

Supporting employees who are caring for someone with dementia

CARERS UK

the voice of carers

etc
employers
for carers

About us

About Employers for Carers

Employers for Carers is an exciting, innovative and growing service for employers. Chaired by British Gas and supported by the specialist knowledge of Carers UK, its key purpose is to provide practical, 'hands-on' help to employers to support the carers in their workforce.

Launched in January 2009 as an employers' membership forum, Employers for Carers now has over 70 member organisations, representing at least one million employees across the public and private sectors. Member services include a dedicated website with a range of practical resources, networking facilities, model policies and case studies, resources for employers and employees and access to expert training and consultancy.

To find out more visit www.employersforcarers.org

About Carers UK

Carers UK is a charity set up to help the millions of people who care for family or friends. At some point in our lives every one of us will be involved in looking after an older, ill or disabled family member or friend.

Over six and a half million people in the UK are caring now but while caring is part and parcel of life, without the right support the personal costs can be high. Carers UK supports carers, provides information and advice about caring, delivers training and consultancy services and campaigns to make life better for carers.

To find out more visit www.carersuk.org

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Foreword



Heléna Herklots

Heléna Herklots
Chief Executive, Carers UK

Demographic change is demanding new responses from our society, workplaces, public services and family life as our population and workforce age. As the number of working age people caring for older loved ones with health conditions such as dementia rises, the impact on people's ability to work is becoming an increasingly critical issue for employers.

Half the UK's 6.5 million carers are juggling paid work alongside caring. Within the total population of carers, the number of people caring for loved ones with dementia is rising and is set to reach 850,000 by the end of the decade.¹ Research has shown full-time working carers are most likely to care for a loved one with dementia.²

The employers and carers we work with are telling us the same story as the statistics – that dementia and the impact on employees of caring is a key issue for workforce retention, recruitment and resilience. Very often the need to care for an elderly parent comes at peak career age. Without the right support, the challenges of combining such caring with work (often also with other family responsibilities) can quickly become too difficult to manage. Employees with valuable experience and skills will then either leave their jobs or struggle to cope in the workplace. From earlier research we already know that 1 in 6 carers leave work or reduce their hours to care.³

The experiences from carers and employers captured in this research show that the current support needs of people caring for loved ones with dementia are not being met, especially by care and support services. Problems of lack of knowledge about how and where to get help, lack of timely and relevant information and support and lack of appropriate, quality and affordable care services are raised consistently in the surveys. This lack of support is compounded by a perceived stigma around dementia, often reported by carers, which explains why it remains such a hidden issue in so many workplaces. The often challenging stages of dementia

1 Alzheimer's Society, from *Dementia 2012* (2012)

2 Carers UK *State of Caring* survey 2013

3 A Carers UK/You Gov Poll in 2013 showed 2.3 million have quit work to care and almost 3 million have reduced working hours to care at some point in their lives.

as it progresses also cause particular stresses and strains for carers and their families when unsupported with information and practical help.

These gaps in care and support for people with dementia are taking a toll on families' health, finances and careers. This must now be addressed urgently in policy and practice covering dementia services, wider care services and support for carers of loved ones with dementia, including the impact of such caring, if unsupported, on people's ability to work. Quality and affordability of care for older and disabled people, including those with dementia, is as much an issue of economic participation as childcare.

From carers' and employers' experiences in this research, we also see what the right support for people with dementia and their families should look like – good quality, affordable and appropriate care services, health and social care professionals with the right skills and training, supportive workplaces and communities, and family carers who are supported to care. Carers UK is committed to working with others to help make this happen.



Ian Peters

Chair, Employers for Carers; MD of British Gas Residential Energy

Employers for Carers has led the way in promoting effective workplace practice to support staff with caring responsibilities, including for family members with dementia. With our ageing population and ageing workplaces, dementia is moving centre stage for us as a business issue, with its effects on carers' mental and wider health being particularly striking.

Addressing this increasingly critical issue is, however, not just about being a good employer, it is good for business – improving productivity and retention of talent in the workplace and reducing staff stress, turnover and recruitment costs.

However this research highlights that much more needs to be done to make supporting colleagues who juggle work and caring for loved ones with dementia part of normal workplace practice, as well as to ensure that people can access the advice, support and services they need to enable them to combine work and family life.

Background: the dementia challenge

What is dementia? *(Source: The Alzheimer's Society)*

- Dementia describes different brain disorders that trigger a loss of brain function. These conditions are all usually progressive and eventually severe.
- Alzheimer's disease is the most common type of dementia, affecting 62% of those diagnosed.
- Other types of dementia include:
 - vascular dementia affecting 17% of those diagnosed
 - mixed dementia affecting 10% of those diagnosed
- Dementia is one of the main causes of disability later in life, ahead of cancer, cardiovascular disease and stroke.
- Symptoms of dementia include memory loss, confusion and problems with speech and understanding.
- Dementia is a terminal condition.

With our ageing population and workforce, dementia is becoming an increasingly significant issue in the workplace as more and more people are combining work and caring for older, sick or disabled parents and other loved ones.

Dementia is also becoming an increasingly well recognised issue both nationally and globally.

At a national level, the Alzheimer's Society's *Dementia Friendly Communities* programme, which launched in 2012, is focusing on improving inclusion and quality of life for people with dementia. Its five year strategy includes a key ambition to work with people affected by dementia and key partners to define and develop dementia friendly communities. The Prime Minister's challenge on dementia also includes an ambition to create communities that are working to help people live well with dementia.

At a global level, as was acknowledged at the first G8 Summit held on dementia on 11 December 2013, the condition affects more than 35 million people worldwide, a number that is expected to almost double every 20 years. As well as the impact on families' health and wellbeing, the socio-economic impact is also huge with 70% of the estimated annual world-wide cost of US\$ 604 billion spent on informal, social and direct medical care.⁴

⁴ Department of Health and Prime Minister's Office Policy Paper, *G8 Dementia Summit Declaration* (11 December 2013)

Within the UK, the Alzheimer's Society estimates that there are already 800,000 people with dementia. This number is set to rise to over 1 million by 2021. Unpaid carers provide a major part of the support to people with dementia and there are already an estimated 670,000 people in the UK acting as primary carers for relatives and friends with the condition.

Many families feel they are providing the best care possible by supporting loved ones with dementia themselves, but caring for someone with dementia is also often highly stressful and can be deeply upsetting. It can also become progressively more demanding, both physically and emotionally. When combined with work responsibilities, this experience can be very challenging for carers, particularly as dementia is often a relatively hidden issue in the workplace. The stigma and lack of understanding that still exists around conditions such as dementia means that people can often feel uncomfortable about mentioning their caring responsibilities at work, even when they clearly need support.

Carers over retirement age are the fastest growing group providing care for loved ones, typically caring for a partner or a parent in their 80s and 90s. These carers often face growing isolation, being unable to carry on paid work or to volunteer and seeing a very significant impact on their own health.

However, the rising number of people of working age caring for a parent with dementia, or a partner with early-onset dementia, means that dementia care is not simply an issue for older age. In many cases working-age people may not only be caring for a parent with dementia but also supporting their other parent who is the primary carer and who may also have significant health and support needs.

While many working-age carers of loved ones with dementia will continue to work, many others will struggle to combine these responsibilities and will leave employment or take early retirement. Dementia is therefore a growing challenge not just for public services and families but also for employers and business. It is not only mentioned regularly by members of the Employers for Carers forum but also featured in Carers UK's *State of Caring* survey 2013 which found that:

- ▶ Nearly one in five carers were looking after family members with dementia.
- ▶ These carers were more likely (than other carers) to be combining this with full time employment.

In recognition of this, Carers UK and Employers for Carers have undertaken targeted research into the impact on employers and employees of caring for someone with dementia. The study was undertaken between October 2013 and January 2014.

The aim of the employer and employee surveys was to improve understanding of the key issues and support needs of employees combining work and caring for someone with dementia, and practical ways in which employers and other parties can help.

A further aim of the employee survey was to improve understanding of the pressures which can cause people to leave work to care and how these can be addressed. This survey was therefore also open to people who had left work to care within the past two years.

Both surveys were conducted online, with all information being treated in absolute confidence.

Key findings

Summary

Both the employer and employee surveys highlighted the need for:

- clearer, more accessible information on dementia – and how to get practical help – at both national and local level.
- a wider workplace response to people caring for loved ones with dementia.
- employers to play a key role in signposting carers in their workforce to sources of information and help on dementia, both within and outside the workplace.
- care and support services to be accessible, available and appropriate for people with dementia, including specialist help when required.

Although the survey findings should be treated with caution because of the nature of the samples (a point which is reiterated within this report), the responses received offer an interesting insight into issues such as the types of workplace and external support that are needed urgently for people who are juggling work with caring for someone with dementia.

Employer survey

In total 85 employer organisations took part in the survey from the private, public, voluntary and community sectors. It is important to note, however, that while they were drawn from all these sectors, the majority were from sectors which were closer to the issues and may therefore have been more likely to be aware of dementia and of caring needs within the workplace than the majority of other employers.

Caring for someone with dementia – impact in the workplace:

- A clear majority of employers (89%) believed that dementia and the ageing population will become an increasingly bigger issue for their organisation and their staff.
- Within this group, over 8 out of 10 employers (84%) thought that it will add more pressure to their staff , 7

out of 10 (71%) felt that it may lead to loss of valuable employees and more than 3 in 5 (64%) said that it may lead to loss of staff health and productivity.

Support offered to carers, including those supporting someone with dementia:

- The overwhelming majority of employers who responded (91%) reported being aware of employees who were caring for older, sick or disabled family members or friends.
- Over two thirds of these employers (70%) stated that they were aware of employees who were caring for someone with dementia.
- The vast majority of these employers said that they offered flexible working arrangements⁵ to carers (83%) and nearly two thirds (64%) said that they offered flexible/special leave.
- Of the employers offering flexible/special leave, the vast majority provided compassionate leave (86%) and emergency leave (84%). Half of the employers in this group also reported offering carers leave (55%) and 2 out of 5 career breaks (41%).
- Over half (58%) reported signposting employees to other sources of support, most commonly to support on caring (72%) and practical help to support employees' own health and wellbeing (70%).
- Other types of support included awareness raising events (46%), remote working (42%) and publicity about workplace support, a specific policy for carers and a workplace network for carers (all 33%).
- Less than 1 in 5 (19%) provided training and support for managers in carer awareness/implementing support for working carers and in training and support for managers in dementia awareness.

Employers' support needs:

- Two thirds (67%) of employers were seeking clearer, more accessible national/public information on dementia for their employees (including how/where carers can get help) as well as for advice and support at all stages of caring.
- Almost two thirds (63%) wanted more practical assistance from care and support services to help ensure their employees are supported to stay in work.
- A similar number (61%) wanted more practical assistance from specialist dementia services for their employees.
- The same number (61%) were also seeking practical tools and information to help them signpost their employees to sources of information and support on caring and dementia.
- Over half (59%) also wanted clearer, more accessible local information on dementia including how carers in their workforce can get practical help and support.
- Other identified priorities were:
 - Practical tools to help employers provide carers and dementia awareness training to managers and employees in the workplace (57%).
 - Information about supportive technologies⁶ which may help people to live more independently and support carers to stay in work (57%).

⁵ These ranged from part-time working and flexitime to home/remote working and (less commonly) job-sharing, compressed or annualised hours, term time working or shift swapping/split shifts.

⁶ Such as alarms, sensors or remote health monitoring.

- Care and support services available outside normal working hours to ensure that working carers and relatives with dementia can get the support they need (54%).
- Timely diagnosis and support by GPs/health professionals so that carers and their families are supported at the earliest stage (52%).
- Links with other employers who are addressing the issues of caring and dementia in their workplaces (48%).

Employee survey

About 1,000 individuals who were caring for someone with dementia took part in this survey. The survey also included those who had left work within the last two years. Four fifths were female (79%) and one fifth were male (21%). Half of the respondents (52%) were aged 40-54 and nearly two fifths (38%) were aged 55-64.

Impact of caring (for someone with dementia) on capacity to work:

- Just over half of respondents to the survey (53%) said that their work had been negatively affected due to their caring responsibilities (tiredness, anxiety, stress etc).
- Over 1 in 4 carers (27%) were worried that caring might have an impact on their capacity to work in the future although it had not had an impact to date.
- Almost 1 in 4 (23%) said that they had changed their working pattern, 1 in 5 (19%) had reduced their working hours and 1 in 10 had taken a less qualified/senior role to fit around their caring responsibilities.
- Only 7% of carers reported that caring had not had an impact on their capacity to work.

“Mum has been at home with us for 13 months. I resigned from my last job when she took ill last year... I have gone from earning £37,500 p.a. to £200 per month. You tell me – what are we supposed to do?”

Caring for someone with dementia as a cause of difficulties/stress at work:

- When asked to identify the one thing about caring (outside of work) that caused the most difficulties/stress at work, top of the list was ‘I cannot be sure that the person I am supporting is getting quality help at the right time’ (21%).
- Next on the list was ‘I have to spend a lot of time co-ordinating care’ (20%) and ‘my relatives won’t accept any outside help and want to manage themselves’ (16%).
- When asked what would be the impact if these areas were improved, three quarters (75%) thought that they would be less stressed and just over 3 out of 5 (62%) thought that they would be less tired.
- Almost half of the carers (49%) thought they would be more able to

“I am just about coping at the moment. I am not sure that I will be able to as the dementia progresses. That is the biggest worry for me as I am the breadwinner in the family and can’t afford to reduce my hours or give up work.”

“Having a provider of paid care workers that one can trust and rely upon would make life easier and less stressful.”

focus on work and 2 out of 5 (39%) thought that it would have a positive impact on their employment if these areas were improved.

Support provided by carers for relatives and friends with dementia:

- Nearly 4 out of 5 (79%) were caring for a parent or parent in law and less than 1 in 10 people (8%) were caring for a spouse or civil partner. Around three quarters (75%) were caring at a distance.
- The vast majority (88%) were providing emotional support (mostly in combination with other forms of support) and help with paperwork and financial matters (83%).
- Nearly three quarters were providing practical help such as preparing/ordering meals or shopping (74%), going to medical appointments (74%) and arranging care and support services/appointments (73%).
- Other types of support included: managing medication (60%), supporting leisure activities (49%), providing personal care (39%) or physical help with walking/getting up and down stairs (38%).
- Just over a third (36%) provided between 1-9 hours of care per week, with around a quarter (26%) providing 10-19 hours and, strikingly, a similar number (24%) providing 35 or more hours of care per week. 14% of carers were providing 20-34 hours per week.

Current support for carers (for someone with dementia) outside the workplace:

- Of the 84% of carers who received some kind of help outside the workplace, 3 out of 5 (61%) said they had support from family or friends with only just over 1 in 3 (36%) receiving practical support from care workers.
- Around a third (30%) reported having equipment⁷ installed in the home of the person they cared for and a quarter (25%) said that they used technology such as alarms or sensors.
- Only 1 in 5 (20%) reported receiving advice, information and training from health and mental health professionals.
- Only 13% had received specialist advice and support from a dementia group and an even smaller number (11%) advice and information about dementia-related medication.
- Less than 1 in 10 carers (9%) received breaks from caring and a significant 16% of carers said they had received no practical help at all.

"I do anything and everything, including arranging appointments for mum's housing provider, arranging access for plumbers, heating engineers for servicing the boiler, electricity meter readings, receiving care appliances (replacement battery packs, wheelchair etc) and professional assessments."

"I spend most of my time trying to coordinate various services, all of which don't really seem to talk to each other. In addition, Social Services and the NHS are constantly restructuring so once you have got one contact name or telephone number, it then changes so you then start the investigative and time consuming task of trying to find out who you should be talking to."

"I try to deal with all the things that have to be done to ensure that the household is run and the care, food etc is in place, as well as all the paperwork and all the things that go wrong on a regular basis. Nothing seems to run smoothly and forever having to sort things out and chase things up is draining."

⁷ Such as grab rails, hoists or ramps etc.

Current support for carers (for someone with dementia) within the workplace:

- Flexible working arrangements were, as expected, the most commonly available type of support cited by carers (48%).
- Nearly 2 in 5 (38%) carers said that they received flexible/special leave arrangements.
- Just fewer than 1 in 5 carers indicated that their employer offered a specific policy for carers (19%), a workplace network (19%) and remote working (18%).
- 1 in 10 carers said they received signposting to information including voluntary organisations that specialise in dementia (10%).
- Fewer carers (7%) mentioned publicity about workplace support available to encourage carers to come forward for support and only 4% reported training and support for managers in carer awareness/implementing support for working carers.
- A significant 18% of carers mentioned that there was no specific support provided at their workplace and 13% indicated that they did not know if there was support available.

"I have not had any support and don't know where I would get it from... I have called EAP (Employee Assistance Programme) in the past but do not feel telephone support is of much use... I really need practical help like paid time off in emergencies and to help get dad to appointments. It is getting harder as he is becoming more disabled."

Support needs of carers (for someone with dementia) within the workplace:

- When asked what support would make a difference, top of the list was *'more flexible/special arrangements for leave'* which was identified by 41% of carers.
- 38% carers indicated *'more publicity about/recognition of caring issues in the workplace so that I feel I can ask for help'* and 37% identified *'more flexible arrangements for working hours and patterns'*. More flexible arrangements was also the top priority for carers when asked to select the one option that would make the most difference.
- The next most popular issues identified were better information about what support is available (35%), more publicity about/recognition of health conditions such as dementia in the workplace (29%) and the ability to work remotely (also 29%).
- Carers also wanted: the opportunity to link with other employees in a similar situation (21%), emergency/back up care support arranged by their employer (20%) and other practical workplace support such as counselling, Employee Assistance Programmes, stress management help (19%).
- Signposting to external sources of practical help was also mentioned (17%) including to voluntary organisations that specialise in dementia (15%).
- Interestingly 1 in 5 carers (20%) wanted better delivery of existing policies (ie their workplace had a policy on supporting carers but that it was not being delivered properly).

"We need recognition of the carer role, similar to that given to the parental responsibilities of employees. An understanding that, however well organised a carer is, sometimes things happen at short notice."

"My workplace is already working towards more flexible ways of working, but back up support ... would be really helpful to know about just in case it's ever needed."

Support needs of carers (for someone with dementia) outside the workplace:

- ▶ When asked what support would make a difference *'practical support from care workers trained to work with people with dementia'* was top of the list (49%). This was also top priority when carers were asked to select the one option that would make the most difference.
- ▶ The next priorities were advice and support that is available at all stages of caring (47%), timely diagnosis by GP/health professionals (44%), help managing or coordinating care, eg from social services (43%) and more/better quality support from care services (42%).
- ▶ Over a third (37%) of carers wanted advice and information about legal issues (eg lasting power of attorney) and managing money/financial support. 37% also wanted (more) support from family and friends and a further 37% wanted care and support services to be available outside normal working hours.
- ▶ A similar number (36%) identified other domestic support (cleaning, gardening, shopping, picking up medication) for them and/or the person they were caring for.
- ▶ Around 1 in 3 (32%) wanted advice and information about dementia-related medication, occasional use of residential care services (30%) and use of a day centre (29%).
- ▶ Around 1 in 4 (27%) mentioned more accessible services in the local community (eg shops, banks, transport and leisure facilities etc) and technology such as alarms, sensors or remote health monitoring (25%).
- ▶ Other issues identified were help with cooking/food preparation (22%), equipment in the home (21%) and advice and nutrition (16%).

"I need a single contact point for care to help me access all the support dad needs and who has the appropriate named contacts. There are too many places to go to at the moment, it's too fragmented."

"I need good adult care facilities to enable me to work."

Emerging issues

Emotional and cumulative impact of caring for someone with dementia

One key issue which the survey highlights is the emotional and cumulative pressures upon employees of caring for relatives and friends with dementia. Caring, especially in this context, does not just have a physical component associated with practical activities but also a mental component associated with stress, anxiety and tiredness. It is striking that:

- ▶ Just over half of respondents to the survey (53%) said that their work had been negatively affected due to their caring responsibilities (tiredness, anxiety, stress, etc).
- ▶ Even where respondents said that caring had not had an impact on their capacity to work to date, over 1 in 4 (27%) were worried that it might in the future.
- ▶ The number of respondents providing emotional support to family members or friends with dementia was very high (88%), which raises the question of who is supporting carers themselves to maintain their own mental health and wellbeing?

"I've been caring for mum since 2000 and have managed a move from her own home to sheltered accommodation and then into a residential care home. Her dementia takes its toll on my mental health. I feel I need some support and advice to help me to cope."

While on the surface people may be appearing to cope with combining work and care, they may be running on adrenalin which will pose a risk to their own health if they do not get support to sustain this dual role. There is an implication here for employers in terms of supporting employees to manage stress and maintain their health and for service providers, NHS, social services departments and Government to ensure that carers have the external back up they need from care and support services.

The 'disconnect' between employer policy and employee experience

Interestingly the percentages of employers who said that they offered different types of support (flexible working, carers policies etc) was much higher than the number of employees who reported getting that support.

For example:

- ▶ 83% of employers offered flexible working arrangements but only 48% of carers reported that this form of support was available in their workplace.
- ▶ 64% of employers said that they offered flexible/special leave while only 38% of employees said that this was available.
- ▶ Similarly 42% of employers said that they offered remote working whereas only 18% of employees

"My employer has a specific policy for carers, but it doesn't seem to amount to anything. There are no longer any resources within the team to allow me, or for that matter anyone working for me, any real flexibility."

reported this and 33% of employers mentioned a specific policy for carers, whereas this was reported by only 19% of employees.

The disparity in these findings suggest that there is a 'disconnect' between employer policy and employee experience, a disparity which is in line with previous surveys. This may be due to a lack of promotion of policies in the workplace, the fact that the communication of such policies and key messages does not always get down to line manager level and/or to the fact that such messages have not been really understood or embedded in the workplace.

More, and specialist, care and support services required

Relating to the above, an important issue which emerges from the survey is the need not just for more accessible and available care and support services but also services which are appropriate for dementia. These need to provide specialist support including from care workers who are trained to work with people with dementia.

People with different stages of dementia can require very different and specialist support. Those with early-stage dementia may need support services to help with everyday tasks like shopping, cleaning and food preparation, but delivered by individuals who understand their condition and can respond to symptoms like confusion, forgetfulness and mood swings in a positive way, rather than causing additional distress. People in the later stages of dementia often require services which can deliver high levels of personal care, manage possible aggression and provide appropriate and positive stimulation and activity.

Supporting the 'sandwich generation'

Another key issue which the survey highlights is the pressure on what is often described as the 'sandwich generation'. This includes people – most often women – who are combining care for an older relative (usually a parent or parent in law and often at a distance) with a range of other family responsibilities such as looking after their own children, grandchildren or another family member or friend. It is striking that:

- The majority of respondents to the employee survey were within the 40 + age group, ie 52% were aged 40-54 and a further 38% were aged 55-64. This is consistent with the peak age for caring identified in the Census and in earlier carer surveys.
- The majority of respondents were looking after a parent or parent in law (79%) and caring at a distance (75%).
- A similar proportion of respondents were women (79%) who were over-represented in our sample (national average of carers: 58% females and 42% males).
- Of the carers in employment, 61% were working full-time, 26% part time and 4% were self-employed. The relatively high proportion of carers in full time employment is consistent with the findings of Carers UK's *State of Caring* survey 2013 which found that carers of loved ones with dementia were more likely (than other carers) to be combining this with full time employment.

"Medical professionals and social workers do not understand dementia and ignore the standards in place."

"I'm permanently tired. I only can work part time now. I still have children to care for aged 15 and 18 at home. It makes life difficult, with my children so young and working with no help and mum's dementia getting worse."

"Easier access to GP and social services appointments would help, and appointment availability at the beginning or end of the day for patients who need support. Early or late appointments would allow me to get to work and juggle work commitments and responsibilities."

Recommendations

With these issues in mind, we make the following recommendations for practical solutions to facilitate better support for employees who are caring for loved ones with dementia. The recommendations include action for employers, health and social care services and government to take. It was not the remit of this research survey to make recommendations on specialist health and care services. These recommendations are therefore focused on practical support issues for working carers which have emerged from this study.

Workplace support

1. A workplace response to people caring for loved ones with dementia.

The Employers for Carers forum and employers on the *Dementia Friendly Communities* champion group, working with Alzheimer's Society,⁸ are leading the way but more needs to be done to raise awareness and share good practice among employers more widely. Employers' organisations and government should work together, including on awareness campaigns, to improve recognition of the business benefits of being 'family friendly' across the life course of care, including supporting employees caring for someone with dementia. Wider caring issues, as well as childcare, should be included in 'family friendly' workplace policies and practices, for example, flexible working and leave. Carers UK has recommended that there should be a statutory right to care leave to help support carers in the workplace, including those caring for loved ones with dementia.

2. Tools for working carers to help manage stress and build resilience.

The high percentage (88%) of carers reporting that they provide emotional support to relatives or friends with dementia raises the question about the emotional pressures on carers themselves. Practical tools to help employees manage stress and build personal resilience should be made available in the workplace and be accessible from home or elsewhere. They should be provided by employers with the assistance of employer support organisations such as employers' forums, Employee Assistance Programmes and occupational health providers. Employers for Carers, for example, has longstanding experience of providing such support for carers in the workplace and Carers UK has developed tools to help carers manage stress and build resilience. The Alzheimer's Society also has extensive expertise in providing information and support to people with dementia and their carers.

⁸ As referred to earlier, the Alzheimer's Society's *Dementia Friendly Communities* programme focuses on improving inclusion and quality of life for people with dementia. The *Dementia Friendly Communities* champion group includes industry leaders, representatives from towns and cities and people with dementia and their carers.

3. Tools for employers to provide carer and dementia awareness training.

In view of the relatively high proportion (57%) of employers who stated that they would like help to do this, practical tools should be provided to help employers to support their line managers and employees in this area. 'Training the trainer' sessions and toolkits, as developed on caring by Employers for Carers, and guides on dementia, as being developed by the Alzheimer's Society, should be made available in the workplace. Such support is best when it is practically focused with case studies to bring the issues alive to people who may not yet have had experience of this form of caring. The relatively low percentage of employers reporting that they provide training and support for managers in this area (19%) and of employees reporting that they are aware of such training (4%) suggests that this is a substantial gap in practice. Employer support organisations such as employers' forums and organisations providing HR or occupational health support should assist employers to use and implement the tools mentioned above.

4. Tools for employers to help them signpost employees to external information and support on caring and dementia.

This issue was identified by nearly two thirds (61%) of employers surveyed and the Employers for Carers forum and the *Dementia Friendly Communities* champion group are currently developing information for employers along these lines. Following this study, Employers for Carers will be producing a short, simple online toolkit for employers that will signpost to relevant sources of information and support on dementia. The *Dementia Friendly Communities* champion group will also be producing a more comprehensive guide for employers that will cover supporting people with dementia in the workplace and supporting those employees who are caring for someone with dementia. Employer and employee forums and support groups and services should ensure that they signpost to, and promote, such resources within their workplaces.

5. Help to link with other employers who are addressing the issues of caring and dementia in their workplace.

A significant proportion (48%) of employers reported that they would like to make links with other employers who are addressing these issues. The Employers for Carers forum and members of the *Dementia Friendly Communities* champion group have already made links with each other to promote these issues and this work should be developed, including with and through other employer networks, to help raise awareness more widely and facilitate exchange of good practice among employers.

Care and support services

6. Accessible information about care and support services for people with dementia and their carers.

This should include dementia specific information which is available at both national and local level, an issue which was indicated by 67% of the employers who responded to the survey. Accessibility and navigation is particularly important for working carers as they often have to find information about services in a different local council from where they live (75% of carers in the survey did not live with the person they were supporting). Information should be provided at national and local level by government departments, local councils and other care providers, GPs, local advice services and older people's and carers' organisations.

7. Advice and support at all stages of caring, from diagnosis to the later stages of dementia.

There should be timely diagnosis accompanied by relevant information and support from the start (as diagnosis alone can be a source of anxiety if not accompanied by practical help). As the condition progresses, the need for an appropriate range of advice and support to be available at all stages of caring featured significantly in the survey, with advice about legal issues (including lasting power of attorney), managing money and financial support identified by over a third of carers (37%). Getting such legal and/or financial advice is particularly important as the condition of the person with dementia deteriorates.

8. Better promotion of technology enabled care and support for people with dementia.

Supportive technologies such as alarms, sensors, remote health monitoring aids and equipment in the home should be available for people with dementia and promoted more widely to families. Employers also recognised the importance of this kind of support in providing peace of mind for their employees and enabling them to work and care; the need for information about such supportive technologies '*which will help people to live more independently and support carers to stay in work*' was indicated by 57% of the employers surveyed.

9. Integrated care services which include specialist, quality support for people with dementia.

Practical help from care workers trained to work with people with dementia was top of the list of what working carers wanted to see in terms of support outside the workplace. An improvement in the quality and reliability of all types of care services is needed and well-coordinated provision across health and social care.

10. Increased diversity and availability of services – growing the care market.

Services also need to be more flexible and available outside normal working hours and include a spectrum of support, ranging from specialist care to help with household chores. There is clearly an unmet need among working carers for further support from external services. Growing the supply of care and support services, including specialist support for people with dementia, is therefore an issue which needs to be considered as a priority at local and national level, by both local authorities and national government.

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