



Dementia-friendly utility guide

A practical guide
to supporting your
customers and
employees affected
by dementia



Document purpose

This guide is for utility organisations of all sizes and in all sectors including energy, water, and communications. It offers guidance on how to increase employees' understanding of dementia and create processes and practices to make the utilities sector more accessible to people affected by dementia.

Title

Dementia-friendly utility guide: A practical guide to supporting your customers and employees affected by dementia

Publication date

February 2018

Target audience

Employees and interested consumer groups of utility companies wishing to improve the dementia friendliness of their organisation by making simple changes. These might include increasing employees' understanding of dementia and improving customer experience.

Acknowledgements

With thanks to the members of the Prime Minister's Champion Group for Utilities, Dementia Demons Service User Review Panel, Dementia Friends Champions Forum, Research Network Volunteers and contributions from Talking Point.

Authors

Emma Bould, Gavin Miller, Amie Harding, Alasdair Murray

Publisher

© Alzheimer's Society 2018. All rights reserved. No part of this work may be reproduced, downloaded, transmitted or stored in any medium without written permission of the publisher, except for personal or educational use. Commercial use is prohibited.



Contact

Alzheimer's Society Programme Partnerships team at
programmepartnership@alzheimers.org.uk

Web

Alzheimers.org.uk/dementiafriendlycommunities



Definitions

Communications provider

These organisations provide local, national and international telecommunications services for customers to use at home, at work and on the move. They also provide phone, broadband and TV products and services – including converged fixed-mobile products and services.

Distribution Network Operator (DNO)

These organisations own and operate the regional networks of cables that bring the electricity to customer homes in geographic areas. They don't sell electricity – this is done by energy suppliers.

Energy supplier

Organisations that look after customers' gas and electricity billing and metering. Customers can have different suppliers for gas and electricity, and can switch suppliers.

Gas Distribution Network (GDN)

Similar to the DNO, the GDNs manage a geographic area of the network of pipes that take gas to customer homes. They don't sell gas – this is done by energy suppliers.

Water supplier

Water suppliers operate the network of pipes which provide high quality drinking water and treat the waste water for household customers. The same services are provided to businesses but their water is sold by a retailer.

Contents

Foreword from Alzheimer's Society	4
Foreword from British Gas	5
Introduction	6
Why do utility companies matter?	8
What is dementia?	9
What challenges do people with dementia face when dealing with their utility companies?	10
What are the benefits of becoming dementia-friendly?	12
What does becoming a dementia-friendly utility organisation involve?	16
What can utility companies do?	18
People – awareness, training and support	18
Process – customer support and communication	26
Place – working in local communities	42
Summary of recommendations	45
Useful resources	46
Other useful organisations	50
References	52



Foreword from Alzheimer's Society

Dementia is one the greatest challenges we face in society today, a challenge we cannot turn our backs on. Dementia can affect every aspect of someone's life, including the way they use energy, and how easy they find it to contact their telecoms provider or pay a water bill. People affected by dementia have said that interacting with their utility providers is one of the areas that most needs to change.

They often have challenges due to lack of awareness about dementia, as well as processes and procedures not supporting people living with dementia and their carers. The utilities sector needs to ensure that all aspects of their operations protect vulnerable customers and support employees who are also carers. From electricity providers to mobile phone companies, energy providers to water companies, the entire utilities sector has a part to play.

Consumers want businesses and organisations that value their customers. This will only be achieved with greater awareness, understanding and support for customers and staff affected by dementia. This guide highlights the many ways a utility company can transform itself to better support people affected by dementia so they can live and participate in their local community.

Becoming a dementia-friendly utility company means being able to help people to continue doing the things they want to do, while being supported to do so for as long as possible. We need to ensure that organisations train their staff to be aware of the impact of dementia, and adapt their products and processes to tackle the challenges customers and staff face.

The Prime Minister's challenge on dementia states that by 2020 the UK will be the first dementia-friendly nation. Becoming a dementia-friendly organisation means providing the opportunities to support every person with dementia through greater awareness and understanding, which will make a huge difference to people affected by dementia and their quality of life. With numbers of people with dementia in the UK set to increase to over a million by 2021 and over two million by 2050, it has never been more timely to take action and improve the lives of people with dementia.

Defeating dementia won't just happen in a lab or care setting, we need a step change in the way people think, talk and act about the condition. The whole of society has a role to play. I am delighted the utilities sector has come together to create this guide and take forward the incredibly important work they are doing to support people living with and affected by dementia.



Jeremy Hughes
CEO, Alzheimer's Society

Foreword from British Gas

As a result of the Prime Minister's Challenge on Dementia and the dementia-friendly communities programme, Alzheimer's Society set up a task and finish group on dementia-friendly utilities.

British Gas was thrilled to be asked to chair the group of utility companies which worked together to produce this guide on how utilities can be more dementia-friendly. Why does making utilities more dementia-friendly matter? Everyone has some sort of interaction with a utility, from managing bills, to turning on the lights, talking on the phone to friends, or simply making a cup of tea. This is why it is essential that utility organisations help customers, especially those who may require additional support, such as those living with dementia.

There are approximately 850,000 people with dementia in Britain today, a third of whom live alone in their own homes, and another third who live in the community with others (many of whom will also have complex health needs). With all these people having some form of relationship with a utility company it is essential we do our bit to make life easier for those affected by dementia. Like other utility companies, British Gas has placed becoming a dementia-friendly organisation as a priority in providing great customer service. Becoming dementia-friendly is the right thing to do not only for our customers, but also the tens of thousands of people employed by the utility sector who themselves may need support.

I hope this guide will be used by utility companies across not only energy, but water and communications too. It aims to provide practical guidance for organisations along with some examples from across the utilities sector about how they have turned guidance into practice.

As essential service providers, and as employers, we have a responsibility to ensure that we help people with dementia live well and independently for as long as they can. If we follow the guidance in this document, we will go a long way to achieving this.



Sarwjit Sambhi
Managing Director, UK Home
British Gas



Introduction

In March 2012, the government launched the Prime Minister's Challenge on Dementia, which has since been extended to the Prime Minister's Challenge on Dementia 2020.

The challenge set out three key commitments to deliver in the areas of: research, health and social care, and the development of dementia-friendly communities. The current government recently affirmed its support for this challenge, and has asked to keep the name Prime Minister's Challenge on Dementia.


Our aim is to support people with dementia to live well in the community, and to ensure continued access to essential utilities such as water, energy and communication. While maintaining access to these essential services, we also need to provide the right levels of customer support when communicating with the organisations.

The scale of the challenge

The following statistics show the scale of the dementia challenge in the UK¹:

 Over **850,000**
people are living with dementia

 **225,000**
will develop dementia this year,
that's one every three minutes

 **1 in 6 people**
over the age of 80 have dementia

 Over **40,000**
younger people (under the age of 65)
live with dementia



Alzheimer's

is the biggest concern of people over 60
(YouGov, 2015)



The cost of dementia is

£26 billion

a year (based on data from 2013)



Dementia

is the leading cause of death in
England and Wales (ONS, 2016)



Unpaid carers save the economy over

£11 billion

a year



The number of people aged 65+
is projected to rise by over 40% in
the next 17 years, to over

16 million

(ONS, 2015)



There are

670,000

carers of people with dementia



Two-thirds

of people with dementia live in the
community. One-third live in care homes

Why do utility companies matter?

A utility company is an organisation that works to supply and maintain a set of essential services including gas, electricity, water and communications. Several utility organisations have helped create this guide in partnership with Alzheimer's Society and people living with dementia.

People with dementia are particularly vulnerable to problems related to energy use and their relationship with energy companies as they tend to use more energy. As we age, our ability to regulate our body temperature deteriorates, and dementia makes this even more challenging. This may lead to people with dementia preferring a warmer environment (Van Hoof, 2008). The result of this can be higher heating bills and problems managing energy.

Dementia can pose many challenges when managing a relationship with an energy company. For instance, a person with dementia may forget to pay a bill. This can result in debts and, in cases where a customer is not identified as vulnerable, their energy supply could be cut off. Confusion and forgetfulness can also mean that people with dementia struggle to manage their energy usage (Lewis, 2012).

Utilities are an essential part of everyone's lives. We all need access to energy, water and communications. Dealing with bills, booking appointments and having unexpected disruption to energy, water or communications can be confusing for a lot of customers. For a customer with additional needs, such as those living with dementia, it can be even more challenging to manage these.

However, this needn't be the case. There are simple and practical steps we can take as an industry to reduce or eliminate the barriers that customers affected by dementia can face when they try to interact with their utility providers. With the help of this guidance, we hope that the utilities industry will take steps to support people with dementia to be in control of their utility needs. This can be done in part by creating environments that understand and support their needs.

This guidance aims to highlight some of the areas that both people living with dementia and their carers may face when interacting with and managing their utilities. To help overcome some of these barriers and challenges, this guidance will cover some basic principles that should be considered by utility organisations that wish to become dementia-friendly. We have worked with a range of companies from across the water, energy and communications industries to compile a range of case studies which help illustrate how the principles in this guide can be applied.

What is dementia?

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease, or a series of strokes. It is not a natural part of the ageing process. There are different types of dementia, but the most common form is Alzheimer's disease.

Dementia is progressive, which means it begins with mild symptoms that get worse over time. Different types of dementia tend to affect people in different ways, especially in the early stages.

A person with dementia might:

- have problems with day-to-day memory – for example forgetting their address, birthday or PIN
- have difficulties making decisions, solving problems or carrying out a sequence of tasks, for example making an online transaction
- have language problems, including difficulty following a conversation or finding the right word – for example, a person may know what they have called an organisation about, but be unable to find the right words to express it
- have problems with perception of where objects are, for example judging distances and seeing objects in three dimensions
- lose track of the day or date, or become confused about where they are
- show changes in their mood, for example becoming frustrated or irritable, withdrawn, anxious, easily upset or unusually sad
- see things that are not really there (visual hallucinations) or believe things that are not true (delusions)
- show changes in behaviour such as repetitive questioning, pacing, restlessness or agitation.



What challenges do people with dementia face when interacting with their utility companies?

Challenges for people with dementia

A YouGov poll (Alzheimer's Society, 2013) found that UK adults think the barriers that people with dementia face are:

- 65% due to issues such as stigma or lack of understanding about dementia from the general public
- 57% due to a lack of formal and informal support from others to carry out activities they want to do
- 53% due to a lack of appropriate activities for people with dementia.

We asked people with dementia about the things that mattered most to them and what utility companies could do to provide a more dementia-friendly experience. People with dementia and their carers told us about the everyday challenges they face when interacting with utility companies.

These include:

- navigating bills and communications from utility companies to determine which information is essential
- accessing and reading meters to ensure accurate bills
- understanding what is expected of them from a utility company, such as providing meter readings and responding to notices of temporary disconnection

- challenges caused by their memory problems such as remembering passwords or information required to access account information – either online or on the phone
- understanding payment requirements where bills may have credit or debit balances, as well as different payment methods such as direct debit
- problems when contacting the utility provider, or being contacted by their provider out of the blue
- worries about other people's reactions if they say they have dementia
- fears of being vulnerable and of fraudulent schemes.



What people with dementia have told us:

‘Imagine this, you live on your own and you have dementia, you suddenly can’t do the things you used to do, everything around you becomes very confusing.’

‘I don’t want to be treated differently from other people, I want people to act with understanding. But the understanding isn’t there – unless people know someone, a relative, they aren’t interested.’

‘People with dementia might not be able to manage their money because they don’t understand what’s happening.’

‘We’re all on the journey of dementia and so are your carers, they are having to all of a sudden deal with everything.’



Challenges for carers

For carers, the most common issues related to low awareness of Power of attorney and deputyship. They described experiencing difficulty with utility companies understanding and acting on these.

What are the benefits of becoming dementia-friendly?

Organisational benefits

- **Complying with the law** – under the Equality Act 2010, all organisations have a legal obligation to ensure consumers are adequately protected and that access to services is as inclusive as possible. This includes making ‘reasonable adjustments’ for customers with disabilities, including people living with dementia. This guide provides information to support utility companies and help them comply with this legislation. Beyond the Equality Act all utility companies must also comply with regulations regarding the protection of customers in vulnerable circumstances, including those living with dementia.
- **Improved customer service** – increased knowledge and awareness of dementia will make employees more confident when helping customers. They will have a greater understanding of potential scenarios and the barriers customers may face, and as a result will be able to provide better customer service and reduce the number of complaints or repeat contact for similar issues.
- **Enhanced brand reputation** – becoming dementia-friendly will help businesses demonstrate that they are socially responsible and value their customers. It will also help organisations better understand the needs of their customers.
- **Creating safe environments** – improving processes and practice to become dementia-friendly will ultimately improve experience and safety for all customers. For example, if street works are taking place and signage around this is made dementia-friendly, this will make the environment clearer to navigate.
- **Future-proofing** – it is estimated that by 2021 there will be over one million people with dementia in the UK. By making changes now, businesses will be anticipating a growing need from customers and employees. Dementia has an impact both on the person with the condition and their families and friends, who may also be your customers or users.



73%

of consumers have ended a relationship due to a poor customer service experience (The Cost of Poor Customer Service, Genesys).

Licensing conditions and obligations

Domestic utility suppliers have a responsibility to support vulnerable customers through obligations in their licences, as well as other legal requirements including the Equality Act 2010. These are set by the relevant regulators for different utilities: Ofgem, Ofwat and Ofcom.

Ofgem

Ofgem is the regulator for electricity and gas markets in Britain. It places a number of obligations on energy supply companies to protect those in vulnerable situations – including those with dementia.

- The vulnerability principle (SLC 0) requires domestic suppliers to identify those in vulnerable situations and to respond to their needs. Their definition of vulnerability is broad and includes customers with mental health problems and dementia.
- One of the services available via the Priority Services Register rules (SLC 26) allow vulnerable customers to nominate a representative to receive communications on their behalf. Suppliers are required to raise awareness of the support available to customers on the Priority Services Register.

Ofwat

Ofwat is the economic regulator of the water and sewerage sector in England and Wales. One of Ofwat's primary duties, as described by section 2(2A) of the Water Industry Act 1991, is furthering the consumer objective. The consumer objective is essentially to protect the interest of consumers. Consumers include, but are not limited to, individuals who are: chronically sick; of pensionable age; with low incomes; residing in rural areas and customers whose premises are not eligible to be supplied by a licensed water company. Ofwat expects water companies to

provide great customer service, which means that water companies really know and understand their customers. It expects water companies to understand and address affordability concerns for both current and future customers. It also expects them to develop effective measures to identify and help customers who are struggling to pay, or who find themselves in circumstances which make them vulnerable. In its 2019 price review (PR19), Ofwat will assess how well water companies are doing this.

Ofcom

Ofcom is the UK's communication's regulator. It has rules in place (General Condition 15) to help support disabled customers. These include requirements for communications providers to offer free Priority Fault Repair to disabled consumers dependent on their landline phone (and, from October 2018, their broadband service). Communication providers are also required to have a scheme allowing third parties to help manage bills of consumers who may have difficulty managing their account.

Alongside these is a new obligation requiring communications providers to establish policies to ensure they take account of the needs of all vulnerable consumers. This will come into force in October 2018. The new rule (set out in General Condition C5) requires communications providers to have clear and effective policies for the fair and appropriate treatment of consumers whose circumstances may make them vulnerable.



Social benefits

- **Helping people to live well with dementia** – being part of the community and being able to continue with everyday tasks are important for helping people to live well with dementia. Becoming a dementia-friendly utility company means enabling people to carry on doing the things they have always done, such as managing their accounts.
- **Improving accessibility for the whole community** – getting it right for customers with dementia means that others will benefit too. Changes such as having clear signage and advance notice when engineering works are taking place in the community allow people to prepare and plan appropriately.
- **Helping people to stay independent** – people with dementia want to remain independent and live at home for as long as possible. Being able to access and manage their utility companies can play a big part in this. Utilities companies can help in a range of ways – including ensuring that engineers safely fix pipes and wires in the road, and that contact centres are able to help customers manage their energy, water, or communications.
- **Improving employee engagement** – giving employees the opportunity to become Dementia Friends and part of a dementia-friendly organisation and community can instil pride that they work for an organisation that cares. This can help improve scores on employee engagement measures, as well as helping employees who may be affected by dementia² in their personal lives. Buy-in from senior leaders in an organisation is essential to enable a full and engaging roll-out strategy.



To find more out about obligations, regulations, conditions and best practice from your sector, please see:

Ofgem (2017). Vulnerable consumers in the retail energy market: 2017.

Ofwat (2016). Vulnerability focus report.

Ofcom (2017). Review of the General Conditions of Entitlement: Revised General Conditions. Annex 14.

² This report uses the term 'people affected by dementia' to include people with dementia and those important to them, which may include friends or family members (including family carers).

What does becoming a dementia-friendly utility organisation involve?

Utility companies can make a big difference for people with dementia and their carers by making a commitment to become more dementia-friendly in three key areas:

People



Awareness, training
and support

Processes



Customer support
and communication

Places



Working in local
communities

The following guidance has been split into these areas to support existing guidance from the British Standards Institute Code of Practice for Dementia-Friendly Communities.

For the utilities industry, becoming more dementia-friendly means:

- understanding the impact of dementia and how it changes customers' needs
- considering how a company's processes and services can help customers affected by dementia
- using this guide to make changes to these processes - this could include raising employee awareness of dementia and the support available or reviewing customer communications
- supporting people who may be showing signs of dementia, or their friends or family members, whether they are customers or employees
- understanding the support already available for people affected by dementia, and how to make customers aware of this.

It doesn't mean that businesses are expected to:

- become dementia-friendly immediately
- diagnose customers who have dementia
- ask customers difficult or intrusive questions
- breach existing legislation such as the Data Protection Act 1998 and the Mental Capacity Act 2005
- ignore normal security processes and procedures.

What can utility companies do?



People – awareness, training and support

Raising awareness of dementia, how it might impact someone and how employees can support both customers and their colleagues will enable a more customer-focused environment. Employees who understand dementia should act in a more considerate way to support all customers in a patient, kind, and respectful manner. This helps the organisation's reputation and leads to more satisfied customers.

Awareness



A dementia-friendly utility provider is aware of the challenges of living with dementia.

'Being dementia friendly is being user friendly.'

'Patience and listening is all that is needed.'

'Once anybody knows and understands they have a few more minutes.'

'Dementia friendly means being people friendly.'

To help utility companies achieve this awareness and understanding, the first step is to roll out the Dementia Friends programme.

Dementia Friends for organisations

A Dementia Friend learns a little bit more about what it's like to live with dementia and then turns that understanding into action. Dementia Friends is about learning more about dementia and the small ways you can help. By becoming a Dementia Friend within their workplace, employees are supporting their customers and colleagues affected by dementia, helping people to feel understood and supported and improving the customer experience. As more and more employees do this, they'll help people with dementia feel understood and supported in their communities.

There are two routes for organisations to roll out Dementia Friends: via online videos or a sector specific presentation. These need to be embedded within organisational procedures such as employee inductions and refresher training, and signposted on online course bookings to ensure sustainability.

Dementia Friends presentation

This is an interactive route including videos, a quiz and a sector-specific activity. This builds on the video to think about the challenges someone living with dementia might face when undergoing a sequencing task when interacting in that industry. It also looks at the challenges that people living with dementia have told us they face when interacting with this sector, to increase employees' understanding. This is an easy way to internally roll out Dementia Friends to large numbers of employees as the presentation has instructions and can be delivered with minimal training beforehand.

Training

E-learning and videos

There are various e-learning courses available online which can support utility companies to embed dementia awareness within their training packages. These can allow employees working remotely and nationally to access information and training. As well as Dementia Friends videos, there are a number of other videos available online which show how organisations can support their customers and employees affected by dementia. These could be played in team meetings to refresh training.

Dementia Friends video

To become a Dementia Friend via the video route, employees firstly watch 'Understanding Dementia' – a four minute video on what dementia is and how it might affect someone. Then employees have to watch a minimum of one of the sector-specific videos.

These include:

Filling out forms



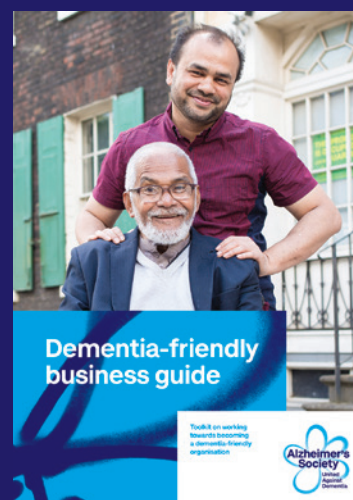
On the phone



Further training

Further dementia awareness training is available through Alzheimer's Society and other organisations for Continued Professional Development (CPD) accredited courses and qualifications. This should ensure that employees understand the legal obligations so they can comfortably support disabled and older customers and those affected by dementia. We would recommend that any customer-facing staff do Dementia Friends training as well as further training. Training is especially recommended for:

- call or contact centre employees
- engineers, tradespeople, plumbers, electricians, meter readers and mechanics
- HR, consumer affairs, consumer vulnerability and Corporate Social Responsibility teams
- media teams
- policy makers and decision makers
- reception, concierge and support staff, and cleaners
- revenue protection, debt collection and credit control staff.



Take a look at Alzheimer's Society's **Dementia-friendly business guide (code 900)** for some ideas of available packages.



British Gas Dementia Friends

In January 2016, we started our journey to roll out the Dementia Friends programme across British Gas. To begin with we reached out to employees looking for volunteers to become Champions who were passionate and able to start building an interest across the organisation. Recognition of the programme soon grew and we are now at over 20,000 Dementia Friends.

We understood that in a complex organisation spread out over Britain, we had to take a unique approach. Instead of 'sheep dipping' our people through an online module, we have blended the full face-to-face information sessions through our network of over 50 Champions with bespoke online modules for managers to lead.

We are confident that if a customer phones us, has an engineer visit their home, or has a new meter installed, they'll be talking to a Dementia Friend.

The Dementia Friends programme is not only having a positive impact on our customers, but on our employees too. They are able to take their learnings back home and to the communities they work and live in.

Rachel in our Customer Care Team says:

'Recently I supported a family whose mum is living with dementia. As they were paying for carers, balancing their finances was proving to be a real struggle. Thankfully I was able to support them with a bespoke arrangement, so they could work through what they could financially manage. I also found a local Alzheimer's Society drop-in where mum could go to some classes to keep her engaged in hobbies. We kept in regular contact and the daughter was so grateful to speak to someone who had experience with dementia.'



Quotes from employees and customers

'I feel everyone working in a customer service role would greatly benefit from a Dementia Friends Information Session. It makes a real difference when you see things from the perspective of someone living with dementia and I'm glad I've become a Dementia Friend.'

Customer Service Advisor, British Gas

'It's really opened my eyes to the sort of challenges people with dementia face every day.'

Manager, British Gas

'I really enjoyed the information session – it made a huge impact. There were some truly interesting facts in there. I left with a much better understanding of the disease, including how dementia can affect your spatial awareness and vision. The session was so inspiring I decided to become a Dementia Friends Champion too!'

Manager, British Gas



UK Power Networks (UKPN) Craig's story

'Just recently I have been getting to know a lady who works in a salon I visit on a weekly basis. We have been chatting and become friends, during our weekly catch-ups. This lady, now a friend, explained to me about her worries and concerns with her dear mother.'

She expressed her concern and really was unsure what to do. Her mother has dementia and the illness has put a huge strain on the family and most importantly the husband who has no real understanding of the illness.

During our chats, I explained I was a Dementia Friend and recommend the website from the monthly brochure we receive. As a result of the information session we had at UKPN it really did give me the tools to understand what this family must be experiencing and of course the person in hand.

My friend was really grateful when I explained and listened to the situation, but more importantly impressed that as a company we invest and respect how this affects family and loved ones... I know my friend will really benefit from the professional advice and learning Dementia Friends can offer, and is now looking to get further support to understand the illness.

I wanted to share the above with you. Knowledge and training is key within our role and as proven in our personal lives too.'



Support

Organisations and businesses need to support their employees to continue working for as long as possible. Failing to do so is against the law, and is damaging to employers and the wider economy.

With an ageing population there is a huge economic case for this. There are a number of benefits, including improved employee retention, reduced recruitment costs, and increased productivity and revenue. Supporting working carers and long-term planning for an ageing

society makes business sense. Alzheimer's Society supports the phasing out of the retirement age but, as part of this, employers must be prepared to address the needs of people with dementia at work.

'Every organisation should be in a position where they can support someone.'

Alan, person living with dementia



Dementia in the workplace

The following statistics indicate the scale of dementia as an issue facing society as a whole. They also reveal the impact on the UK working environment:

- Nearly one in nine employees in the UK have a type of caring responsibility.
- 650,000 people in the UK care for older relatives or people living with dementia.
- There are 42,000 people between the age of 30 and 65 years old with young-onset dementia.
- 18% of people diagnosed with dementia under the age of 65 continue to work after a diagnosis of dementia.

- 89% of employers believe that dementia will become a bigger issue for their organisation as the workforce ages, the retirement age rises and the number of people with dementia increases (The Centre for Economics and Business [CEBR], 2014).
- The average person diagnosed with dementia while still at work is estimated to have been in their current job for at least nine years (CEBR, 2014).
- The early retirement of those diagnosed with dementia costs English businesses £627 million a year.

Figures from: Dementia UK: Update, Second edition (Alzheimer's Society, 2014) and Supporting employees who are caring for someone with dementia (Employers for Carers and Carers UK, 2014).

Supporting employees living with dementia

Living with dementia can have a big emotional, social, psychological and practical impact on a person. Many people with dementia describe the impact of the condition as a series of losses, and find adjusting to them challenging. Many people with dementia are able to continue working, particularly in the early stages, and would want to continue to do so. Those with young-onset dementia (diagnosed when they were under the age of 65) often also have financial commitments such as mortgages or dependent children so will need to stay working for as long as possible.

A dementia diagnosis doesn't necessarily mean a person can no longer do their job. However, dementia is a progressive condition and over time it will increasingly impair a person's ability to work. As this happens, they may need support to help them stay at work. Some people with dementia may want to continue working for some time after their diagnosis, or feel they have to because they

need the money. They may experience anxiety about telling their employer about their diagnosis. All employees should have a clear pathway of support to ensure they are supported at every stage of their journey.

Legal obligation and flexible working

The Equality Act 2010 requires employers to avoid discrimination and make reasonable adjustments to ensure people with dementia or carers are not disadvantaged in the workplace. Dementia is often not considered a disability, despite the Equality Act specifically mentioning it as one. Employers are obliged to make reasonable adjustments and to consider requests for flexible working from all employees, especially people with dementia and carers under the Flexible Working Regulations 2006.

Despite legal protection for working carers, many carers and people with dementia are unaware of their rights. Organisations must make a concerted effort to raise awareness among all employees of the Equality Act, Flexible Working Regulations and the right to time off for family and dependents.

Discrimination by association

Carers are also protected under the Equality Act 2010 through discrimination by association. This means they must be offered reasonable adjustments when appropriate.



Dementia is a disability

Dementia is a disability according to the Equality Act 2010. The following are included in the definition of disability:

- Paragraph A2: the person must have an impairment that is either physical or mental (see paragraphs A3 to A8).
- Paragraph A6: A disability can arise from a wide range of impairments which can be progressive, such as motor neurone disease, muscular dystrophy, forms of dementia and lupus (SLE).



A dementia-friendly utility provider supports its employees living with dementia, and their carers, and is flexible in order to meet their needs.



British Gas Carers Policy

British Gas has demonstrated a well-developed and comprehensive approach to carers, which has widespread coverage across the organisation. Supported from the highest levels of the organisation, its core message is that supporting carers in the workforce isn't just about being a good employer, but is also good for business: it reduces staff turnover, cuts recruitment and training costs, retains talent and experience, builds resilience and improves wellbeing.

The link between policy and business benefit is a crucial one, because it provides a rationale and reason for managers to buy into it. British Gas also has a well-established carers network and support procedures in place including carer's leave. This support has now included dementia specific support and signposting for those caring for someone living with dementia.

British Gas has a solid suite of policies which includes practical arrangements aimed at carers, along with support for line managers and networking for employees. Their Carers Policy, which in addition to dependant and emergency leave, provides up to one month's matched leave per year. For example, if an employee takes five days annual leave for caring responsibilities British Gas will match this with an additional five days. There is no service requirement to be eligible for this leave apart from registering with the carers network and informing their line manager of their caring responsibility. Since the introduction of this scheme, on average employees only take less than three days carer's leave per year. This shows that schemes will not be abused. There are numerous benefits associated including increased employee retention, reduced sick leave or unexplained absence and improved employee wellbeing.

Carers are also supported through an Employee Assistance Programme which includes carer-specific support.



For more information about the support employers can provide employees, take a look at Alzheimer's Society's **Dementia-friendly business guide (900)**. This resource looks at the three key phases of supporting employees with dementia:

- **Phase 1:** Supporting employees in the early stages of dementia.
- **Phase 2:** Ongoing support and management.
- **Phase 3:** Leaving work.



BT Carers Policy

BT has developed a rigorous process for supporting carers working for the organisation, introducing a Carer's Passport to ensure that managers understand how they can support their direct reports.

BT has toolkits available for working carers, such as the flagship scheme of this programme – the 'Carer's Passport'. This can be completed by any BT employee with caring responsibilities that could impact on their ability to work, now or in the future. The BT Carer's Passport describes the nature of the caring responsibilities and adjustments that the individual might need to make. It also outlines action to take if they need to leave work suddenly, together with agreed communication between them and BT if they are unable to attend work.

Lesley at BT describes how it helped her:

'In the early stages, it was just the flexibility to go to appointments with her. Or slightly longer lunch hours so I could have my mum and dad round for an hour to give them something to eat which gave my dad a break. I worked from home, so it was easy for me to make the time up.'

When Lesley's dad found it too difficult to cope, Lesley built an annex on her home and moved her parents in with her.

'Working from home with flexible hours became invaluable. Without this I would probably have had a breakdown myself. I started work at 7am to give myself a head start, just in case I needed to help her later. In addition to memory problems she'd often lose her balance and fall. Being on hand I could nip downstairs from the office and dress the wound or run her to the doctor's for help.'

In the later stages of the illness, a stroke meant her mum needed full-time care, so she moved to a nursing home around the corner.

'Mum was the most important person to me, so I kept to the same routine of starting work early then going to see her when she woke and then at lunch time and after work. If there was a problem I could be called and with her in two minutes. I was lucky to have an understanding manager. But it worked because I was able to keep my job under control and could work weekends to make up time.'

During these later stages, the BT Carer's Passport became available. Lesley, who was changing jobs and managers at the time, says: 'It was a great help as a starting point, explaining my responsibilities when starting a new job.'

Lesley was working in the office in June 2013 when she had an 'uncontrollable urge' to be with her mum.

'I immediately went and she died unexpectedly in my arms ten minutes later.'

'The best thing BT has ever done for me in the 35 years I have worked here is allow me to be with, and look after, my mum. And for that I will always be grateful.'



Processes – customer support and communication

The needs of people with dementia have to be considered in all aspects of a business to ensure that products and services are relevant. Safeguards should be established to protect people with dementia where necessary. This can be done by engaging with people living with dementia or specialist organisations. People may not want to identify themselves as living with dementia, or may not be aware they have dementia. Systems, processes and support mechanisms that consider these aspects ensure all customers who require support have access to it. Championing the needs of vulnerable customers in all parts of an organisation will ensure that during any interaction, a customer is supported and understood.

Audit of processes, procedures and support mechanisms

Organisations should audit the following areas and with these considerations in mind:

Strategy

- Is supporting customers or employees affected by dementia included within your organisation aims, ethos or objectives?
- Do you have a consumer vulnerability strategy, policy or team?
- How does dementia fit in to your consumer vulnerability strategy or policy?
- How are the needs of people with dementia considered when making business change decisions, such as altering or launching products, changing services, or policy statements?
- Do employees understand the legal and regulatory obligations for supporting and protecting vulnerable customers?
- How do utility organisations inform vulnerable customers of the best tariffs and deals?

Identifying vulnerable customers

Utility companies should understand that the definition of a vulnerable customer is broad. A customer may be vulnerable because of their circumstances, personal characteristics or health, an inability or disinclination to act or a combination of these. They might also be vulnerable because of

the wider economic and social environment in which they live. Ofwat has reported that as much as half of the population will find themselves at some point in temporary circumstances that may make them vulnerable. Organisations must keep in mind that customers can move in and out of vulnerability (Ofwat 2016). Frontline staff should be empowered and incentivised to use their judgement to identify and assist customers who might be vulnerable.

People with dementia told Alzheimer's Society that they were happy to share information about their dementia diagnosis with their utility provider, subject to companies being very clear about how this information is used. They also told us they are concerned that companies make assumptions about what a person with dementia can and cannot do, especially in the early stages. Companies need to ensure that information held on any customer's disability or dementia is treated sensitively, and is used only to enhance customer experience and not for sales messages.

Regulators including Ofwat want to see companies making greater use of the customer data they already hold to get a better understanding of vulnerability. They also want to see them do more to make support accessible and seamless, and to anticipate and provide support before problems escalate. This may include signposting to better tariffs and to other organisations who can provide financial advice and support.

Tariffs, buying services and price comparisons

People with dementia told Alzheimer's Society that they want to have the same opportunities as people who do not have the condition, or those with access to online price comparisons, to get a good deal on their utility bill. They told us that they were frustrated that comparing their tariff and switching providers was too complex. They told us that they wanted to be made aware, in a clear and accessible format, of how much they are being

charged for their energy and whether they are on the cheapest tariff. Regulators and the media are interested in ensuring vulnerable customers get a fair price, and are concerned that suppliers are not doing enough to help customers access better deals that can help them to reduce their bills.

Companies should not rely on vulnerable customers to actively choose the cheapest tariff. The regulators want to see suppliers support vulnerable customers to become empowered and confident, as their circumstances can put them at a disadvantage in accessing the best deals. Utility companies should proactively reach out to vulnerable customers to help them with this.

Creditors should understand legislation and should always begin by assuming the borrower has the mental capacity to make the relevant financial decision. Having dementia, or acting in an unusual manner, does not necessarily mean that the borrower lacks the mental capacity to make a financial decision. They should allow the borrower the time they need to make the decision and repeat key information about the credit arrangement. The creditor will need to assess whether the borrower:



The following questions can be helpful for identifying vulnerable customers:

- Has the customer reported a health condition (especially one that leads to them using more energy or water)?
- Are there signs that a customer has had a change in their life circumstances (for example unemployment, caring responsibilities, divorce)?
- Does the customer sound worried or stressed over the phone?
- Does the customer routinely miss payments?
- Has a customer who normally pays on time stopped paying or become irregular in paying?
- Does the customer seem to have difficulty understanding or accessing information?

- understands the financial decision they are making
- is aware of the potential consequences of their decision
- is able to retain and use the information provided to make their decision
- is capable of communicating their decision.

If there are concerns the borrower does not have the mental capacity to make the relevant financial decision, the creditor can consider:

- delaying the decision
- following internal practices and procedures
- checking whether a third party has authority to act for and on behalf of the borrower
- contacting external organisations for assistance, such as the Office of the Public Guardian (OPG).

Communication

A dementia-friendly utility provider makes communication clear and simple.

Organisations in the utility industries use a lot of specific jargon and unique discourse for talking about consumption, meters, tariffs, bills and service interruption. There is a danger that when this language and jargon appears on communications for customers (including written, digital and conversations), it can make it difficult for them to engage and trust the organisation. Suppliers should be transparent with charges, policies and schedules, with this information readily available and written plainly without jargon. Customers should be offered flexibility to meet the particular needs of the customer, from offering different channels of communication, to flexible payment options and access to information.

Any strategy for contacting customers should be accessible and flexible, but consistent across every department. It should allow the customer to determine how they prefer to be contacted including: email, text messaging, post and instant messaging, as well as call routing. Organisations should encourage the use of a method of contact which meets the customer's needs and enables them to interact in the way that suits them (Employers' Forum on Disability, 2010). To support people with dementia to stay in control of their utilities, companies need to ensure all their communication is clear and simple and their frontline staff are patient.

Communication channels and information

- How is information provided to customers?
- Are there alternative methods of communication or interaction offered to suit the circumstances of the individual?
- Do you provide information in written form with high level summaries available, as well as by telephone or online?
- Are key employee groups aware of Power of attorney, Mental Capacity Act 2005 and deputyship?
- Do you have a ring-fenced call centre team to support customers in vulnerable circumstances?

- What processes do call or contact centres have in place to support additional needs or alternative requirements for people with dementia?
- Could there be face-to-face support for vulnerable customers if needed?



On the phone

People with dementia can find communicating via phones demanding and frustrating. Some of the things people living with dementia have said about this are:

'Automated systems are a nightmare.'

'You can only remember so much of the phone call, they can spill off all this and that, but they've lost you.'

'I'm often put on hold for quite a long time and by the time they put me through to somebody I've forgotten what I phoned up about.'

'Speaking to call centres, it is difficult to understand what call handlers are saying and it is difficult for both of us. It is also hard when you keep getting passed along to someone else. In some organisations like banks, it is often difficult to find someone to speak to in the first place!'

'I dread dealing with companies on the phone. It's so stressful. Where do I start? I plan it all out, pin and password at the ready. Eventually I get through to a robot with six options. Listen to all, forget the one I need, make a mistake and you're back at the beginning. Waiting in the queue for a human. Music blaring at the other end, forget you have phoned, ask more security questions. They talk too quickly and give you too much information. They don't listen – they have to follow the company line and push for you to commit to something.'



People with dementia can have a number of challenges, including:

- difficulty expressing themselves or finding the right words
- difficulty navigating automated phone systems
- forgetting who they are ringing and why they are ringing
- difficulty remembering information given or instructions given
- anxiety about unexpected questions which they have not prepared for
- time pressures and not having enough time to think about the questions or process information
- being bombarded by too much or unnecessary information
- having to follow too many steps while using automatic call handling systems
- being passed around to many different people leading them to repeat themselves
- being required to speak to the person in question when the carer or family member is ringing
- having to talk to a lot of people to resolve an issue
- anxiety when picking up the phone
- not having a record of the conversation, any decisions or agreements made.

In addition, those acting on behalf of someone living with dementia often face barriers when discussing account or customer information.

The person's experience is dependent on the patience and understanding of the staff member on the other end of the phone. Companies should also understand concerns that cold calls and scams undermine the confidence of people with dementia. Employees should not pressure people with dementia into a decision. Instead they should offer to follow up on their conversation via email or letter so they have a written copy to refer to later.



Legal obligations

Organisations must ensure that their call routing systems do not prevent disabled people or people with dementia from accessing their services, products or support. Organisations should consider the potential impact of a system on disabled customers. They should anticipate customers' needs by making reasonable adjustments to the system, for example a repeat function or allowing customers to speak directly to an agent. If call routing systems are inaccessible or there is a failure to make reasonable adjustments, people with disabilities (including people with dementia under the Equality Act 2010) may make claims for indirect or direct discrimination.



Over 70%

of people aged 70+ have some kind of hearing loss (Action on Hearing Loss, 2016). As we age, we gradually lose some hearing due to a condition called presbycusis. This includes loss of hearing of high frequency sounds like 'sh', 'k', 'p' and 'f' in everyday speech.

Age UK, 2017

Things to consider include:

- Do your employees have a priority telephone number for vulnerable customers to use?
- Are your advisers Dementia Friends?
- Are your call handlers trained to have an understanding in dementia?
- Are your call centre staff under time restrictions?
- Do you have a skilled and trained person who can help the customer?
- Are your call handlers equipped to deal with everything rather than send the customer around the organisation, and do your callers have to repeat information that has already been provided?
- Are your callers most commonly requested or most important items first on the menu list?
- Are your options spoken clearly and slowly, and is there a repeat function on each layer of the menu?
- Is there an option to speak to an agent at each menu level or is the call transferred to a handler if no option is selected?
- If a customer is in a call queue, are they given an expectation of how long they'll be on hold and offered a call back facility?

- Do your call handlers understand any priority services the organisation offers?
- Do your call handlers have a working knowledge of the Mental Capacity Act 2005, Power of Attorney and deputyship?
- Are there other ways of communicating if this method doesn't work for the customer?



'It's difficult to know how much I am being charged for my energy and how much I am using. It would be really helpful to know if I was paying the most competitive rate.'

Person with dementia



TalkTalk lets customers use their voice as their password

TalkTalk uses the latest voice biometric technology which allows customers to use their voice as their password rather than having to answer lots of security questions, remember passwords or PINs.

By working closely with Alzheimer's Society, TalkTalk was able to gain valuable insight about the needs of customers with dementia. TalkTalk recognises the challenges people with dementia face when trying to complete everyday tasks and this simple and secure verification process can help to improve the customer experience of people living with this condition. Customers call TalkTalk, complete the verification process, then opt to set up TalkSafe by repeating a simple phrase three times. This creates a "voiceprint," which will be used in any further calls.

TalkTalk is proud to be the first internet service provider to offer this technology to its customers.

For more information on TalkSafe, watch TalkTalk's video 'What is TalkSafe?'

Written communication

People with dementia told Alzheimer's Society that their bills and letters were often complicated and confusing. They told us they wanted energy companies to provide them with simplified bills, even if this meant missing out on potentially useful information. They should be laid out with the most important information and how much an individual needs to pay clearly presented.

They may find the following difficult:

- determining what information is important
- deciphering what is expected of them
- understanding jargon and language that is not easy to understand
- confusing marketing messaging
- reading complex information in a bill
- reading a long document
- reading a page with bright logos.

Well-written communications that are simple, clear and easy to understand will result in the customer feeling in control and knowing what is expected of them, and will help them to take any necessary action.

Things to consider include:

- Are people with dementia consulted about the design of your communications?
- Is it clear what action your customers need to take if any?
- Are your communications simple and easy to understand?
- Have you avoided jargon?
- Have you laid your communications out in a logical way?
- Have you included appropriate diagrams and images throughout your communications?
- Is your key information in a box to help it stand out?
- Are your paragraphs a manageable size for people to read?
- Do your communications feature the right amount of information?



'It's a major challenge to read the bill.'
Person with dementia

'There is so much advertising coming through, it's not just a bill – it's wrong.'
Person with dementia

'The bills they send me are clear and concise and I know exactly what I'm being charged for. Since they have started sending me these new bills I understand the billing process so much more and they no longer confuse me.'
Person with dementia



Websites

However, people with dementia expressed concerns about online communication and interacting with organisations that rely too heavily on information being available online.

They found this especially true for complaints procedures. People with dementia told Alzheimer's Society that they may struggle to use the internet, especially as the condition progresses. In addition, half of one group of people with dementia we spoke to did not have access to the internet³. They suggested that energy companies, charities and government could provide support to help them access online services.

People with dementia may find the following difficult:

- identifying the important content
- locating the necessary support
- finding the correct link to follow
- reading complex fonts
- understanding what information is required of them to log in.

Well-designed, simple and clear websites will empower people to stay in control of their finances and reduce the number of enquiries and calls.



'People should never be more than three clicks away.'

Admiral Nurse

'Online – people with dementia lose confidence in themselves and lose trust.'

Person with dementia

'Passwords are a nightmare – I keep having to change my password every three weeks.'

Person with dementia

'Their website is easy to use and means I can access my dad's account without having to speak to anyone as he has given me permission to act on his behalf and the account log-in details. I find this much easier than trying to speak to someone.'

Carer for a person with dementia

Things to consider include:

- Are people living with dementia consulted regarding design?
- Is the text clear?
- Is the messaging simple?
- Is it easy to navigate?
- Is the process for resolving an issue simple?
- Is the text short and easy to read?
- Are images simple and relevant?
- Are the headings clear?



³ The group consisted of eight people with dementia, four of whom did not have internet access.



BT – Dementia Friends Team a customer's perspective

'Both my parents have been diagnosed with dementia. They both still live in their own house, but the level of support has slowly increased since my mother was diagnosed. We had to take the decision of taking over their day to day personal affairs which included registering the Enduring Power of attorney for their financial affairs and redirecting their post.'

Since then I have had to deal with many organisations on behalf of my parents and while everybody you speak to is most sympathetic with the situation, BT are the only ones I have spoken to who have a dedicated team. When I rang the BT Customer Service number the lady was very helpful in the first instance and was using the system to provide me with the best solutions. After about 10 minutes she then found some information that pointed her towards a specialist Dementia Team within BT and I was transferred immediately.

I didn't have to go into great detail in terms of my situation as there was empathy as soon as the conversation started. The lady quickly identified the service that I needed, one that was based on their experience and knowledge of dementia patient behaviour, Network Controlled Calling (NCC). The service was set up within days.

The next challenge would be dealing with the 'fall out' from my parents. Within a couple of hours of the service being set up my Mother tried a number that was not on the list and assumed there was a fault on the line. She went round to the neighbour's house and registered the fault. My brother was visiting at the time and was able to let me know the situation so I emailed the Dementia Team to ask if the engineer would know about the NCC. I was reassured that they would and in addition have informed all the neighbours of the situation and that there is no fault on their line.

They have saved my parents money as well as worked practically with my brother and I to help manage the situation and enable them to stay safe and secure in their own home.'



British Gas Power of Attorney

Through an initial audit by Alzheimer's Society of some of the processes we had in place around Powers of attorney, it was clear that improvements could be made. Many people living with dementia find Power of attorney arrangements are crucial to helping them live independently for longer, as they give trusted family/friends the ability to speak on their behalf when talking to utility companies like British Gas. To ensure we have the best processes possible, we invited the government's Office of the Public Guardian (the specialist section of the Ministry of Justice which promotes Power of attorney schemes) in to review our existing systems. They found that our processes were unnecessarily complicated and time consuming. With their support we have designed new processes with the customer front and centre of our new system. We have made it easier and clearer for both our frontline employees and the customers needing it to get this important structure in place.



E.ON's Smart meter research

'Recently I had the great opportunity to attend a service review session with David, Ray and Joe who are all living with dementia.'

The purpose of the session was to share our smart meter communications to get the attendees' feedback on what worked or didn't work so well for them.

During the session I learnt a lot about how dementia affected them individually. David, for example, struggled to say what he had in his mind. He likened it to writing a sentence, but for every word he wanted to write, he had to look up how to spell it in the dictionary first before he could write it down. Ray said he could be very aggressive without meaning to be, his brain was telling him to stop, but the words just came out, which could be very upsetting. Joe told us he couldn't always remember key or important words so ended up having to describe them – so for example a police helicopter outside the window, was a thing in the sky with whirly bits that flew.

The time I spent with them was very useful. I explained a little about smart meters and how they worked and showed them some of the smart letters we sent out. They liked the matter-of-fact information that was clear and simply laid out, however they told me that they found the red writing that we used to headline our letters scary and off-putting. They also said that if we put the information in a bill they were much more likely to take notice than if they received it as a separate letter, which they'd be likely to put in the bin!

They told me providing different ways of responding to a letter or request for information was very important. For example for David, phoning and talking to someone was difficult and he didn't have access to go online. They also told me that if we had a third party named on the account, it would be great for us to contact them and let them know upfront about what information we needed to book the appointment. Finally they also said they liked any information that they could keep in a drawer and refer back to.

Following on from the visit I am going to be looking at all the feedback to look at what we can change. We're also looking at how can include some of the questions that we ask when booking the appointment into our letters, as well as alternative ways to make the headline and key points of the letter stand out.'

Nicola Hirst,
Smart Performance Lead.

Customer support

A dementia-friendly utility provider has the skills and processes in place to support people whose lives are affected during all stages of the dementia journey.

To help those affected by dementia, utility companies should look at whether their customer journeys, processes and products are dementia-friendly. This does not necessarily mean there must be processes specifically for people with dementia. There may already be processes in place to support those in vulnerable situations more generally.

'It's not rocket science, it's just customer service plus!'

Person with dementia

'I need actual quarterly readings taken by the electric company and provision of quarterly bills so unusual usage can be picked up earlier. I now have to read the meter each time I visit to avoid an excessive annual bill because for example the hot water tank peak rate has been turned on and left on'

Person with dementia

Processes and procedures

People affected by dementia would benefit from clearer processes for dealing with Lasting powers of attorney (LPA) that are understood by all staff and are customer friendly. For instance, carers told us that some companies only accept original versions of LPAs. This caused anxiety for carers about loss of an incredibly important document they need for making many different decisions. Utility companies could amend their process to accept certified photocopies of the LPA, which are legally valid, to resolve this issue. Carers told Alzheimer's Society that they found it difficult to act on behalf of the person with dementia. Organisations often wanted verbal or written consent from the policy owner in order to proceed, which sometimes is not possible. In one example, a carer who had a LPA was still not allowed to speak on behalf of the person they cared for.

'The energy company refuse to speak to me or my mum despite them being aware that my dad, whose name is on the account, has dementia. They need to acknowledge that my parents are married and that my mum can speak on dad's behalf. Even though I have explained to the company that I have Power of attorney for my dad they are not prepared to talk to me. They keep requesting the original copies of the legal documents which I am not prepared to send so we are currently in a stand-off... they need to gain a better understanding of dementia and how it affects people.'

Carer of a person with dementia

- How are processes or procedures which customers interact with assessed for how they can be adapted to support the considerations of people living with dementia, carers or family members?
- Can systems accept Power of attorney or deputyship changing account names or delegated users?
- How are complaints made from people living with dementia, their families or carers recorded or appropriately logged to understand their issues or concerns?
- Do you monitor complaints from people affected by dementia and what procedure do you have in place to ensure they are acted on sufficiently and appropriately?



Ofcom requires all communications providers to offer third party bill management, enabling a trusted friend or relative to act on behalf of an individual in matters relating to their account.



Sandra's story

Dealing with deputyship

“After a five month wait we finally got the paperwork from the Court of Protection to manage my father-in-law’s finances. He wasn’t in a place where he would agree to the simpler Power of attorney and so this was a last resort, requested by social services. He has been in a residential home for 19 months and is unlikely to return home. Now we have the deputyship we are beginning what appears to be a bit of a battle with the various organisations to register it. So, this is my ongoing description of how I am spending my lunch hours at the moment...”

Today’s lunch hour was spent speaking with my dad’s energy provider. I noticed on dad’s bank statements he is paying over £100 a month in direct debit even though his bungalow has been empty for 19 months and no fuel at all has been used. I am assuming that it is some kind of ‘payment into a pot’ system, and they have £2,000 in overpayments. More in hope than expectation, I go onto the website to see if there is any clue as to how to register our deputyship and sort these matters out...nothing that I can find. Google again comes up with offerings about the company supporting vulnerable customers however.

I steel myself for the usual wait on the phone and the explanation which generally results in the call handler ‘having to go off to check’. That is what happens and I am told to either post or email the court paperwork to an email address I am given. I double check that 1) emailing is OK and 2) that it is the correct email. So off I go to scan in the paperwork and send off an email. Immediately it bounces back as ‘no such email exists’. I again go onto the website to see who I can write to to get the correct address. I end up sending in a complaint as it is the only viable option I can find – explaining what has happened and asking for the correct email address.

Someone calls me back promptly the next day, but cannot speak to me as it concerns my husband’s father. So we have an odd conversation where we arrange for them to call me back tonight so I can pass the phone to my husband, he can give them permission to speak to me and I can get the details to send off the paperwork. Apparently we will hear from them in ten days. The complaints lady is very charming, but please – just put it on the website.’

A dementia-friendly utility provider makes customers aware of the extra support available to them.

Utility companies already do a lot for customers and often work together to ensure they are safe. Energy and water use a Priority Services Register to capture information on their customers' needs or circumstances if they require additional support or priority service. However, many of our customers are unaware of the benefits of the register and are therefore not on it, meaning there is little awareness that they may need extra support. The industry needs to ensure that the

support on offer to customers is visible to customers and easy to access. There should be active communications to raise awareness of the Priority Services Register, who it is for and the benefits of being on it.

Utility organisations can provide a lot of support to people affected by dementia but, in some cases, specialist support may be required from another organisation. People with dementia and carers have told us that this kind of signposting to advice and support had helped them to resolve problematic issues.



E.ON's Care and Assessment Tool

The Care and Assessment Tool utilises a search facility which E.ON's advisors can input information into, to capture a range of vulnerabilities, including age, health-related issues, life events and financial difficulties at both a customer and household level. From this effective data capture the tool then provides the advisor with a bespoke selection of servicing options to support the vulnerable customer.

For example a customer who is living with dementia, over 60 and has a reduced household income would be eligible for the following support:

- addition to the Priority Services Register (PSR)
- setting up of a Letter of Authority
- a review of their tariff and whether they are on the right meter (specifically prepayment meters or credit)
- energy efficiency advice and signposting to E.ON (see **E.ON's online energy saving toolkit**)
- referrals to third parties for support
- benefit entitlement checks and hardship funds
- a transfer to the Obligations teams to see if they could qualify for support under Energy Company Obligation.

In addition the data on the needs of vulnerable people will be set to review at defined periods to ensure the data remains up to date and relevant.

Agents should be briefed and encouraged to do this, and to signpost to the following schemes and organisations:

- Free gas safety checks
- Cold Weather Payment
- Winter Fuel Payment
- Warm Home Discount
- Network provider options (for example BT's "Choose to refuse")
- Trading Standards TrueCall pilot
- CPR Callblocker
- Telephone Preference Service (TPS)
- National Fraud Authority
- Phone Pay Plus
- Money Advice Trust and National Debtline
- Citizens Advice.

'My husband's frontotemporal dementia means that he struggles with finances and this led to us getting into debt. Our energy company were really helpful and gave me the details of a local charity which helped us clear our debt. They were polite and good at listening to me.'

Carer of a person with dementia

'We expect all suppliers to do much more to offer free gas safety checks to those who are eligible for them.'

(Ofgem, 2017)

'Caller line identification should be provided free of charge.'

(All-Party Parliamentary Group on Nuisance Calls, 2003)



Gas Distribution Network Locking cooker valve

Cadent, SGN, Northern Gas Networks and Wales & West Utilities can all fit a lockable safety device to the pipework of a gas cooker or hob free of charge.

This device can help people living with dementia live safely and independently for longer. The valve can easily be turned off and on and locked by a carer or loved one, meaning that someone with dementia can continue to use their gas cooker safely. When the valve is turned off, the gas supply is isolated meaning that no gas can escape. The gas can only be turned back on when the carer is back in the home.

This service is free and offered by the Gas Distribution Network nationwide across England, Wales and Scotland, regardless of gas supplier.

This simple safety device can help someone live longer and safely at home, providing reassurance to carers and friends or family members that gas cookers will not be left on and unattended by accident. Members of the Gas Distribution Network have been working within the communities they serve, including with safeguarding and community groups, to promote this simple safety device.



Supporting customers in financial difficulties

Organisations need to provide clear advice and support to customers who might be in difficulty with their payments and bills, as well as identifying customers before they ask for help.

Suppliers should see a part payment or missed payment as a sign of potential financial difficulty, focus on why someone may have missed a bill, and then offer help and support. It is also helpful to work with debt agencies in the local area so they are also aware of the needs of vulnerable customers.

Organisations could offer the following:

- switching the customer to a more appropriate tariff
- helping customers make efficiency savings on their usage – for example by providing water saving devices, energy efficiency advice or insulation
- helping customers access advice on benefits, council tax reduction, tax credits and other financial support
- suspending collections, giving payment holidays or changing payment dates
- refunding fees and late payment charges
- accepting reduced repayments in the short term
- cancelling non-essential direct debits or standing orders
- signposting to charitable trusts or independent advice.

Things to consider include:

- Do customers have an opportunity to inform you about their dementia or know that they should?
- Are flags or markers in place within systems to identify potentially vulnerable customers?
- Do customers trust your organisation or feel safe to tell you about their diagnosis?
- Are employees aware of flags and markers?
- Are customers asked if they require any adjustments or further support?
- How are customers' changing circumstances or adjustments captured? Do you have a system and what do you do with the information?
- How confident are you that customer-facing employees can talk about issues relating to their utility service in order to support people with dementia?





Place – working in local communities

Accessible environments are very important for supporting people with dementia to continue doing things for themselves for longer, at home and within their community. Small changes to layout or signs, for example, can go a long way to reducing stress and confusion.

When utility companies have to fix problems in the street such as telephone wires, gas pipes, water or electricity supply, they often cause disruption to the local environment. While these changes are unavoidable, there are steps that can be taken to minimise the impact, especially to those living with dementia.

Utility companies should consider:

- clear signage to help people navigate around the disruption
- minimising blocking paths and pavements which mean people would have to walk in the road
- advance warning where possible to help people prepare ahead of time
- ensuring local vulnerable customers are identified and then supported if there are any outages
- providing clear information packs about what to do in case of an emergency or disruption.

Utility company employees may need to enter the homes of people with dementia. This could be for example to fit a new meter or fix problems with a phone or internet line. When employees enter a customer's home, care also needs to be taken to minimise disruption.

They should consider:

- calling ahead to help a customer prepare for the visit
- always showing identification and leaving a note or card so any carers or family know you have visited
- making vulnerable customers aware of any password schemes to ensure that they can safely identify engineers on the doorstep
- ensuring all tools and equipment are safe, and not causing potential trips or falls in the home
- being patient and clearly explaining to the customer why they are there if they forget or become concerned
- being flexible with appointments when a customer requires a carer or third party to be present
- signposting to any relevant local support and services.

Safeguarding

A dementia-friendly utility provider ensures they improve the lives of people living with dementia within the communities they operate in.

If employees enter the homes of vulnerable adults, organisations will need to comply with a variety of government guidance, legislation and best practice recommendations by having safeguarding policies and procedures. Regulators also need to ensure that vulnerable customers are protected in emergencies and from risk of abuse. They should also ensure vulnerable customers have access to utilities that could negatively impact a person's health if they don't have them.

In order for these processes to succeed they need to be up to date. Employees also need to know their responsibilities and what steps to take if they identify a safeguarding issue.

- Are processes up to date?
- Do employees know what the organisation's safeguarding policies are?
- Do employees know where to turn for more advice?
- Do employees know what to do if a customer is being subject to nuisance calls?
- Are colleagues aware of signs of and supporting customers who've experienced scams, fraud, financial abuse, physical abuse, or at risk of trips or falls?
- Are colleagues aware of how to escalate wider concerns about scams within the company, industry and regulator?

Protecting vulnerable customers against fraud and scams

Older people, people affected by dementia and other vulnerable customers are at higher risk and are often targeted by criminals with scam calls, post and visits which are detrimental to their financial, emotional and psychological wellbeing (DODs, 2016).

Other facts about frauds and scams include:

- The Chartered Trading Standards Institute (CTSI) estimates that only 5% of financial scams were reported annually.
- The APPG recommends that telecom companies block numbers known to be making nuisance calls.
- Ensuring that customers in vulnerable situations have continuous access to heat and light is vital to health and wellbeing. Standard Licence Condition (SLC) 27 from Ofgem prohibits suppliers from disconnecting pensioners during winter, and requires suppliers to take all reasonable steps to avoid disconnecting premises that include any pensioners, disabled or chronically sick customers in winter.



UK Power Networks

Stuart Hill, East of England Manager

'I was working on an underground cable fault next to a footpath and around the excavation were a number of barriers. I noticed a gentleman standing back from the barriers, looking anxious. I approached him and asked if he was OK, he seemed confused and unsure as to whether he could walk along the path with the barriers in place.

I explained to the gentleman why the barriers were there and the detail behind the works being carried out. He explained he was walking past, so I walked along with him past the barriers to make him feel more comfortable. I feel that the knowledge I had gained through the Dementia Friends session helped me understand that gentleman's situation and how he was feeling when confronted with a situation he was not expecting. The barriers were not normally on this gentleman's route and it made him feel anxious. Walking and talking with him helped ease his worries.'



There are huge benefits for businesses and organisations from engaging with their local community. These include gaining a better understanding of the needs of their customers, supporting local staff and raising the organisation's local profile.

Dementia Friendly Communities

Dementia Friendly Communities are geographical communities which are committed to working towards making their area accessible, inclusive and supportive for people living with and affected by dementia. Everyone, from local government and health boards to the local corner shop and hairdresser, shares responsibility for ensuring that people with dementia feel understood, valued and able to contribute to their community.

Organisations should join their local community to support and engage with the issues that matter to people in their area. It provides a support mechanism, network of local businesses and a platform to engage your local community and customer base.

You can search for a list of your local Dementia Friendly Communities on the Dementia Friends website (dementiafriends.org.uk) and on the national Dementia Action Alliance website (www.dementiaaction.org.uk).

Volunteering

Volunteering for a local Alzheimer's Society, Age UK or dementia service is an opportunity for organisations and businesses to support their local communities. Organisational volunteer days or time could be used to offer skills-based volunteering or local support for key services.

Take a look at Alzheimer's Society's **Dementia-friendly business guide** for some ideas or email volunteers@alzheimers.org.uk



Wessex Water creating a dementia-friendly city

At Wessex Water customers are at the heart of everything we do and we are committed to providing help when it's needed. As part of our strategy to support customers in vulnerable circumstances we have been working closely with Dementia Action Alliance, particularly with the local Bath branch. We are one of 36 companies in Bath that have signed up to make Bath a dementia-friendly city. This is achieved by each company setting themselves a dementia action plan to ensure that businesses are continuously improving.

Wessex Water's action plan includes pledging to make all our customer-facing staff Dementia Friends, holding lunchtime sessions with Alzheimer's Society and 'tea and talk' sessions with our HR and Occupational Health teams for staff who have family members with dementia.

One of the key areas on our action plan is the review of our signage. We have been working to ensure that all our road signs are dementia-friendly. We are looking to extend this further to make all our street works easy to navigate for those with dementia or sight loss.

Summary of recommendations

People



Utility companies should:

- ✓ ensure that staff working with vulnerable customers have dementia-awareness training appropriate to their level of need
- ✓ provide face-to-face support to help people affected by dementia to manage challenging situations
- ✓ work to improve customer awareness of existing support offered to vulnerable customers, along with charities and government
- ✓ encourage people affected by dementia to inform organisations of their dementia diagnosis where appropriate.

Processes



Utility companies should:

- ✓ provide support appropriate to level of need to vulnerable customers, including people with dementia, with a roll-out of new technology
- ✓ support digital inclusion of people affected by dementia
- ✓ consider how their contact centres can support people with dementia
- ✓ assess their products and services to ensure people with dementia are considered throughout.

Places



Utility companies should:

- ✓ signpost to key support and safeguarding organisations when appropriate
- ✓ consider how to support and protect their customers and the public during disruptions, emergencies or work
- ✓ join their local dementia-friendly community in their region.

Useful resources

General

Alzheimer's Society publications

alzheimers.org.uk/publications

Publications order line: 0300 303 5933

Alzheimer's Society publications provide information about all aspects of dementia.



People – awareness, training and support

Alzheimer's Society resources

Creating a dementia-friendly workplace: a practical guide for employers

alzheimers.org.uk/workplace

A resource providing guidance on supporting staff members who have dementia, or those who are caring for someone with dementia while still in employment.

Dementia-friendly business guide

alzheimers.org.uk/business

An informative guide for businesses and organisations to help them gain an understanding of dementia, how it impacts organisations and the practical steps they can take to support employees, clients and customers both through their processes and environments. We hope managers will use this guide as a tool to review existing approaches to supporting people living with dementia in the workplace.

Dementia Friends

dementiafriends.org.uk

A free initiative run by Alzheimer's Society. Employees can watch an online video or complete a 45-minute face-to-face session to become a Dementia Friend, or do a one-day course to become a Dementia Friends Champion.

Employment and dementia position statement

alzheimers.org.uk/info/20091/what_we_think/138/employment_and_dementia

A briefing on dementia in the workplace.

How to help people with dementia: a guide for customer-facing staff

alzheimers.org.uk/customerfacing

An Alzheimer's Society booklet containing practical advice on communicating with and assisting people with dementia.

Training and consultancy

alzheimers.org.uk/training

Alzheimer's Society develops and delivers high quality training and consultancy services to staff across all sectors to provide them with the skills, knowledge and understanding to confidently care for and support people living with dementia.

Other resources

Employers for Carers, Toolkit for Starting and Sustaining a Carers' Network

www.employersforcarers.org/resources/toolkits

Flexible working regulations

www.gov.uk/flexible-working

Supporting employees who are caring for someone with dementia

www.employersforcarers.org/resources/research/item/875-supporting-employees-whoarecaring-for-someone-with-dementia

Key findings and emerging issues from a survey of employers and employees conducted by Carers UK and Employers for Carers, with ten recommendations for employers, health and social care services and government to facilitate better support for carers.

Tips for employers who want to be more dementia friendly

www.dementiaaction.org.uk/assets/0000/8841/DEEP-Guide-Tips-for-employers.pdf

www.dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Tips-for-employers.pdf

Practical tips for employers produced by the Dementia Engagement and Empowerment Project (DEEP).

Time off for dependants

www.gov.uk/time-off-for-dependants

Training and Massive Online Open Courses (MOOCs)

SCIE Dementia Gateway Open Dementia eLearning Programme

www.scie.org.uk/publications/elearning/dementia/index.asp

University of Derby, Bridging the dementia divide MOOC

www.derby.ac.uk/online/mooc/bridging-dementia-divide

University of Tasmania, Understanding dementia MOOC

www.utas.edu.au/wicking/understanding-dementia



Processes – customer support and communication

Call centre, What do people living with dementia in the UK really think about using call centres?

www.callcentre.co.uk/what-do-people-living-with-dementia-in-the-uk-really-think-about-using-call-centres

Dementia Diaries, How do the dementia diarists experience call centres

www.dementiadiaries.org/entry/2541/how-do-the-dementia-diarists-experience-call-centres

Direct Marketing Association, Call centre vulnerable consumers

www.dma.org.uk/uploads/call-centres-vulnerable-consumers_final_53d7c237289c1.pdf

Dementia Engagement and Empowerment Project (DEEP) Guides

www.dementiavoices.org.uk/resources/deep-guides

DEEP produces a series of guides for organisations and communities who want to work well with people with dementia and support their involvement. These include titles such as Dementia-friendly tips for employers, Choosing a dementia-friendly meeting space and Involving people with dementia at conferences and events.

Dyscover Aphasia Charity, Aphasia – What a difference some help makes (video)

<https://www.youtube.com/watch?v=KWVoqM9jmEM>

Gov.UK – Dos and don'ts on designing for accessibility

<https://accessibility.blog.gov.uk/2016/09/02/dos-and-donts-on-designing-for-accessibility>

Scope Aust – Are you Communication Accessible? (video)

<https://www.youtube.com/watch?v=egpDZSxDZUc>



Place – working in local communities

Alzheimer's Society resources

Dementia-friendly business guide – How to do an audit

alzheimers.org.uk/business

A more in-depth guide and checklist focusing on internal spaces including toilets, navigation, lighting, flooring and entrances, as well as external places including car parks.

Dementia-friendly signage

alzheimers.org.uk/downloads/download/2055/dementia_friendly_signage

This signage can be downloaded and printed to help make your environment dementia friendly.

Other resources

The Stirling standards for dementia-friendly design

www.dementiaaction.org.uk

A person-centred approach for dementia-friendly design developed by the University of Stirling Dementia Services Development Centre.

Practical guidance

Dementia friendly environments checklist

www.dementiaaction.org.uk/assets/0000/4334/dementia_friendly_environments_checklist.pdf

Based on work by Innovations in Dementia, this simple checklist looks at physical features such as signage, lighting, and more. Use it to assess small changes in your organisation's public spaces which may make a positive difference to your employees or customers.

Recognition

Alzheimer's Society resources

Building dementia friendly communities: A priority for everyone

alzheimers.org.uk/site/scripts/download_info.php?fileID=1916

Dementia Connect Online Directory

alzheimers.org.uk/dementiaconnect

Services directory for people affected by dementia.

Volunteering opportunities

alzheimers.org.uk/volunteer

Other resources

Dementia Action Alliance

www.dementiaaction.org.uk

Other useful organisations

The following organisations can offer guidance or resources for managers. The list can also be used to direct a staff member with dementia, or who cares for someone with dementia, towards sources of support and advice.

General

ACAS

www.acas.org.uk

Telephone: 0300 123 1100 (Helpline)

Textphone: 18001 0300 123 1100 (Helpline)

Age UK

www.ageuk.org.uk

Alzheimer's Scotland

www.alzscot.org

Business Disability Forum

www.businessdisabilityforum.org.uk

Carers Trust

www.carers.org

Carers UK (and Employers for Carers)

www.carersuk.org

CIPD (Chartered Institute of Personnel and Development)

www.cipd.co.uk

Citizens Advice Bureau

www.citizensadvice.org.uk

Dementia Action Alliance

www.dementiaaction.org.uk

Dementia Friends

dementiafriends.org.uk

Dementia Services Development Centre

www.dementia.stir.ac.uk

Dementia UK

www.dementiauk.org

Department for Work and Pensions

dwp.gov.uk

Employers for Carers

www.employersforcarers.org

Rare Dementia Support

www.raredementiasupport.org

Inclusive Employers

www.inclusiveemployers.co.uk

Lewy Body Society

www.lewybody.org

Local Government Association

www.local.gov.uk

Public Health England

www.gov.uk/government/organisations/public-health-england

YoungDementia UK

www.youngdementiauk.org

References

Age UK (2017). Causes of hearing loss.

www.ageuk.org.uk/health-wellbeing/conditions-illnesses/hearing/causes-of-hearing-loss

Age UK (2015). Later life in a digital world. www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Later_life_in_a_digital_world.pdf?dtrk=true

All-Party Parliamentary Group on Nuisance Calls (2013). Inquiry into the unsolicited marketing industry 2013.

Alzheimer's Society (2013). Building dementia-friendly communities: A priority for everyone.

Alzheimer's Society (2014). Dementia UK: Update.

British Standards Institution BS 18477: 2010. Inclusive service provision
Citizens Advice's 'Access for all: the importance of inclusive services.

Centre for Economics and Business Research (2014). Cost of dementia to English businesses.
<https://cebr.com/reports/cost-of-dementia-to-business>.

Employers' forum on disability (2010). Your call is important to us: Improving access to contact centres.

The Equality Act 2010. www.legislation.gov.uk/ukpga/2010/15/contents

Financial Conduct Authority (2015). Occasional Paper no.8: Consumer Vulnerability.

Financial Times (2014). Businesses lose out by neglecting dementia pound.

KPMG (2016). Millennials v Grey Pound – Who holds the key to future retail success? www.home.kpmg.com/uk/en/home/media/press-releases/2016/05/millennials-v-grey-poundwho-holds-the-key-to-future-retail-succ.html

Lewis, A (2015). Designing for an imagined user: Provision for thermal comfort in energy-efficient extra-care housing, *Energy Policy*, 84, 204–212.

Ofcom (2017). Review of the General Conditions of Entitlement: Statement and Consultation.
https://www.ofcom.org.uk/_data/assets/pdf_file/0026/106397/Statement-and-Consultation-Review-of-the-General-Conditions-of-Entitlement.pdf

Ofgem (2017). Vulnerable Customers in the retail energy market https://www.ofgem.gov.uk/system/files/docs/2017/10/consumer_vulnerability_report_web_003.pdf

Ofwat (2015). Affordability and debt 2014–15. <https://www.ofwat.gov.uk/publication/affordability-and-debt-2014-15>.

Ofwat (2016). Vulnerability focus report. <https://www.ofwat.gov.uk/publication/vulnerability-focus-report>.

Ofwat (2016). Vulnerability report practitioners' pack. <https://www.ofwat.gov.uk/publication/vulnerability-practitioners>

Ofwat (2017). Vulnerability. <https://www.ofwat.gov.uk/regulated-companies/vulnerability>

Office for National Statistics (2015). National population projections for the UK, 2014-based.

Office for National Statistics (2016). Internet users in the UK: 2016.

Trading Standards, (2013). Trading Standards Pilot in Angus Council to reduce unwanted phone calls to older and more vulnerable consumers.

UK Regulators Network (2015). Essential services: getting extra help.
<http://www.ukrn.org.uk/wp-content/uploads/2016/07/UKRN-accessibility-leaflet.pdf>

Van Hoof, J, Kort, H.S.M, Hensen, J.L.M (2008). Thermal comfort and HVAC design for people with dementia, Proceedings of the International Federation on Ageing's 9th Global Conference on Ageing, Montréal, Canada, Saturday 6 September 2008. Available at www.janhensen.nl/publications_folder/08_ifa_montreal_hoof.pdf

YouGov (2015). Concerns about later life. <https://yougov.co.uk/news/2015/07/26/alzheimers-greatest-concern-over-60s/>



**Alzheimer's Society is the UK's leading dementia charity.
We provide information and support, improve care, fund research,
and create lasting change for people affected by dementia.**

If you have any concerns about Alzheimer's disease or any other form of dementia, visit **alzheimers.org.uk** or call the **Alzheimer's Society National Dementia Helpline** on **0300 222 1122**. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

Alzheimer's Society

43–44 Crutched Friars
London EC3N 2AE

0300 222 1122

info@alzheimers.org.uk
alzheimers.org.uk

Code 888



Registered charity no. 296645. A company limited by guarantee and registered in England no. 2115499. Alzheimer's Society operates in England, Wales and Northern Ireland.