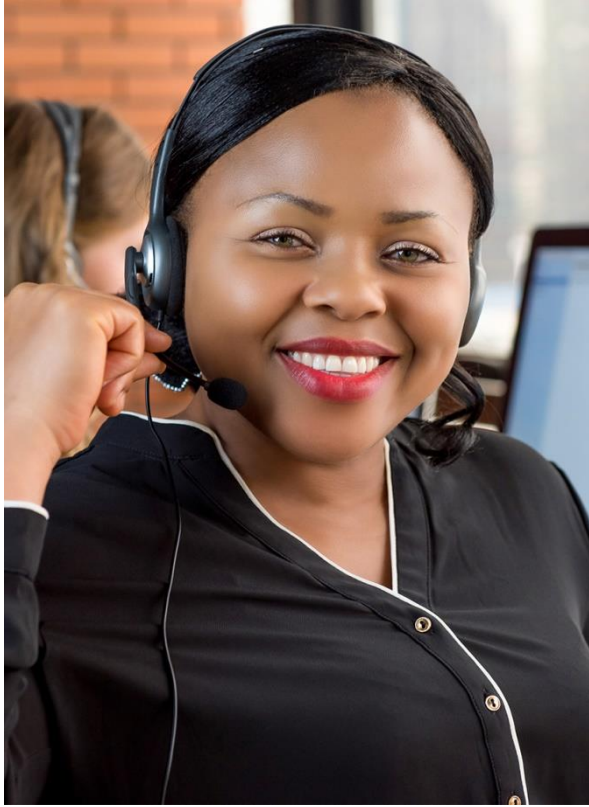


# Toolkit



## **SUPPORTING DEMENTIA CARERS**

### **SUPPORTING EMPLOYEES WHO ARE CARING FOR SOMEONE WITH DEMENTIA**

#### **About dementia**

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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 include vascular dementia (17%) and mixed dementia (10%).

Dementia is one of the main causes of disability later in life, ahead of cancer, cardiovascular disease and stroke. It 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 someone with the condition.

The Carers UK's State of Caring Survey has found that nearly one in 5 carers were looking after family members with dementia and these carers were more likely (than other carers) to be combining this with full time employment.

However, the stigma and lack of understanding that still exists around conditions such as dementia means that people often feel uncomfortable about mentioning their caring responsibilities at work, even when they clearly need support.

#### **About this toolkit**

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This Toolkit has been produced by Employers for Carers (EFC) to help you:

- Reach out to employees in your workforce who might not realise that they are caring
- Develop your workplace support for carers
- Raise awareness and increase the uptake of your policies and practices that support carers

## What can you do?

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### **Be flexible**

Top of the list of support needs in our dementia survey of working carers was flexibility. Dementia is a progressive condition and your employees may find that caring creeps up on them and they find themselves doing more and more alongside juggling their job. Working carers may only need small things like access to a private phone/space so they can check on the person they care for or, in some circumstances, a more permanent change to their working pattern may be required. Remember that one solution doesn't fit all situations/people - carers themselves are best placed to tell you what they need.

### **Raise awareness in the workplace**

It is vital to promote workplace support for carers in as many ways as you can; on-line, noticeboards, induction procedures/materials, staff handbooks, policies, pay slips etc. Think about the language you use as people don't easily identify with the word 'carer' – looking after each other is something that we do and people will be caring because they are they are a husband, a wife, a son, a daughter, a friend or good neighbour. Using words such as 'looking after' and 'supporting' in awareness campaigns/policies is more likely to resonate with employees who are looking after someone with dementia.

### **Create awareness in the workplace**

It's not enough to just have a policy, make your workplace a place where carers feel able to ask for support – make it 'ok' to talk about caring and dementia. In our dementia survey (and previous surveys) the percentage 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 that this was available.

This may be due to a lack of promotion of policies in the workplace, the fact that communication of these policies does not get down to line manager/employee level and/or to the fact that such messages have not really been understood or embedded in the culture of the workplace. Employees are often worried that they will be treated less favourably or seen as less committed if they take up policies. Managers will be working carers too – lead by example.

### **Signpost carers to external support and sources of information**

Think about how you can signpost carers to sources of external support, e.g. to specific health condition charities such as the Alzheimer's Society or organisations which can provide general advice to carers such as Carers UK. At the end of this toolkit there is a list of useful organisations for people looking after someone with dementia.

## **Establish a workplace carers network or support group**

Evidence suggests that networks provide employees with invaluable peer to peer support – it doesn't have to be specifically for staff caring for people with dementia; all carers will have things in common. Staff networks can be led by working carers themselves and don't have to be face to face; you can develop on-line networks. Several EFC members have networks and EFC can offer advice and support.

Offer in-house support for carers: these might be short tailored training sessions to help working carers to build resilience/manage stress and to help them identify other sources of support. Or you could include an element on caring in existing courses on stress management, health and well-being etc. EFC can provide in house courses of this type.

## **Promote existing employee support schemes (and caring issues within these)**

Ensure that caring issues are covered in any existing support for employees which you may provide through Employee Assistance Programmes, welfare services or occupational health services. Evidence suggests that EAPs and other support services are often underused so ensure that such schemes are promoted actively within the workplace, including their relevance to employees who may have new or urgent caring responsibilities for someone with dementia.

## **Provide in-house training and support for line managers**

This is critical in raising awareness of caring in the workplace, including the business case for supporting carers, and promoting culture change. It might consist of separate training sessions or you could include a module on caring in existing line manager training. EFC can provide in house courses or modules of this type with practical case study examples.

# **Top ten tips for employees caring for someone with dementia**

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### **1. Don't do it alone**

It might feel like you're the only one dealing with this but actually the experience of looking after a family member, partner or friend is very common. It's something that will happen to most people at some point in their lives. One in every eight adults in the UK is a carer and Carers UK's State of Caring survey has found that carers of loved ones with dementia were more likely (than other carers) to be combining this with full time employment. At the start caring can be bewildering, confusing and demanding. No one is super human and all carers need some support and back-up.

One of the most important things to accept is that you cannot do this all by yourself without serious risks to your health and well-being.

Carers UK has an online support forum that is open 24/7 and an advice line (see below).

## **2. Get some practical help**

Most people need some sort of practical support to help with caring for a loved one with dementia. This could be equipment to help you lift the person you care for, an alarm system for peace of mind, someone to look after the person you care for while you go to work, or a more substantial break where the person you care for goes into residential care.

Paying for this sort of help can be expensive so it pays to shop around and get good advice. There are a variety of organisations that can offer advice on buying equipment like hoists, wheelchairs and other disability aids. When it comes to having someone coming into your home to carry out care there is clearly the need to have someone you trust. Some people organise replacement care informally from friends and family or they buy in the help they need from a reputable commercial care agency.

If you need this sort of help on a regular basis - be it equipment or care - it is a good idea to contact social services or the social work department of your local council who can offer a range of support for disabled people and their carers.

To determine what help is needed and how much it might cost, social services will carry out an assessment of the person you care for, called a community care assessment and sometimes they might do an assessment of your needs, called a carer's assessment.

Following the assessment, you will be given information about any services and support they can give you. This sort of help is usually means tested so you may end up having to pay something towards the costs. If you are over 65 and live in Scotland, any personal care provided at home is free of charge.

To request an assessment contact the social services or social work department of your local council/trust. Contact details should be on their website, or you can ask your GP or any other health professional you are in touch with to refer you.

## **3. Look after your own health**

There is no doubt that without the right support caring can all too easily damage your health. You'll need to find the balance between caring and looking after your own health needs. It is not an easy balance to find, but remember – the better your physical

and emotional wellbeing, the better you will be able to cope with the demands of caring. If you only do two things make sure you:

- Tell your GP - although there isn't a national register of carers, make sure you tell your GP that you are a carer. Ask them to write the details on your notes. Ask your GP for a regular health check and, if necessary, a flu jab. If they know you are a carer, some GPs offer special flexibility with appointments, or are more willing to make home visits. Carers are usually busy and sometimes don't find time for their own health. A good GP who understands carers can be a gateway to getting all kinds of help, such as counselling, other medical services, and referrals to your local Social Services or Social Work Department.
- Watch your stress levels - stress is a fact of life for most carers, particularly those juggling work with caring. Not being able to relax or have some time out has long-term detrimental effects on your health. It's easier said than done but it is vital that you learn to recognise the signs of stress and take action.

#### **4. Talk to other people in similar situations**

Carers groups and carers centres give support to carers by providing information, arranging social events and giving carers time to speak to other carers about problems or experiences. Many carers find carers groups a great source of support. You can search for local support groups on the Carers UK website.

Your employer may have a carers network and if not think about getting together with other carers in your organisation to form your own informal network. It is useful to talk to other people juggling work and care and together you could approach your employer to ask for support for carers in the workplace.

#### **5. Care for your career**

Juggling the demands of caring with the responsibilities of a paid job is a tough call. People often feel pulled in two directions and over the last 2 years as many as 600 people a day have given up work to care. Those who fall out of work pay a heavy price – facing financial hardship and missing out on their own pension. So it pays to think carefully before giving up your job and explore all the options for support.

As a working carer of someone with dementia, you are likely to need a range of support at different times - from access to a telephone to check on the person you care for, to leave arrangements to deal with someone coming out of hospital. Telling work about your caring role is not always an easy step and you might feel it depends on whether your employer is likely to be supportive. Find out by asking your colleagues, HR officer or union representative. There may be existing support that you are not aware of, or you may find that your employer is open to exploring ways to support you.

## 6. Know your rights at work

You may find that the best or only way to manage your work and caring responsibilities is to change your work arrangements. You have some legal rights in the workplace and your employer may also offer additional support through their own policies and practices. You have a legal right to:

- request flexible working – if you have worked for your employer for more than 26 weeks
- take ‘reasonable time off’ to deal with an emergency involving a dependent
- 8 weeks (unpaid) parental leave per child - if you have at least one year's continuous service with your employer and are responsible for a child under 18.
- be protected from discrimination – you cannot be treated less favourably than someone else because you are caring for an elderly or disabled person.

## 7. Care for your pension

If you are thinking about reducing your hours (or even giving up work) to care think about the impact on your pension – both your State Pension and your employer's pension. Not everybody automatically qualifies for a full basic State Pension on reaching retirement age. The amount of state pension you get usually depends on how many qualifying years of National Insurance you have built up. If you miss paying these because you have taken time out of paid work, then you may lose out.

However, if you leave your job because you are caring for someone who is disabled, ill or frail then the state will credit your contributions for you. However, this isn't automatic and only happens if you claim the right benefits and take the right action. Contact the Carers UK Adviceline on 0808 808 7777 or visit the [Carers UK website](#).

## 8. Make the most of your money

For most people, caring hits your finances. Unlike medical care, social care is not usually free and you or the person you care for might have to pay for the support you need. Your income can take a dramatic drop through giving up work or reducing your working hours; you may face extra costs, such as heating, petrol and laundry, because you are looking after someone with dementia.

Whether you can claim help from the benefits system will depend on a number of factors including your income, savings, how old you are and whether you have worked and paid National Insurance contributions. It's also important to make sure the person you care for is claiming everything they are entitled to.

Benefits are not the only way of getting financial help. You may be able to apply for:

- a reduction in your Council Tax or Rate Rebate bill

- help with health costs, eg to pay for dental treatment
- a grant to help adapt your home to meet the needs of the person you care for
- help to manage your heating costs, eg to install central heating, changing to a better tariff to reduce fuel bills
- charity grants

The benefits system is very complicated and finding out what you are entitled to can be difficult. Contact Carers UK's Adviceline at: [advice@carersuk.org](mailto:advice@carersuk.org) 0808 808 7777

## 9. Think about the future

As hard as it might be to contemplate, there will come a time when you are no longer caring. When caring ends it can be extremely hard. If the person you care for goes into a residential or nursing home you may feel both relief that the caring is over and guilt that you couldn't do more. Bereavement is one of the most difficult things we can face. If your entire life has been focused around caring for someone then bereavement can hit even harder. Putting your life back together after caring is not easy and everyone needs some emotional support and assistance in coming to terms with it.

By facing the future and thinking about life after caring you can minimise the shock when the time comes. Many people say that when caring ends they feel adrift, without purpose or direction. Although caring can be all-consuming, it's important that you keep as much of your own life going as you can - work, friends, hobbies and interests.

## 10. Get information and practical advice

Organisations you may find useful:

### **Alzheimer's society**

[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

Dementia connect helpline 0333 150 3456

### **Admiral Nurses Helpline**

[www.dementiauk.org](http://www.dementiauk.org)

Helpline 0800 888 6678

### **Age UK**

[www.ageuk.org.uk](http://www.ageuk.org.uk)

Advice line 0800 678 1602

### **AT Dementia**

<http://atdementia.org.uk>

0115 74 84220

## **Carers UK**

[www.carersuk.org](http://www.carersuk.org)

Adviceline 0808 208 7777

## **Citizens Advice Bureau**

<http://www.adviceguide.org.uk>

England advice line 03444 111 444

Wales advice line 03444 72 20 20

## **Independent Age**

<http://www.independentage.org>

Advice line 0800 319 6789

## **NHS Direct**

<https://www.nhs.uk/conditions/dementia/carers/>

Advice line 0300 123 1053

## **Power of Attorney (Office of the Public Guardian)**

[www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)

0300 456 0300

## **Three Next Steps**

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- Circulate 'Top ten tips for employees caring for someone with dementia' to your team and colleagues.
- Monitor the take up of support by colleagues who are caring and determine the benefits to them and to your organisation.
- Tell members of your team that your organisation is a member of EFC and that all our resources are available to them. Circulate your organisation's membership code to your team so that they can access these resources.

## Contact Employers for Carers

T: 020 7378 4956 E: [client.services@carersuk.org](mailto:client.services@carersuk.org)

W: [employersforcarers.org](http://employersforcarers.org) | [efcdigital.org](http://efcdigital.org)