-and-support/everyday-living/working-and-ms/information-for-employers>

an internship programme, it found that its internal HR policies had inadvertently led to the individual being "labelled". The workplace overcompensated by labelling the person as an MS sufferer, inadvertently exacerbating the worker's sense of stigma.

One employee with MS, cited in an MS Trust report on workplace accommodations, was able to continue working as usual just by reducing the amount of overtime she did.<sup>68</sup> In the case of MS, employers may need more regular updates from affected employees, Dr Heron notes.

"With a chronic and relapsing condition like MS, regular reviews can ensure fitness for work, employee safety and reasonable accommodations are all maintained," he adds. "But the biggest improvement for workers and employers comes from an increased focus on capability, and less on what people cannot do. Greater employee awareness and openness about these conditions is also helpful to reduce stigma."

So will these accommodations be enough? Although improved treatments mean patients relapse less frequently, the nature of the illness means that employees and employers need to communicate about fitness for work. Unlike AD, where sufferers tend to deteriorate over the first decade after diagnosis, people can have MS for many years; their lifespan is generally only moderately shorter than those without the disease, Ms Langdon says.

Line managers can also allow an employee to schedule their duties around the time to take medicines, such as infusions, or attend medical appointments. There are examples of

healthcare providers trying to accommodate patients and their employers, for example, St Bartholomew's Hospital in London has begun offering infusion services on nights and weekends so that patients aren't required to miss work.

## AD

While most workplace accommodations for AD involve carers (see below), there are some examples of companies that are already trying to help those recently diagnosed with dementia to extend their working life.

UK retailer Sainsbury's received accolades from AD charities after Doron Salomon thanked the company for employing his mother for five months after a medical exam found her to be unemployable in October 2017. Mrs Salomon, 61, was diagnosed in late 2013, just a year after starting work at the company as a bookkeeper. After the medical exam in 2017, Sainsbury's found other jobs for her to do and eventually created a new role until it became impossible for her to fulfil her new duties.<sup>69</sup>

In another case study, provided by the Alzheimer's Society UK, Gavin, an employee of Bunzl Healthcare in Manchester, had been working for the company for seven years, picking and packing products for distribution, before receiving his diagnosis three years ago. After sharing his diagnosis with colleagues, two years after receiving it, they helped him to deal with larger orders and eventually transferred him to the packaging benches after he became confused with product codes and locations while picking and sorting items. He has since moved to a four-day week to enable him to rest more between working days.

<sup>68</sup> See <https://www.mstrust.org.uk/life-ms/your-finances/working-life>

<sup>69</sup> *Independent*, "Sainsbury's praised for helping employee with alzheimer's keep job", March 6th 2018, <https://www.independent.co.uk/life-style/sainsburys-alzheimers-disease-worker-keep-job-kenton-store-twitter-a8241866.html>

Yet, along with these positive stories are examples of employees whose working lives are cut short before they need to be. Lorraine, an employee in a hospital mental health team for more than 24 years, who was only two years away from retirement, was diagnosed with early onset AD. When she spoke with her manager, other managers insisted on being present; although Lorraine's manager tried to amend her duties, she took time to come to terms with the diagnosis and lost her job.

"I have so much to offer," Lorraine said. "I help to train emergency services and healthcare staff. I could have worked for longer. It was my right to work for longer and they denied it."

Some of the workplace adjustments for AD can include installing sound barriers to minimise distractions, clearer signs, memory aids such as phone apps to help with concentration or colour-coded signage to enable the affected person to find their way around the building, planning dementia-friendly meeting spaces and allocating some duties to other employees.<sup>70</sup>

Similar adjustments can be made for people with migraine and MS, Dr Heron says, and many of these are low-cost, such as moving an employee's desk to a quieter area to help with concentration, or temporarily reallocating certain tasks to other employees. In some cases, job restructuring with specialist advice may be needed.<sup>71</sup>

In the case of both MS and AD, cognitive fatigue and impairment are among the key issues for employers to grapple with, according to Ms Langdon and Dr Karlawish.

Ultimately, adaptability is arguably the greatest accommodation an employer can make to their employees with neurological conditions,

those interviewed agree, whether this involves changes in an employer's physical space at work, working schedule or greater recognition of caring roles.

"When you are talking about chronic fluctuating conditions like migraine and MS, it's about having a flexible approach, not a one-size-fits-all solution," says Ms Walsh of EFNA. "Often, a very small adjustment is needed to be functional in the workplace. Someone might need to start at 10 am rather than 9 am, have an anti-glare screen, or a room to lie down in. It can be something very small, but it needs recognition among top-line management." This flexibility is also needed in the case of employees living with AD.



**When you are talking about chronic fluctuating conditions like migraine and MS, it's about having a flexible approach, not a one-size-fits-all solution.**

*Donna Walsh, executive director, European Federation of Neurological Associations*

### **The role of disability legislation in the workplace**

Although there has been some work at the EU level on chronic diseases and their impact on employment, most legislation falls under the area of disability discrimination, according to Mr Tromel.

"If you are certified disabled, you will have protection from discrimination and the right to workplace adjustments. This is what could

<sup>70</sup> Available at: [https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/creating\\_a\\_dementia-friendly\\_workplace.pdf](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/creating_a_dementia-friendly_workplace.pdf)

<sup>71</sup> See <https://askjan.org/disabilities/Alzheimer-s-Disease.cfm>

allow you to continue work and adjust your work schedule or work environment," he said. "People who are not certified have no protection."

The EU's Council Directive 2000/78/EC of November 27th 2000 establishes a general framework for equal treatment in employment, which requires employers to "take appropriate measures...in order to eliminate disadvantages".<sup>72</sup>

Article 5 of the directive states: "In order to guarantee compliance with the principle of equal treatment in relation to persons with disabilities, reasonable accommodation shall be provided. This means that employers shall take appropriate measures, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer."<sup>73</sup>

The UK Equality Act and Northern Ireland's Disability Discrimination Act, which are based on the directive, make it illegal to discriminate against someone because they have a recognised disability. The laws require employers to put in place "reasonable adjustments", to allow employees to do their job. The Americans for Disability Act has similar provisions.<sup>74</sup>

Yet, given that people with chronic conditions experience more work absences—in many cases leading employers to suggest that they apply for permanent disability—many employees are reluctant to disclose conditions for fear that it could lead to termination of their jobs, according to Dr Heron and Mr Tromel.

Introducing policies that would include a component of compensation for employers could be an important step forward, Mr Tromel said.

At an individual condition level, some projects are being conducted at the European level. An expert group run by the European Headache and Migraine Association is looking at how to encourage changes in HR practice on the workplace agenda. Meanwhile, the Participation To Healthy Workplaces And Inclusive Strategies in The Work Sector, an EU project advocating employment for people with chronic diseases, has outlined seven policy recommendations to improve awareness of chronic diseases in HR departments, including the development of "integrated employment support systems".<sup>75</sup>

The UK's Fit for Work programme is a good example of a programme that looks at someone's capabilities, rather than their disability, Mr Tromel observed.

"We are not yet in an environment where companies are making the effort to find solutions that would allow the person to continue with work," he added. "This is a waste of talent for the company and a waste [of potential revenue and productivity] for government."

Recognising what the individual needs is beneficial to employers as well, by creating a more diverse environment, which is more likely to contribute to business success.

"By providing reasonable workplace accommodations to persons with MS or other neurological conditions, employers are able to retain talented employees, contribute

<sup>72</sup> Available at: <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex:32000L0078>, Article 2 (2ii).

<sup>73</sup> Council Directive 2000/78/EC, <https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32000L0078:EN:HTML>

<sup>74</sup> Available at: <https://adata.org/factsheet/ADA-overview>

<sup>75</sup> Available at: <https://www.path-ways.eu/project/>



to workforce diversity and increase overall workforce morale, as well as meet the relevant legal obligations," Mr Trommel adds.

A number of OECD members do allow people to have disability benefits that permit them to work part time, Mr Trommel added, noting that Finland and the Republic of Ireland are two such countries.

The Alzheimer's Society in the UK has called on the government for a number of changes, including for decisions about benefits, including the Employment Support Allowance (ESA), to be taken by professionals from the Department of Work and Pensions (DWP) trained to understand the impact of dementia. Currently, applicants for the ESA must get a note from their general practitioner and do a health assessment at the DWP, where staff with expertise in their condition may not be conducting their individual assessment.

In addition, JobCentre Plus in the UK, which is a division of the DWP that delivers working-age support, have the Access to Work scheme, helping those with long-term health problems stay in a job.

### **Provision for carers: a work in progress**

The issue of how employers provide for employees who are also unpaid carers is becoming increasingly crucial as, for example, one in ten people in the US over the age of 65 has AD.<sup>76</sup> They will, at some stage, require care, as will those with MS. Even those affected by migraine may require assistance from a carer. Many carers are forced to either reduce their hours, which may negatively affect current

and future earning potential, or give up work entirely. Many of these carers are often women between 40 and 50 years of age, or even younger, and some are still looking after children of their own.

In addition, interviewees say, those with MS often rely on family members for care during relapses, meaning the impact of MS on workplaces extends beyond the sufferers themselves.

In the UK, employers are obliged to consider requests for flexible working from carers under the Flexible Working Regulations (2006).<sup>77</sup> In Europe, both Italy and France have legislation covering flexible working in force; German workers employed for more than six months have a more limited right to request flexible work, and their employer may reject their request. The US has no comprehensive legislation affecting flexible working, although in some cases employers may be compelled to allow their employees to adjust work schedules under the Family and Medical Leave Act (FMLA), although the FMLA doesn't require any associated leave to be paid.<sup>78</sup>

The Alzheimer's Society also notes that carers of people with dementia report struggling to access support services during working hours, a challenge that it says "increases isolation and pressure on working carers".<sup>79</sup>

The UK has been a leader in bringing attention to the problem of unpaid carers and their impact on businesses, and some companies have provided good examples of how to support their workers. Employers for Carers, a business organisation, notes that, with three in five people likely to end up caring for someone

<sup>76</sup> See <https://www.alz.org/alzheimers-dementia/facts-figures>

<sup>77</sup> Available at: "Alzheimer's Society's view on employment of people with dementia," <https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/employment>

<sup>78</sup> Available at: <https://www.personneltoday.com/hr/flexible-working-arrangements-vary-around-globe/>

<sup>79</sup> Ibid.

at some point in their lives, the business case for supporting these workers should be clear. One of its members, utility company Centrica, maintains an employee carers network of more than 1,000 people, and offers an innovative carer's leave policy that provides up to one month of matched leave per year. Supermarket retailer Sainsbury's, with an estimated 20,000 staff providing care informally, is one of the few FTSE 100 companies with a specific policy for carers, including flexible schedules and work adjustments, such as allowing mobile phones on-site in case of emergencies.<sup>80</sup> Centrica allows employees to take career breaks, work variable hours, do part-time hours and telecommute, according to Simi Dubb, the company's director of diversity and inclusion.

"Whilst there are currently 1,118 registered carers within our network, we estimate that 60% of our 30,000 employees will be carers at some point in their working lives," Ms Dubb says. "It is therefore our duty to have the right policies in place to provide a supportive environment to help minimise [the] juggling both roles can cause."

By allowing its staff to balance work with caring responsibilities, Centrica can attract and retain a diverse and skilled workforce. This in turn reduces turnover, cuts recruitment and training costs, builds resilience, and improves employee engagement and wellbeing, the company believes.

Centrica has seen financial benefits from its policy, saving around £1.8m (US\$2.4m) a year by providing paid leave and peer support to help its employees avoid unplanned absences and presenteeism due to caring responsibilities.<sup>81</sup>

"Only a third of companies currently have these sorts of policies for carers in place, despite the fact that it is actually something that benefits our business enormously," Ms Dubb adds. "On a national level, if UK businesses were to implement flexible working policies, it is projected that up to £4.8bn could be saved a year."

Although UK policy currently only allows employees to request flexible working once they have been in the job for six months, Centrica allows flexible working for carers from day one, Ms Dubb said, adding that such a right should become standard practice.

Employers have a range of options to provide for carers through employee benefits and greater flexibility in the workplace, but those interviewed say efforts to extend protections for carers are a "work in progress".

"It's a much larger conversation about what are our social obligations to provide long-term care," said Dr Karlawish. "If you see it as only a company problem, you are missing the larger issue."



**With three in five people likely to end up caring for someone at some point in their lives, the business case for supporting these workers should be clear.**

*Employers for Carers*

<sup>80</sup> Employers for Carers, [https://www.employersforcarers.org/images/EFC\\_Business\\_Case\\_April\\_2017.pdf](https://www.employersforcarers.org/images/EFC_Business_Case_April_2017.pdf)

<sup>81</sup> Available at: <https://www.centrica.com/news/carers-uk-and-centrica-announce-new-partnership-improve-lives-carers>

## Conclusion

Employers will need to be more aware of neurological conditions in order to preserve a strong and productive workforce and retain the growing number of employees who are also carers.

As demographics worsen and retirement ages are extended, employers will need to develop and strengthen policies that will accommodate this population's changing needs. This report looked at three neurological conditions that employers and their HR departments need to build awareness of to better understand the impact of AD, MS and migraine.

Education in the workplace around the capabilities of those living with migraine, MS and AD will help employees living with these conditions (and carers who are employees) feel supported. This is because presenteeism, where employees remain at work but are working at less than full productivity, is a bigger problem than absenteeism for employers. Key stakeholders in businesses—HR, occupational health and line managers—will need to work closely together to find effective solutions that are tailored to the individual needs of employees living with these conditions and employees who are carers.

Importantly, minor adjustments can be easily introduced in the workplace, often costing very little to the employer. Some of these accommodations are simple to introduce and can include, for instance, adjustments to lighting for those living with migraine, moving a workstation away from sources of heat for those with MS, and installing sound barriers to minimise distractions for people with AD. These needn't put an excessive financial burden on employers.

Some companies like Centrica are undertaking innovative work around carer's leave and others could learn from their example. Overall, more needs to be done to support employees who are carers, especially with the rise in AD numbers.

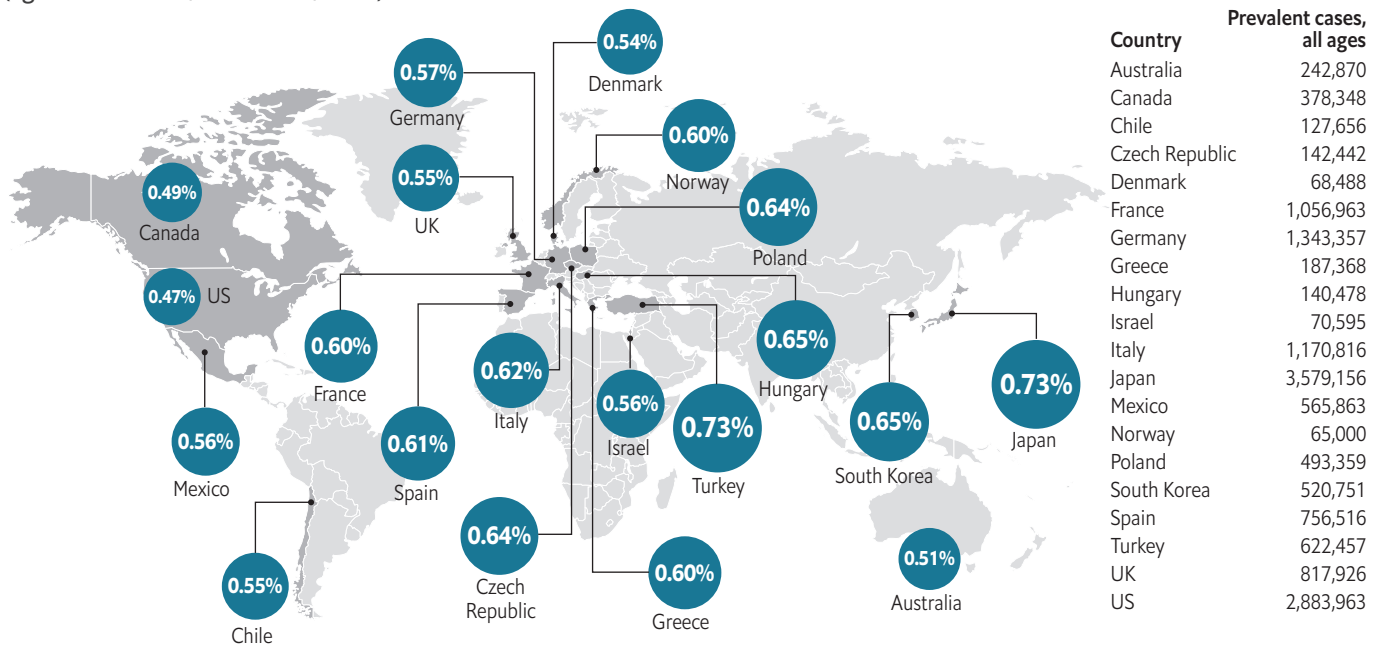
Employers will be able to see benefits from the accommodations as they bring in improved diversity in the workforce (especially women, who are particularly affected by these conditions), increased productivity and a boost in employee morale.

The lack of investment in social care in different countries are subjects that will require additional research in the future. More research into how employers' bottom lines are affected by making adjustments to employees with neurological conditions will also be needed, as these conditions are not just the domain of healthcare and social care systems.

## Appendix

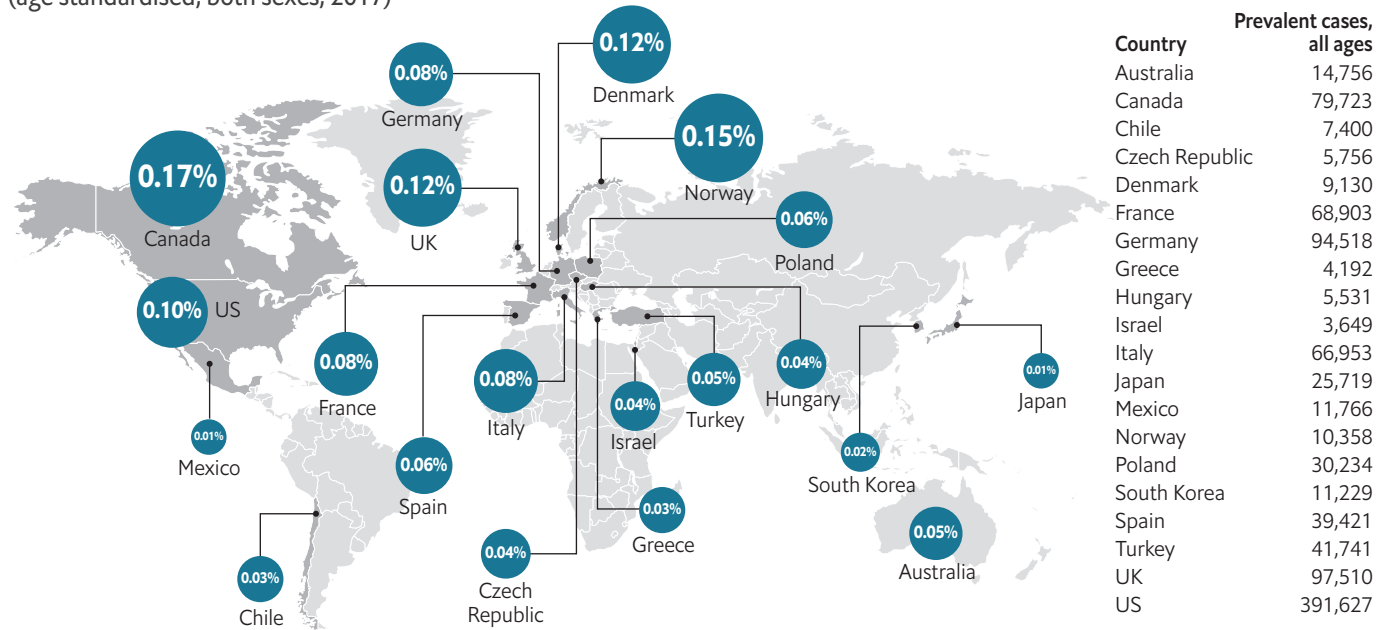
The following figures present prevalence data on three neurological conditions across selected OECD countries. This original data comes from the Global Burden Disease Study 2017.

**Figure 5: Prevalence of Alzheimer's disease and other dementias in selected countries**  
 (age standardised, both sexes, 2017)



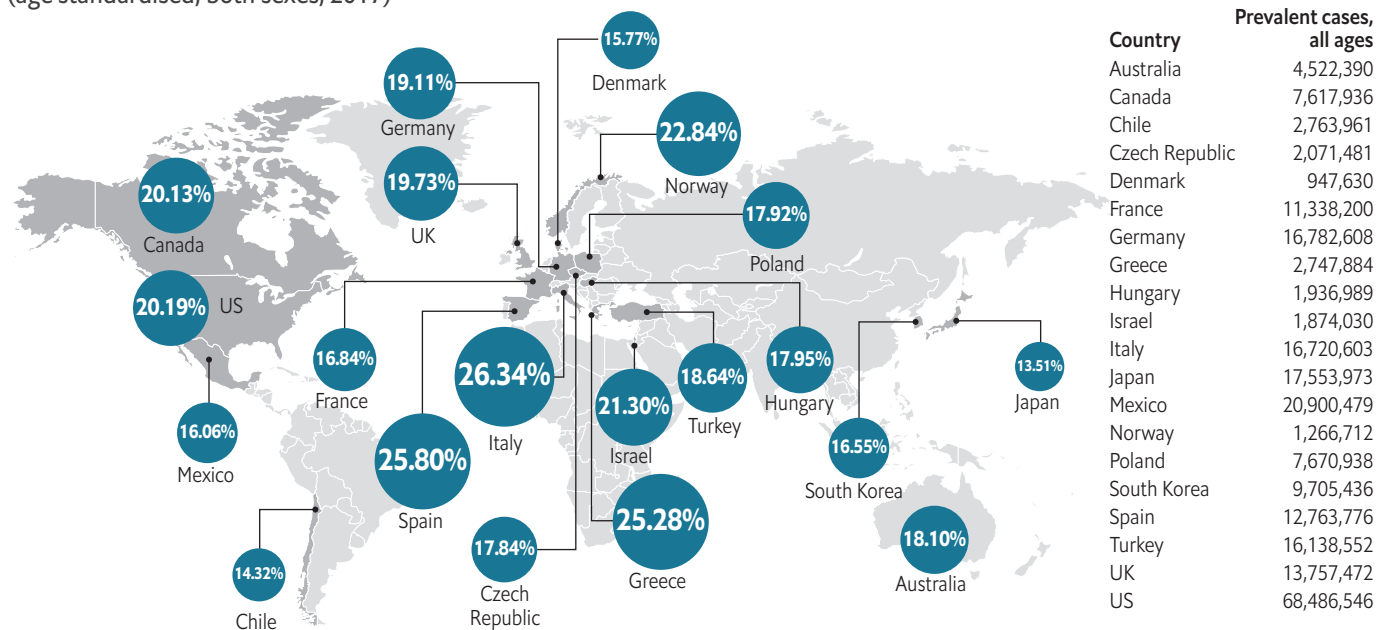
Source: Global Burden of Disease Study 2017, Institute for Health Metrics and Evaluation at the University of Washington.

**Figure 6: Prevalence of multiple sclerosis in selected countries**  
(age standardised, both sexes, 2017)



Source: Global Burden of Disease Study 2017, Institute for Health Metrics and Evaluation at the University of Washington.

**Figure 7: Prevalence of migraine in selected countries**  
(age standardised, both sexes, 2017)



Source: Global Burden of Disease Study 2017, Institute for Health Metrics and Evaluation at the University of Washington.

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## LONDON

20 Cabot Square  
London, E14 4QW  
United Kingdom  
Tel: (44.20) 7576  
8000  
Fax: (44.20) 7576  
8500  
Email: london@eiu.  
com

## NEW YORK

750 Third Avenue  
5th Floor  
New York, NY 10017  
United States  
Tel: (1.212) 554 0600  
Fax: (1.212) 586  
1181/2  
Email: americas@eiu.  
com

## HONG KONG

1301 Cityplaza Four  
12 Taikoo Wan Road  
Taikoo Shing  
Hong Kong  
Tel: (852) 2585 3888  
Fax: (852) 2802 7638  
Email: asia@eiu.com

## GENEVA

Rue de l'Athénée 32  
1206 Geneva  
Switzerland  
Tel: (41) 22 566 2470  
Fax: (41) 22 346 93  
47  
Email: geneva@eiu.  
com

## DUBAI

Office 1301a  
Aurora Tower  
Dubai Media City  
Dubai  
Tel: (971) 4 433 4202  
Fax: (971) 4 438 0224  
Email: dubai@eiu.  
com

## SINGAPORE

8 Cross Street  
#23-01 Manulife  
Tower  
Singapore  
048424  
Tel: (65) 6534 5177  
Fax: (65) 6534 5077  
Email: asia@eiu.com