

# Retail therapy

Helping people with  
dementia enjoy spending



Community

Prevention

Inequalities

Life expectancy

Economy

Finance and wealth

## Acknowledgements

This report is the result of a year-long programme of work engaging people with dementia, retailers and policy experts across the country to understand the barriers people with dementia face on the high street, and develop innovative solutions to bridge this gap. This involved:

- Quantitative research to determine the gaps in spending and the economic opportunities for retailers to better engage people with dementia
- A literature review and in-depth interviews with people affected by dementia and their carers to understand key barriers faced
- Two focus groups with industry and policy experts to gather best practice and understand barriers for retailers to adapt shopping environments for inclusivity
- An innovation forum to develop robust and innovative solutions – from tech to regulatory and policy solutions

For more information on methods, please see the appendix.

The "Spending with dementia" project has been supported by abrdn Financial Fairness Trust.

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## Executive summary

In the UK, an estimated 900,000 people are currently living with dementia. That number is set to almost double – to 1.6 million people – by 2040.

Around two-thirds of people with dementia continue to live in the community. Getting out and about can give them a sense of purpose and reduce the risk of social isolation.

Shopping is among the favourite activities named by people with dementia – it's shown to help improve their health and wellbeing. But they currently face significant barriers that make it hard to spend their money on the products and services they want.

Research by the Alzheimer's Society has shown that **1 in 4 people with dementia give up shopping post-diagnosis** and around **63% believe shops aren't doing enough to help people with this condition**. Our report seeks to find out why.

We know that older people already 'under-consume' - they spend a smaller proportion of their disposable income than at other ages- and too often face barriers when trying to shop. In this report we explore the specific barriers faced by people with dementia and their carers. Addressing these barriers is vital in the context of an ageing society – and as part of wider efforts to realise the **longevity dividend**.

We found that the UK economy would see a considerable boost if we were able to help those with dementia spend their money more easily. **We estimate that consumer spending could go up by £948 million each year if our spending environments were more welcoming to people living with dementia and other cognitive impairments.**

This means that ensuring high streets and other spending environments are more dementia-friendly isn't just a nice-to-have. As more and more of us live with dementia, there's huge value in helping customers with dementia to spend more easily. And making places more inclusive and accessible will make access to products and services more welcoming for all.

This report draws upon insights from a range of sources, including people with dementia, their carers, and professionals working in retail, hospitality, transport, and dementia care/research.

Over the past year we carried out a range of interviews, focus groups and roundtables to gather insights and information. What we've heard makes it clear that action is lagging.

Our research identified six key issues which create barriers to spending for people with dementia:

**1. Difficulties getting out and about**

- People with dementia are often forced to give up driving and can struggle to use public transport and engage in active travel.

**2. Not feeling like they can buy what they want and need**

- People with dementia can struggle to navigate and make informed choices in online and offline retail environments.

**3. Feeling misunderstood or disrespected when out and about**

- People with dementia told us that staff and members of the general public can make them feel uncomfortable and act as a barrier to their enjoyment of retail and leisure.

**4. Feeling anxious about navigating retail and leisure environments**

- Busy and over-stimulating environments in some retail and leisure settings can be overwhelming for people with dementia. Poor signage and bad design can create major barriers to access.

**5. Low confidence in accessing and managing financial services**

- Access to money is vital for people with dementia, but they can face barriers to engaging with financial services; there are particular risks for people with dementia in buying financial products and services.
- Those without a Lasting Power of Attorney (LPA) face significant challenges, and inflexible and inconsistent approaches to those with an LPA can make it hard for carers to support them effectively.

**6. Challenges paying for goods and services**

- People with dementia can struggle with payment, leading to confusion, frustration and embarrassment.

- While many people with dementia find contactless payment very helpful, differing payment limits can cause confusion.

*'If we are able to do better for people with dementia, we can do better for so many people with disabilities'*

(Disability Manager: retail sector leader)

## Recommendations

We identify three areas for action to make shopping and leisure venues more accessible for people with dementia and cognitive impairments, many of which could also be helpful for older people and those with physical impairments too. The areas are:

- **People:** we must ensure that people with dementia can access support from people who understand their condition, and who are equipped to help when they go out and about.
- **Infrastructure:** we must build **physical and digital infrastructure** that's inclusive for the growing number of people living with dementia; we must also create the right **legal structures** to enable them to live well.
- **Technology:** we must harness the potential of existing and emerging technology to make life easier for people with dementia and their carers.

With regard to **people**, we need action to:

- **Ensure staff in retail and leisure settings are available and equipped to support people with dementia.** For example:
  - o The Government should convene leisure and retail providers to work with dementia charities, to **develop enhanced training for staff who work with people with dementia**. This should include minimum mandatory training standards for customer-facing staff in regulated industries.
- **Make it easier for people with dementia to find support.** For example:
  - o The Government should convene retail and leisure providers, regulators and dementia experts to **develop a 'kitemark' system to accredit those online and offline retailers and leisure providers who sign up to a minimum standard of support for people with dementia**.

- o Retailers and hospitality venues should provide 'relaxed environments /days / showings' (drawing on the model of 'slow shopping') as a matter of course.
- **Develop the future workforce (including volunteers) to be fit for a future where more people are living with dementia, including enabling more people with dementia to work and volunteer.** For example:
  - o Town and shopping centre managers should work with dementia experts to consider how to train future staff and the volunteer workforce to better support people with dementia.

With regard to **physical, digital and legal infrastructure**, we need action to:

- **Implement dementia-friendly design across new retail and leisure environments, online and offline, and adapt and retrofit existing environments to be more dementia friendly.** For example:
  - o Regulators should work with dementia experts to develop and adopt standards for dementia-friendly design, as part of wider inclusive design principles.
- **Get the legal framework right to support people with dementia.** For example:
  - o The Government should conduct a **review of legislation surrounding LPAs** to consider whether procedures could be simplified, and to explore the potential for new processes which would enable people with dementia and their carers to share decision making.
  - o The Government and NHS should work together with dementia experts to **identify effective ways to 'nudge' people towards setting up an LPA.**

With regard to **technology**, we need action to:

- **Make existing technology more accessible and useable.** For example:
  - o The UK Payments System Regulator should allow customers with dementia and other cognitive impairments to **personalise contactless debit card limits with all banks**, including setting their own payment limits.

- **Build on existing and emerging technology to support living well.** For example:
  - o Developers should work with dementia experts to **develop a 'digital lanyard'** to help frontline staff identify customers with dementia and cognitive impairment, and to relieve those customers' concern over being visibly identified.
- **Encourage innovation for the future.** For example:
  - o The Government should use its convening power to **bring together technology investors and entrepreneurs** to consider the potential for new developments to support people with dementia.

Making change in these areas will require the Government, regulators and businesses to work together with dementia experts – including people with dementia and their carers - to improve the use of data, create clearer standards, and develop shared infrastructure. The Government must use its convening and regulatory power to encourage the changes needed.

Making change now will allow people with dementia to spend independently for as long as possible, help them and their carers to live better lives, and help the population as a whole enjoy 'retail therapy'.



## About the report

This report is the result of a year-long programme of work engaging people with dementia, retailers and policy experts across the country to understand the barriers people with dementia face on the high street, and develop innovative solutions to bridge this gap. This involved:

- Quantitative research to determine the gaps in spending and the economic opportunities for retailers to better engage people with dementia
- A literature review and in-depth interviews with people affected by dementia and their carers to understand key barriers faced
- Two focus groups with industry and policy experts to gather best practice and understand barriers for retailers to adapt shopping environments for inclusivity
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The "Spending with dementia" project has been supported by abrdn Financial Fairness Trust.

## Why support spending by people with dementia?

The Alzheimer's Society estimate that around 900,000 people are currently living with dementia in the UK<sup>1</sup>, and one in every three people in the UK aged 80 and over lives with dementia.<sup>2</sup> By 2040 the number of people with dementia will almost double – reaching 1.6 million people.<sup>3</sup> And as two-thirds of those with dementia live within the community, helping them continue to live well should be a community effort.

People with dementia make up a significant and growing proportion of the consumer market. The so-called 'dementia pound' (the spending power of households affected by dementia) in the UK is set to be worth £22.7 billion by 2030.<sup>4</sup> Our analysis shows that **helping them spend the way in the ways they'd prefer could raise the UK's consumer spending figures by between £110 million and £1.6 billion each year.**

Household spending is the largest component of aggregate demand in the UK. The distribution of different ages in a country's population affects consumption patterns and is a crucial determinant of GDP. Older households (those led by someone aged 50 or over) already dominate consumer spending in the UK; by 2040, 63 pence in every pound could be spent by older households.<sup>5</sup>

However, at present, once someone receives a dementia diagnosis, their spending tends to drop. **Nearly 1 in 4 people with dementia give up shopping post-diagnosis.**<sup>6</sup> With over 42,000 people under 65 living with dementia<sup>7</sup> this equates to many years of lost shopping. At the same time **63% of people with dementia believe shops aren't doing enough to help people with this condition.**<sup>8</sup>

This failure not only costs our economy, but also affects people with dementia and their carers, as they miss out on goods, services and activities that they need and enjoy.

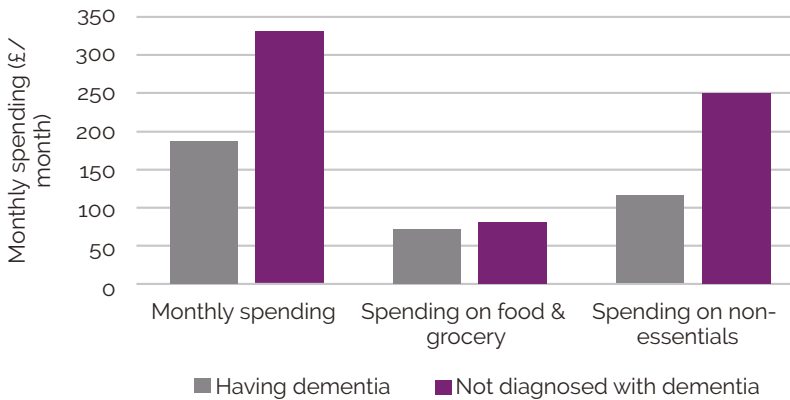
As a growing number of people are living with dementia, it's vital that policy makers and retailers respond to their needs and aspirations.

## Realising the economic opportunity

At present, **older people with dementia or cognitive impairment spend less than those with 'normal' cognition** of the same age. Using our own modelling, we found that **cognitive impairment is strongly related to lower spending**.

In England, **individuals aged 50 and over who are living with dementia spend much less than those who aren't**. The difference is especially marked for non-essential spending.

**Figure 1: Monthly spending by dementia status**



People with better self-rated cognitive abilities spend more on leisure and non-essential goods. Those who report their mental abilities as “poor” spend 58.2% less on leisure, 51.4% less on non-essentials and 38.7% less in total than those who feel that they have excellent mental abilities.

Other factors, such as age, income, mobility, internet access and access to a car, further influence spending. For example, previous ILC research has demonstrated that **poor mobility drives down spending** – spending by people aged 75 and over with a walking impairment is 10.9% lower than that of those without.<sup>9</sup> Helping people with dementia get out and about and spending will also help others who face barriers to accessing the high street.

We predict that the difference in spending between those with severe cognitive impairment and those without will grow by 93% over the next three years. If nothing else changes, the cost to the our economy will be enormous.

When the further impact of reduced spending among those with mild cognitive impairment is considered, the case for action is clear.

## **Helping people with dementia have a good life**

Making it easier for people with dementia to continue spending post-diagnosis will not only boost the economy but can also help improve their health and wellbeing, providing them with a sense of purpose and an opportunity for social interaction.<sup>10</sup>

*“I know from experience that [my father] continuing to engage with the world as much as he could, and doing things, rather than giving up, meant that he did live well... I mean he died with a smile on his face in his own home, which is what he wanted... I know that was due to a large part of him trying to keep engaged with the world...”*

(Focus group participant: cared for her father who had dementia)

Many people with dementia find going shopping in person important for their wellbeing, mental health and self-esteem. It can be especially important for people who've had to give up other activities they previously enjoyed. Many people with dementia value their independence and try hard to continue to shop regularly even as other activities become more difficult.

The same is true of continuing other leisure activities that involve consumption – such as going out to eat, to pubs, or to the cinema. These activities offer opportunities to stay active, stimulated and engaged and can offer a sense of purpose and wellbeing.

However, in our discussions with shop staff we heard that they had seen fewer customers with dementia in their stores since the country returned to shopping after the lockdowns of the COVID-19 pandemic.

Enabling more people with dementia to get out and about and spend their money on things they enjoy and value is therefore a critical part of supporting them to live well with dementia.

## **Striking a balance**

Throughout our discussions with people with dementia and their carers, and with people involved in the retail and leisure industries, it's been clear that there's a balance to be struck between enabling people with dementia to continue to spend their money as they see fit (including in ways that may appear unwise to others), and protecting people who no longer have mental capacity.

Our discussions suggest that at present, people with dementia are generally excluded from retail and leisure environments before they're ready to stop spending and going out, and that the impacts on their wellbeing are significant.

Under the Equality Act, people with dementia have the right to access goods, facilities and services; the Act requires that reasonable adjustments be made to support their access. But our retail and leisure environments currently fall short of these standards too often. As a result, people with dementia, their carers and the wider economy suffers.

While safeguarding people is, of course, vital, the need for protection must be balanced against individual freedoms. In this report we explore how more could be done to help people with dementia retain these freedoms for as long as possible.

## Public policy context

Neurological conditions, which include dementia, are now the leading cause of death in the UK.<sup>11</sup> And, as noted above, the numbers of people with dementia are expected to grow significantly in the years ahead.

In recognition of this reality, David Cameron's government set up the Prime Minister's Challenge on Dementia in 2012 to address what he described as "one of the biggest global health and care challenges – a challenge as big as those posed by cancer, heart disease and HIV/AIDS".<sup>12</sup>

The Prime Minister's Challenge aimed to deliver improvements in health and care, create dementia-friendly communities, increase the number of Dementia Friends<sup>a</sup> and boost dementia research. The second Challenge in 2015 proposed that by 2020, England would be:

- The best country in the world for dementia care and support, for carers and those diagnosed alike
- The best place in the world to undertake research into dementia and other neurodegenerative diseases

However, while the issue of dementia has risen up the political agenda in recent years, there remains a gap between rhetoric and reality. And a lot of Government funding has gone towards medical research, rather than towards helping those with dementia to live well.

The majority of people with dementia are supported by the social care system, which is significantly underfunded. The means-tested approach to social care requires those with assets greater than £23,250 to pay for their own care as 'self-funders'.<sup>13</sup> Around two-thirds of the total cost of dementia care in the UK is paid for by self-funders.<sup>14</sup> On average, a person with dementia pays £100,000 for care over their lifetime.<sup>15</sup>

Despite a longstanding recognition of the need for a fairer social care funding system, progress remains stalled. At the same time the social care budget – held by local authorities but largely funded by central Government – has shrunk, leaving a growing funding gap. The Health Foundation estimates this gap will amount to a figure between £6.1 billion and £14.4 billion by 2030/31.<sup>16</sup>

<sup>a</sup>An Alzheimer's Society initiative that gives participants information about dementia, allowing them to help people with dementia in their community.

In 2021, the Johnson government announced plans for a health and social care levy.<sup>17</sup> A 1.25% increase in National Insurance payments was intended to provide additional funding for social care. However, plans for the levy were scrapped in 2022. At the time of writing only an additional £500 million has been promised for social care.

The inadequacies of the social care system mean that unpaid and family carers are the mainstay of support for many people with dementia. In our research we saw the vital role that carers play in supporting people with dementia to continue activities that they enjoy – including retail and leisure spending. Unpaid carers save the UK economy £13.9 billion annually,<sup>18</sup> but carers are often under-supported and can experience negative consequences such as psychological/physical morbidity, social isolation, and financial difficulties. Carers are also more likely to drop out of the workforce early as they struggle to combine their caring responsibilities with work and other commitments.

## **Government priorities**

While over recent decades governments have voiced support for people living with dementia, the main investments made under the Prime Minister's Challenges have been in the area of bio-medical research. While this is vitally important, support for the 900,000 already living with this condition continues to lag. The ongoing context of austerity, now being compounded by the cost of living crisis, means that the challenges faced by people living with dementia have only grown as support from statutory and voluntary sector providers has been cut back.

In 2019 the Conservative manifesto promised a 'Dementia Moonshot' which would double spending on dementia over the next 10 years, to reach a total of £800 million. However, these pledges have yet to be reflected in annual budgets. Recently the Alzheimer's Society has publicly called for action on the barriers to living well with dementia, alongside work on treatment, diagnostics and care.<sup>19</sup>

## **Living well with dementia**

Work on living well with dementia has primarily been led by voluntary sector organisations – for example through the Dementia Friends initiative, which received Government support via the Prime Minister's Challenge. Developed by the Alzheimer's Society, this initiative aims

to give participants a better understanding of how dementia affects people, equipping them with knowledge to assist those with the condition in everyday situations.<sup>20</sup>

The Society's 'dementia-friendly communities' initiative has also encouraged work to support dementia inclusion by involving local government, shops and community hubs in working together to create environments that are welcoming and understanding of those with dementia.<sup>21</sup> In 2020, there were approximately 350 dementia-friendly communities in the UK,<sup>22</sup> and over 2.5 million people registered as Dementia Friends.<sup>23</sup>

## Supporting innovation

In October 2022 the Alzheimer's Society, together with Innovate UK and Challenge Works, launched a new Longitude Prize on Dementia. The aim is to encourage creation of personalised, technology-based tools that are co-created by those living with early-onset dementia. The £4.1 million prize is designed to encourage the development of new technology to support living well with dementia.<sup>24</sup>

## Dementia and businesses

The Prime Minister's Challenge envisaged the creation of 4 million Dementia Friends by 2020<sup>25</sup>; it intended these people to be the key vehicle through which businesses would become more dementia-friendly. The Challenge asked businesses to integrate Dementia Friends training with other mandatory training. However the Government has failed to support businesses in implementing this plan. It has failed to create a proposed central online dementia information hub for businesses, and has not measured the increase in Dementia Friends across FTSE 500 businesses.<sup>26</sup>

Again, work has been led by the voluntary sector and trade bodies. For example, the Alzheimer's Society released a *Dementia-friendly retail guide* in partnership with the Association for Convenience Stores (ACS), which offers shops guidance on making staff, store environments and facilities more accessible to those with dementia.<sup>27</sup>

## Legal framework

### Inclusion

People with dementia have a right to inclusion under the 2010 Equalities Act. The Act requires businesses to make reasonable



adjustments for people with disabilities; it also establishes age as a protected characteristic.<sup>28</sup> However, despite the Act, people with dementia and their carers continue to face discrimination.<sup>29</sup>

## Protecting people with dementia

While the Equality Act secures people's right to access goods and services, as noted above people with dementia may also need protection in retail and leisure environments, particularly when they no longer have the mental capacity to make decisions.

Customers with dementia can be particularly vulnerable when purchasing financial services or products. The Financial Conduct Authority (FCA) recognises this and provides guidance for financial organisations working with 'vulnerable customers', as part of their consumer priorities.<sup>30</sup> The FCA highlights three key actions firms should take to ensure they are treating vulnerable customers fairly:

- Understand the needs of vulnerable customers
- Ensure frontline staff have the necessary skills and capabilities to respond to a range of vulnerabilities
- Taking practical action to ensure that communication, customer service, and product and service design are accessible to all

The FCA recommends that businesses internally monitor their ability to meet these criteria.

Once diagnosed with dementia, and as their condition develops, individuals are at risk of losing their mental capacity and not being able to make informed decisions. The Mental Capacity Act 2005 provides a statutory framework around decision making by and on behalf of people who lack, or may lack, capacity.<sup>31</sup> The Act has three broad objectives:

- To support people with impaired capacity so that they can make decisions for themselves
- Where they can't take a particular decision for themselves, to provide them with a protective framework for others to make decisions about them
- To provide a framework for those who have to make and implement decisions in relation to people who don't have the capacity to make those decisions themselves

The Act established provisions under which a designated decision-maker can act on behalf of someone who lacks capacity. The mechanisms for this are:

- **Lasting Powers of Attorney (LPAs):** an individual can nominate an attorney to act on their behalf if they should lose capacity in the future. Attorneys can be nominated for financial and health decisions.
- **Court-appointed deputies:** deputies can take decisions on welfare, healthcare and financial matters as authorised by the court; they're only appointed if the court can't make a one-off decision to resolve the issues.

The Care Act 2014 also established new systems for safeguarding adults.<sup>32</sup>

## What prevents people with dementia from spending?

People with dementia and other cognitive impairments face a number of barriers to shopping and leisure activities, both in the high street and online. In this report we look at a range of key issues raised by participants in our interviews, focus groups and round tables. In the following sections, we look at some of the specific barriers and how these affect people with dementia and their carers, consider what's already being done to address these issues, and identify where the gaps are. We then explore the key areas for action.

People with dementia and their carers told us they faced a number of key challenges:

- Difficulties getting out and about
- Not feeling like they can buy what they want and need
- Feeling misunderstood or disrespected
- Feeling anxious about navigating new environments
- Low confidence in accessing and managing financial services
- Challenges paying for goods and services

## Getting out and about

If people with dementia are to continue to enjoy retail and leisure activities, they need to feel confident in getting out and about. However, at present they can face challenges making their way to shopping and leisure destinations, whether by public transport, private car, or on foot.

Key barriers include:

- No longer being able to **drive**
- Lack of confidence in **accessing public transport**
- Problems with **getting lost or disorientated** while travelling on public transport, or actively by bike or on foot

*"I have become less confident going out because just before the diagnosis, I was tripping up a lot. And I'm just a bit edgy going out on my own. You know, I'm just a bit bothered that I would fall..."*

(Interview participant: living with dementia)

Among the people with dementia that we spoke to, some were entirely dependent on carers to leave the house and those without family members living nearby often struggled to get out at all.

### Driving

Although one in three people with dementia in the UK still drive, as symptoms become more severe, they affect the skills required for driving safely. This can mean that driving may eventually become impossible.<sup>33</sup> Giving up driving can be a very difficult experience for any older person, leading to a loss of independence, which in turn has a real impact on wellbeing<sup>34</sup>.

In addition, carers told us they face barriers when going out by car with loved ones who have dementia, in particular:

- **Inability to find parking spaces** on local high streets
- **Narrow parking spaces** that make it difficult to get in and out of a car

Blue Badges, which allow drivers to access disabled parking, etc, are available for people with severe mobility problems. As dementia can affect balance, coordination and spatial awareness some individuals with dementia do have access to the badge<sup>35</sup>, but we heard that

some carers had struggled to get a Blue Badge for themselves or their loved ones.

## Active travel

We also heard about challenges travelling by bike, including:

- Forgetting a bike left outside shops
- Being unable to carry shopping while travelling by bike
- Challenges in navigating new or unfamiliar road layouts

One carer told us their loved one had ended up cycling down the motorway because the road layout had recently changed.

We also heard about challenges when travelling on foot, including:

- Physical challenges walking even short distances
- Challenges with becoming lost and struggling to ask for help or describe their locations

## Taking public transport

The challenges of driving and active travel mean that public transport can be vital for people with dementia, but this can also be daunting.

*“...after fairly early on, she didn't use public transport by herself.”*

(Interview participant: carer for partner with dementia)

The Alzheimer's Society found that, before the pandemic, 1 in 4 disabled people were prevented from using public transport due to negative attitudes from other passengers.<sup>36</sup> For those living with dementia, this is only one of the many reasons why they may no longer take public transport. Other key challenges include:

- **Busy, noisy environments with high levels of audio-visual information** that can increase cognitive load, resulting in disorientation and high levels of stress
- People can find it **difficult to plan journeys and purchase the correct tickets given multiple options**: this is exacerbated by inconsistency in ticket machine interfaces across different transport systems
- **Increased automation on transport systems**, which can pose a challenge for those who rely on human interaction to overcome their confusion when making decisions

- **Uneven surfaces and limited seating** that create mobility barriers

In our discussions we also heard that missing the right stop or getting on the wrong bus could be a significant issue. Our research participants told us that bus timetables could be confusing, and that increasingly, they're only provided digitally, leaving those who don't have access to a smart device without information.

In some places, particularly rural areas, infrequent bus services can make it difficult to use public transport to access leisure activities, or go shopping.

*“Trying to understand bus timetables... [it's] too much information – information overload – it is really overwhelming and difficult for people with dementia to understand...”*

(Interview participant: former carer at a retirement home).

While some participants in our research had positive experiences of **community transport schemes**, others still faced barriers around understanding timetables etc.

## Buying tickets

The ticket purchase process was a source of stress across all modes of transport: some of our respondents with dementia reported that buying online was particularly confusing.

Travel companies told us that they encouraged passengers to book online before travelling in order to minimise confusion at the station, but online purchasing processes are often off-putting, due, for example, to the large number of questions to answer and options to choose from.

*“Going to buy a ticket in advance, you know, they're asking you all sorts of questions... do you want to travel going forwards or backwards? Do you want to sit with a table? Panic! All these things affect you with dementia! Whereas before, if I think back, it wouldn't been anything - I would have flown through all that no problem at all”*

(Interview participant: living alone with dementia)

## Long distance journeys

People with dementia also told us they faced challenges with long distance travel.

Studies have found that air travel can be one of the most daunting tasks for people with dementia.<sup>37</sup> Train stations and airports are busy, noisy and unfamiliar environments, with an overload of available information.

***“One lady lost her husband with dementia in the airport, and took a couple of hours to find him again... they missed his flight... if you do get separated, it is such a busy complex environment, and sheer volume of people... it can be really difficult to reunite people.”***

(Focus group participant: Diversity, Equity and Inclusion manager at an airport)

But overall, participants in our research had somewhat more positive experiences in airports than with trains. Some of those with dementia who had to make long train journeys by themselves mentioned feeling anxious about making connections or getting on the wrong train.

***“I’ve started to go and I meet my other daughter in York as well. So when I go there it terrifies me, especially if I’ve got to change trains, that’s horrible.”***

(Interview participant: living alone with dementia)

## **Existing solutions**

As noted above, Blue Badge schemes should be made available to *all* people with dementia; schemes like this can enable people with dementia and their carers to travel by car for longer.

Some communities are also doing innovative work to provide more support for people with dementia when they travel in their local areas. These are often part of dementia-friendly communities initiatives. They may include offering dementia awareness training to retail and travel staff, and implementing card systems or other mechanisms through which people with dementia can signal a need for additional support.

Some bus and train companies are also seeking to implement dementia-friendly design principles as part of a wider commitment to accessibility. For example, Network Rail’s design manual for creating inclusive environments highlights people with dementia as a key group to consider when thinking about inclusive design.<sup>38</sup>

## Good practice: a dementia-friendly rail route

Arriva Rail Northern has worked with the Alzheimer's Society and other organisations to take practical action, creating a dementia-friendly railway route on the Bentham line between Leeds and Morecambe.<sup>39</sup> The partnership held workshops for frontline staff on the Bentham line, as well as apprentices and year-in-industry students, British Transport Police, and other rail stakeholders.<sup>40</sup> The partnership carried out audits at the stations along the line, identifying ways to simplify buying tickets, displaying information and navigating platforms. It also organised dementia-friendly walks along the Bentham line to complement the journey. The project's success attracted interest from several other train companies, who have shown interest in replicating this in their own areas.

Most train operating companies also currently offer: assisted travel for people with cognitive disabilities; the option to book a member of staff to accompany passengers with dementia on train journeys; and support for those travelling with a carer. Operators also make physical copies of timetables available.

Similarly, airport operators have taken steps to put more support in place for people with dementia. Our participants with dementia and their carers told us that the support they valued included:

- **Personal wheelchair assistance** from the point of arrival to boarding the plane
- **Help points** where customers can push a button and be met by a trained member of staff
- **Special assistance lanes** that permit passengers to go through security at a slower pace, ensuring carers aren't separated from their relatives

Guidance from the UK Civil Aviation Authority sets out standards for supporting people with non-visible disabilities such as dementia. This states, for example, that people with dementia shouldn't be separated from their companions at the airport or in flight.<sup>41</sup> However in practice, our participants found these standards weren't always met.



***“...the one thing I hated was coming back through passport control, because invariably, one passport would not be read, so we're on two different sides there and that's not a good idea.”***

(Interview participant: carer for partner)

However, people with dementia and carers often aren't aware of the available options; some of our participants also reported not being able to get the support that should be available. For example, one participant described being unable to get on a train because rail staff were only allowed to support one disabled person at a time.

Train operators recognised that low awareness was a challenge:

***“...it's very likely that some customers are not aware of that support and therefore don't feel safe enough to take the train... it's a common challenge for customers with many disabilities, because either they've heard horror stories, and therefore they don't want to travel because they think it will happen to them, or they've been on one journey, and they've had one bad experience.”***

(Focus group participant: Diversity and Inclusion manager for a rail operator).

## Buying what we want and need

People with dementia enjoy shopping: participants in our research were clear that they valued having the choice to shop both online and in-person. However they can sometimes have difficulty finding the items they want to buy and may need support as they shop.

At the same time, carers of people with dementia told us they can feel torn between their loved ones' desire to shop independently and the additional security and ease of taking over and shopping for them.

Many participants also raised the need to manage the financial risk involved when loved ones with dementia shop by themselves.

### Shopping in person

People with dementia and other cognitive impairments can face problems when shopping in person, which include:

- Difficulties **making informed choices** when shopping
- **Struggling to find items** in a store, with similar-looking aisles making it hard to navigate stores and find products
- Struggling to **articulate what they want to buy** to staff
- Being overwhelmed by **too many options**
- **Buying items they don't need**, such as food for a cat they don't have
- **Forgetting what they've added to their basket** – leading to missing or multiple items<sup>42</sup>

*“Some customers forget why they've come in and what they need... they try and describe what they need – but [don't] always makes sense...”*

(Interview participant: frontline retail professional)

Some people find that their dementia affects them in ways that can make shopping particularly challenging, and even risky. For example, studies show that frontotemporal dementia is associated with poor impulse control, such as excessive spending and compulsive shoplifting.<sup>43</sup>

Some other people with dementia 'shoplift' without understanding what they're doing. Customers with dementia may forget to pay

for items. Our participants said this was more likely to occur when using self-checkout machines, and retailers noted a significant rise in people forgetting to pay at these checkouts. If not handled sensitively, these situations can be traumatic, and make people reluctant to shop alone, especially if the police are involved:

***"... often, people will use self-service checkout, they'll tap their card, assume that that's gone through and paid, and then they walk out, it's called a walk off."***

(Interview participant: policy manager at a chain of small retail stores)

***"...the alarms went off – and mum got in a horrible state at the thought of shop-lifting... it was traumatising..."***

(Interview participant: carer for parent)

***"So unfortunately, [accidentally forgetting to pay] left me a little bit fearful. I know it sounds stupid. It's in the back of my mind that I might do it again."***

(Interview participant: living alone with dementia)

## **Existing solutions**

Some retailers have already taken deliberate steps to make it easier for people with dementia to shop independently – for example by offering 'slow shopping' experiences where staff have more time to offer support (see below), and by training staff to offer support (see ***Feeling understood and respected/Existing solutions/Staff training***). Some retailers have also taken steps to improve the retail and leisure environment (see ***Good practise: 'Dementia Space' pop up***).

## Good practice: 'Slow shopping'

In 2015, Sainsbury's and Tesco announced that they were piloting the idea of 'slow shopping' sessions – a scheme to help older customers and those with dementia and other disabilities enjoy a more relaxed shopping experience. The scheme is intended to replicate the slower-paced, more personal environments of smaller, local shops. Tesco introduced a dementia-friendly checkout for customers in its Chester superstore while Sainsbury's introduced slow shopping in its Gosforth store.<sup>44</sup> Both supermarkets have since extended their slow shopping schemes to include two more stores in Scotland, supported by Alzheimer's Scotland,<sup>45</sup> while Sainsbury's is currently running a trial with Alzheimer's Scotland in partnership with Dementia Friendly Prestwick, with the aim of extending the pilot to other stores.

Customers with dementia who shopped alone **valued staff members that would act as a 'personal shopper'**, accompanying them around the store and helping them to find and purchase the items they want. This one-to-one assistance is often taken on informally. Those with dementia highlighted that if a member of staff is patient and willing to guide them through the shop, it significantly improves their confidence. The most important aspect was that staff led with kindness and understanding.

The retail professionals we spoke to acknowledged that the way in which staff interacted with customers was key to the experience of people with dementia. Kind and helpful interactions could make a huge difference in facilitating independent shopping. We discuss the need for staff training in ***Feeling understood and respected/Existing solutions/Staff training***.

However, we heard that offering a personal service is often easiest in smaller stores where staff know their regular customers:

***"...it's easier to support vulnerable customers as they know them in local stores, say, outside London...it's easier to know how to support the customer in smaller places... [as there's a] greater opportunity to know them in the community..."***

(Focus group participant: Diversity and Inclusion manager for a high street pharmacy)

***“She had the intention of buying something... like cat food – and probably walked out with everything other than what she needed... I want to know that staff can recognise that buying 10 boxes of tea bags might not be normal”.***

(Focus group participant: store manager of a small shop)

We also heard that well-trained and compassionate staff could also play a role in preventing the riskiest behaviours – for example, by identifying customers who might have dementia and offering support before problems arise.

***“We actually haven’t had instances of people going out and not paying because... one of our values is ‘be kind’... that wouldn’t have happened, because we would have been supporting them around the store...”***

(Focus group participant: area manager for a chain of small stores)

The retail professionals we spoke to explained that they normally deal with instances of accidental shoplifting informally, offering reassurance and support. And staff working in smaller shops, told us they managed these behaviours by walking around with customers who may ‘shoplift’, chatting and providing gentle prompts.

***“I once noticed a customer with dementia was shoplifting, I wanted to help her... I said ‘let’s get hold of your family... so they can help you’ and I got in contact with her family. Then she came back with a suitcase with stuff... rather than go down the police route... when you know [a customer], you can follow them around the shop, and keep them distracted, and be aware of what to look for.”***

(Interview participant: frontline professional for a large retail store)

Some of the people with dementia in our research recalled being supported by dementia-aware staff in these kinds of situations.

However, in practice the main way that our participants overcame the challenges of shopping with dementia was through carers accompanying people with dementia to the shops. Unfortunately, because carers often found this experience draining, it meant that they often ended up taking over and shopping on their loved one’s behalf.

## Shopping online

Shopping online can offer the opportunity for people to shop at their own pace and without the anxiety associated with interacting with others. However some people with dementia can be reluctant to use the internet.

Attitudes varied among our participants.

### **Those who shopped online said that they found it relatively easy.**

Some found it helped them retain or regain a sense of independence, for example after having to stop driving.

But **many of our participants with dementia said that they didn't shop online** due to a range of barriers including:

- **Lack of confidence** due to unfamiliar apps and electronic devices
- **Difficulty reading** due to problems seeing and reading the text
- **Design issues** with similar, non-contrasting colours or busy visuals making sites and apps hard to navigate
- An **excess of choice** making the shopping experience confusing

Participants were particularly reluctant to buy groceries online, as they valued being able to see and handle food items. In addition, some felt it was difficult to return unwanted/overpurchased food items online.

In our interview sample, we found that participants with early-onset dementia were more likely to show a preference for shopping online. However, it was unclear whether this was because they were already doing so before the onset of dementia, whether they had more online experience, or whether there were other factors at play.

While shopping online has some advantages, the ease of buying things can put people with dementia who struggle with impulse control and making informed judgements at risk of overspending.

***"I've been doing a lot of online shopping with eBay and Amazon... it's quite easy to go along and do all of that. Then suddenly, you find out that you've overdrawn the account."***

(Interview participant: living with dementia)

Online shopping can't include the prompts from carers or staff that are available when shopping in person. And online advertising can mean that people with dementia are more easily persuaded to buy items they don't want or need.

***“A lot of people purchasing policies do so online, so it’s very, very hard to check capacity: while over the phone, you can hear if someone’s not understanding, but online, you just can’t do that.”***

(Interview participant: manager at an insurance company)

## **Existing solutions**

There are few safeguards in place for people with dementia in the online retail environment. Some carers told us they sought to safeguard loved ones by changing their passwords, but restricting people’s freedom could cause conflict and agitation.

Previous studies have recommended that online retailers should ensure they’re not overstating the benefits of goods targeted at vulnerable customers, such as medical devices.<sup>46</sup> Others have recommended that algorithms could eliminate fake or unregulated health products.

However, while there may be potential to extend these principles to some other products, it will never be possible to regulate all online shopping environments.

## **Avoiding scams on and offline**

***“You know, we found something recently: the direct debit, we don’t know what it was for. But ... payments [have] been going out every month for about six months, for nearly 40 pounds. And when we told the bank, they found that it was going to a bank in Kenya, that apparently collect lottery subscriptions”***

(Interview participant: carer for partner).

Fraud is the most common crime in the UK, and more than half of fraud is cyber-related.<sup>47</sup> People with dementia are particularly vulnerable to fraud as they can find assessing risk and managing their money difficult, especially if they live alone. Age UK found that those who have dementia or reduced cognitive function are most at risk of being victims of financial abuse, compared to any other factor.<sup>48</sup>

We found that it was common for people with dementia to experience doorstep cold calls. They also receive scam postal and phone calls, in which they’re asked to share personal financial information.

One carer described those with dementia as ‘sitting ducks’ to financial abuse, with scammers actively targeting vulnerable people.

Individuals are often multiply targeted, as once they fall victim to one scam, their contact information can be added to lists that are shared between scammers using similar tactics.<sup>49</sup>

We also heard that people with dementia could struggle with excessive mail, even from legitimate companies. This can cause confusion and increase the risk of falling victim to scams, or over-purchasing products. Some participants discussed how their relatives with dementia had signed up to unknown, regular postal subscriptions, which could be scams. These often involved regular small direct debits, too small to draw the attention of banking staff or of carers checking statements.

Some carers said that they regularly went through letters their relative received, throwing away letters from charities asking for money. However many were uncomfortable infringing on their loved ones' privacy in this way.

Online scams can be particularly dangerous for people with dementia, as they can take place with little input by the person being scammed. Unlike postal or phone scams that coerce financial information out of someone, online scammers can access financial information when an individual clicks on a bogus link, or opens a corrupt file. Once someone clicks on a fraudulent link, it can download malware to their device, which can capture data or even take control of the victim's computer.<sup>50</sup> Many participants mentioned that they were fearful of online banking due to the perceived increase in risk of being victims of a scam.

***"I won't bank online, I don't trust it – because many people get their account hacked... I don't want to come into a situation where I lose all my money..."***

(Interview participant: living with dementia, without a carer)

Promoting digital confidence is key to ensuring that people with dementia can safely manage their money online. Teaching digital literacy is easiest pre-diagnosis, so it's vital that accessible online banking toolkits are geared towards those aged 50 and over.



## Existing solutions

There has been action at both national and local levels to make it harder for scammers to gain access to people with dementia. These include 'No Cold Calling' zones and technology that can block unwanted calls.

Charities that work with older people and those with dementia continue to offer practical advice and guidance on avoiding scams. Advice is also available online.<sup>51</sup>

However, people with dementia, particularly those living alone, continue to be at significant risk from scams.

### Good practice: No Cold Calling Zones

Local authority and police partnerships in the UK are creating No Cold Calling Zones (NCCZ). These aim to decrease doorstep crime incidents by specifying a zone where doorstep callers aren't welcome, identified by door stickers and signage. Each NCCZ is requested by residents who have stated that they don't want unsolicited visits (cold calls) from businesses.<sup>52</sup> An NCCZ can be set up following a consultation process:<sup>53</sup> at least 66% of residents within the potential NCCZ must agree to it being created.<sup>54</sup> NCCZs have been implemented by Hampshire County Council, which collaborated with Hampshire Constabulary and partners. The initiative was found to be successful across Hampshire.

### Good practice: 'trueCall' call blockers

In 2017, the Prime Minister announced a £500,000 project to provide high-tech 'trueCall' devices that block nuisance cold calls for people with dementia and other 'vulnerable' groups.<sup>55</sup> Coordinated by the National Trading Standards Scams Team, the device completely blocked all recorded messages, silent calls and those not from numbers that had been pre-identified by the home owner. The call blockers were reported to block around 99% of unwanted calls. The project ran for under a year and provided over 1,500 homes with 'trueCall' devices:<sup>56</sup> the number of people who felt worried about receiving unwanted calls fell by 60% after using the product.<sup>57</sup>

## Feeling understood and respected

*“I don’t think he wanted ever wanted any drama and attention – during any slip-ups. Other people’s reactions were more of an issue than his own.”*

(Interview participant: carer for parent)

One of the main reasons people with dementia and their carers told us they stopped spending money in ways they had previously enjoyed – such as going shopping or visiting leisure businesses – was because they didn’t feel understood or respected when interacting with staff and the public. Lasting negative experiences can leave people feeling embarrassed, fearful and anxious when leaving the house.

Our participants raised three key areas of concern:

1. Staff awareness and understanding
2. Public reaction and attitudes
3. Having access to non-stigmatising support

### Feeling understood and respected by staff

Research by Anchor found that people with dementia were worried about the ability and willingness of staff to offer support, especially when they:

- Forgot their address
- Forgot where they were
- Couldn’t find the right words to describe what they needed
- Didn’t behave in a “socially acceptable” way.<sup>58</sup>

Our participants with dementia gave a number of examples of when they had felt disrespected by shop staff. We heard that these situations were more likely to occur when they were accompanied by a carer. These included:

- Staff addressing their carers rather than the customer
- Staff turning to carers when the customer needed more time to pay
- Lack of understanding of dementia-driven behaviour, particularly for customers with early-onset dementia

***“Staff can very much think... you're supposed to be helping do it for them. But that's not actually what we're there for. They don't understand that. It's actually better for a person with dementia do it themselves... we're there to support their independence rather than take over... it validates them as a person.”***

(Interview participant: former carer)

***“[We need to] make sure you don't just ignore them and go straight to the carer... obviously you're on minimum wage, so you can't just stop and spend 10 minutes with them... but at least acknowledge that they're there...”***

(Interview participant: frontline staff member at a pub)

Retail professionals recognised that they, and other staff, don't always get it right when they interact with people with dementia. As there are no formalised professional standards relating to the conduct of general retail and hospitality staff, there are wide variations in the level of assistance customers may receive in retail and leisure settings.

Retail professionals told us that high staff turnover in customer-facing roles can be a real challenge – both because it's hard to ensure there are always trained staff available, and because changes at familiar shops can cause anxiety for customers with dementia.

***“It was interesting: even though my teams are really experienced, they still get different areas of comfort zones, when they have... different dementia customers with different stages. They feel a little bit insecure... ‘Am I doing the right thing?’... And a couple of the comments I had were, you know, any help, support, training, guidance, advice, to help all our customers, especially dementia customers, come in and feel that they are they're in the right place or in a safe place would be really appreciated.”***

(Interview participant: CEO of a small retail store)

## **Feeling understood and respected by the public**

Negative responses from other customers towards people with dementia can make shopping a daunting process.

***“Other customers can be very rude ... they will say ‘tut tut,’ or say ‘hurry up’ or swear at customers that do need a bit more time... sometimes it can be when someone is paying, they can take a bit more time... or you are helping people around the shop... the general public can be a bit unforgiving...”***

(Interview participant: frontline staff member at a large retail pharmacy).

Frontline staff told us that they had witnessed members of the public being impatient with people with dementia, and carers told us that people could be rude to their loved ones, especially when they didn't adhere to social norms.

***“I'd say the activities would be... where you'd have to have a certain decorum and conduct oneself in a particular fashion. And Mummy, in the early days, didn't appreciate the etiquette. That filtering process in her stage of her dementia at that time... we'd be there at a concert, and she'd be talking or want to get up... just as if she was just sitting in front of the television... [so] we didn't go to as many of those events as we used to. ....And that impact was not going to certain places and doing certain activities.”***

(Interview participant: carer for parent).

### **Good practice: 'Dementia Space' pop up**

In Newcastle, the 'Dementia Space' is a pop-up at the Grainger Market, funded by a partnership between Newcastle City Council and local organisations.<sup>59</sup> It's part of efforts to make Newcastle a dementia-friendly city.

The space offers a relaxed area for people with dementia who are out and about to sit down or have a coffee while out shopping. It also offers information and advice, learning sessions, and regular activities for those with and without dementia. The space also displays household objects with dementia-friendly design that can be purchased in the market.

The Dementia Space team organise 'slow shopping' days across the market, which offer a less stressful and busy experience for people who may want additional time and support navigating stalls.

## Identifying customers with dementia

While some participants noted that having a doctor's note, Alzheimer's card or 'sunflower lanyard' (see below) reduced their anxiety when shopping by ensuring that issues would be dealt with sympathetically, not all were comfortable being identified in these ways.

***"I suppose the issue is ...they're not wearing a badge that says, 'dementia sufferer'... and that tends to be a problem... Dementia is a scale: you have the most severe cases ...and you have other cases which are far less obvious. It's also variable. Sometimes someone can appear very rational and other times less so..."***

(Focus group participant: Diversity and Inclusion manager at a retail pharmacy)

As dementia is a hidden disability it can be hard for staff to identify customers who need support. Symptoms vary from person to person, and can change over time. Some people with dementia may not know they have the condition, and may not perceive that they need support.

The majority of retail professionals we spoke to said that they struggled to identify customers with dementia. While some larger organisations offered their staff dementia training, this rarely covered all staff. Untrained staff may be left to direct people with dementia to get support from those with training. They said it can also be difficult for staff to distinguish between customers with cognitive impairments and those with other issues or needs.

These issues can be particularly challenging on the phone. Even with training, call centre staff – such as those working for utilities companies and financial providers – find it hard to identify support needs over the phone, especially as customers are likely to interact with a different member of staff each time.

Being unable to identify people with dementia was a real concern for some providers. For example, staff from financial services companies told us they feared selling a product to a customer who appeared to have capacity but didn't. They also recognised that while reimbursement would be an option if this did occur, families may find claiming it distressing.

In other circumstances staff recognised that people with dementia may not disclose their conditions due to a fear it may impact the service they receive.

***“If we say to people, are you vulnerable? They say [no], regardless of whether they are or they’re not... because they worry that they won’t have the policy at all. We supply travel insurance and people won’t necessarily tell you because they’re frightened you’re not going to even insure them.”***

(Interview participant: manager at an insurance provider)

Similarly, the transport professionals we spoke to made it clear that they find it especially difficult to understand if a customer travelling alone has dementia, as they may not want to overtly express their need for support.

***“It’s more independent travellers who don’t have somebody with them and who maybe aren’t articulating that they have a challenge. That’s more difficult for our colleagues to deal with.”***

(Focus group participant: Diversity, Equity and Inclusion manager at an airport)

Frontline staff also recognised that it would be wrong to assume older customers had dementia simply because they were struggling to make a decision, or with a process. A careful balance must be struck between creating triggers for offers of support and reinforcing ageist stereotypes:

***“I think it’s easy to assume that because we’re dealing with people who are older, therefore you have dementia. And that is not the case... vulnerability, dementia, Alzheimer’s, issues around your memory, they’re all indicators that something’s going on. One doesn’t necessarily equal the other. We don’t want to be the reason why you’re struggling to make a decision today – as it may not be dementia, it could be completely unrelated. And so wanting to signpost, wanting to make it clear, but not wanting everyone to think that the moment that someone’s struggling to pass security, they must have dementia. Trying to avoid knee jerk reactions.”***

(Interview participant: manager for an investment provider)

Unfortunately when people with dementia aren’t identified it can lead to issues. For example, companies with ‘zero abuse policies’ can sometimes approach situations in a heavy-handed way, increasing agitation for customers with dementia.

***“Vulnerable customers may be more likely to get on the wrong train: previously there was an issue where staff might confuse a vulnerable customer with someone cheating the system – but now they’re given training, this is generally ok.”***

(Focus group participant: Diversity, Equity and Inclusion manager for a rail company)

***“We have a zero tolerance [policy] on abuse to staff... but, while we try to ensure the team... can differentiate between someone who is abusive and someone who can’t help what they’re doing as we don’t want to make things worse by raising the alarm, mistakes can be made which can make a vulnerable customer anxious... We can accidentally make a situation worse by pressing the panic button when their aggressive behaviour stems from anxiety and they just want to be helped.”***

(Interview participant: manager for a pharmacy retailer)

## **Existing solutions**

Providing vulnerable customers with one-to-one support, especially from familiar faces, can help them feel more at ease in retail and leisure environments. And some retail and leisure organisations are already taking steps to ensure that their staff know how to identify and support people with dementia effectively.

Our participants with dementia reported feeling best supported when interacting with regular staff members who knew them – meaning that small shops and leisure venues were often more accessible to them.

***“...we always went to the same [wine shop] they all knew him – so he had no problem dealing with shop staff. He knew them no problems.”***

(Interview participant: carer for partner)

Many participants reported that shop staff were more sympathetic if they had relatives with dementia. Broader awareness of dementia not only helps staff members understand how to interact with people with dementia most effectively, it can also help them identify people who may need support.

In addition there are a number of schemes which exist to help people with dementia to flag their need for support without having to ask directly. These include the hidden disabilities ‘sunflower lanyard’

scheme, which is recognised globally and across sectors.<sup>60</sup> The green lanyard with a yellow sunflower design is designed to allow individuals to discreetly indicate that they may require additional assistance, without having to ask or explain themselves.

There are a range of other dementia cards and identifiers available. For example, the Alzheimer's Society provides free personalisable 'Helpcards' that a person living with dementia can carry around with them.<sup>61</sup>

As technology emerges there may be potential to create digital versions of these schemes.

### **Good practice: dementia-friendly banking**

Since 2019, Santander has worked with the Alzheimer's Society to become dementia friendly. Initiatives include training staff, creating more dementia-friendly products, making branches more dementia-friendly, and improving internal policies.<sup>62</sup>

Over half of the company's staff – more than 11,500 people – have become Dementia Friends and 130 have received extra training to become 'Dementia Ambassadors' and act as regional key points of contact.<sup>63</sup> Santander has also created practical guides<sup>64</sup> which explain how Santander can help both customers and colleagues affected by dementia. The guide explains how to register an LPA and supported banking options. These options include a 'carer's card,' registered in a carers' name, which gives carers limited access to their loved one's funds to allow the carer to help with everyday tasks such as shopping. Others support customers who may struggle to remember their card and banking PIN: these include the option for customers to log into online banking using their fingerprint or face ID, and the option to request a chip and signature card.

Broader awareness campaigns – such as the Alzheimer Society's Dementia Friends initiative and dementia-friendly communities programme – can also help address wider societal attitudes, and help change the way in which other members of the public treat people with dementia when they are out and about.



## Good practice: Salford, a dementia-friendly city

Salford is one of over 350 dementia-friendly communities in the UK.<sup>65</sup> Action across the city is coordinated by the Salford Dementia Action Alliance. This is a partnership of nearly 80 organisations that are committed to working towards a range of actions that include: integrating Dementia Friends training into their internal training programmes; tailoring their services for those with dementia; and creating inclusive spaces that make those with dementia living in Salford feel part of the wider community.

For example, Salford community leisure is a community benefit society with charitable status, operating 60 venues across the city.<sup>66</sup> It offers:

- Classes that allow local people with dementia to get active and socialise, including dementia-friendly swimming sessions and monthly 'Healthy hearts and hips' programmes
- A 'caring for carers' initiative which offers reduced prices on memberships for carers and allows them to accompany someone with dementia free of charge
- A project, organised with the Sporting Memories Network, to offer activities based around sporting memories

## Staff training

Ensuring staff are trained can make an enormous difference in ensuring that people with dementia are treated with dignity and respect. Dementia Friends training is now widely taken up, and some retailers have invested in enhanced dementia training. However, there's little consistency in the training provided across different providers and sectors.

In our conversations, many small and some large companies told us that they tried to support a 'culture of kindness,' but they didn't always have formal training or guidance about the specific needs of people with dementia. The small retailers we spoke to considered informal, on-the-job training vital, but made it clear that they need external support for more specialist issues. Unfortunately, some retailers weren't aware of the external support already available, such as the Dementia Friends training and guides provided by the Alzheimer's Society.

Creating standardised training is challenging because of the different regulatory and training regimes that exist across different sectors:

- 1. Pharmacies** (including retail pharmacies) have **generally offered Dementia Friends training** to all pharmacy staff since 2019, incentivised by the NHS. However, financial incentives have stopped more recently,<sup>67</sup> and training isn't refreshed or offered regularly, nor is it incorporated into everyday training.
- 2. Rail companies and airports generally offer training on supporting vulnerable consumers**, informed by the relevant regulatory bodies (the Office of Rail and Road, and the Civil Aviation Authority). These bodies set out clear expectations on the number of hours that must be spent on in-house training to support customers with disabilities (including induction training and refresher training) – although this isn't specific to customers with dementia.
- 3. Most large financial organisations offer training on assisting vulnerable customers.** Many have also offered staff one-off Dementia Friends training. FCA guidance on supporting vulnerable customers isn't mandatory but does evaluate adherence to the guidance. It specifies that staff must have the skills and capabilities to recognise and respond to vulnerable customers.
- 4. Most retail and hospitality organisations offer no formal training**, as they are generally small organisations. The Association of Convenience Stores encourages retailers to support vulnerable customers, including those with dementia. Dementia Friends training is offered by some larger retail and hospitality companies, but it isn't standard practice across the large companies in these sectors.

## Good practice: 'Mission Dementia' in Austria

The 'Mission Dementia' initiative is an e-learning platform developed by MAS Alzheimerhilfe, the Danube University Krems and the Austrian Police Officer Training Academy. It aims to provide the police with a working tool for solving complex situations that involve individuals with dementia, by changing the way police approach certain situations.

Police stations that complete training receive dementia-friendly accreditation.

The initiative won the SozialMarie prize for social innovation,<sup>68</sup> and is now being rolled out to other sectors, with training adapted to each sector's different requirements.<sup>69</sup>

## Navigating retail and leisure environments

*“...Walking around with the shop can be quite daunting. Aisles always look the same, you know, up and down, up and down, and people with dementia struggle with spatial awareness.”*

(Interview participant: former carer)

Continuing with enjoyable activities, such as going to the cinema, museums and the theatre, can help improve the quality of life for people with dementia. Engaging in these activities can help stimulate memory and intellectual engagement.<sup>70</sup> But all too often there are barriers to continued participation which mean people with dementia stop doing things they enjoy – for example 69% of people with dementia have stopped going to the cinema because of a lack of confidence.<sup>71</sup>

The main issues with navigating online and in-person environments are:

- Getting disorientated or lost
- Having trouble finding what they need
- Understanding busy environments with lots of stimulus, or feeling stress because of them

Research on designing retail spaces for inclusion found that people with dementia may become disorientated or get lost in unfamiliar stores or shopping venues. They can find it especially difficult to find entrances, exits and toilets. This confusion can be exacerbated when they don't know who to ask for help. In addition, non-routine outings can leave some feeling anxious and agitated.<sup>72</sup>

### **Good practice: dementia packs for visitors**

Lords Cricket Ground offers a visitors pack for customers with dementia that contains information on meeting points, store tickets and a map of the ground, with toilets clearly located. The pack can either be pre-ordered or collected on the day. Volunteers trained as Dementia Friends are also on hand throughout the day.<sup>73</sup>

## Good practice: tracking devices designed for people with dementia

There are currently a range of tracking devices available that are designed to support people with dementia and their carers.

<sup>74</sup> Advanced devices allow users to track the wearer and their movement and can be programmed to alert people with dementia and/or their carers to risky situations – for example by sounding an alarm if the wearer deviates from a pre-determined or regular route.

Shops and leisure centres can be hard to navigate for people with dementia, and there are some visual features that can be especially confusing.

In retail and leisure environments:

- Certain floor patterns can be confusing: zigzag patterns may look like cracks or snakes, and black patches can often look like holes. Shiny patterns and surfaces can also cause disorientation.
- Overhead signs in shops can be difficult to see, exacerbating social disorientation and wayfinding difficulties for those with dementia<sup>75</sup>
- Inconsistent use of colour for different signs can be confusing
- Text signs can be harder to interpret than symbols – and inconsistent symbols (such as quirky signs to distinguish ladies' and gents' toilets) are unhelpful
- Low lighting levels are a challenge – particularly at tills when struggling to identify coins and notes
- Layout changes can make it difficult to locate products or services people could previously find

Online:

- Websites may be busy and overload customers with information
- Some website designs may not have enough colour contrast for readability, have too much text to take in, or use confusing background sound

There can also be physical barriers when visiting in-person environments; our participants reported a range of problems. For example, narrow shop aisles can deter wheelchair users, especially

in smaller shops. **A lack of visible resting places** discourages supermarket use for those unable to walk long distances. In addition carers can find it exhausting to accompany loved ones around shops, especially if the carers themselves are older or have physical disabilities.

Many people with dementia experience height loss due to changes in their bones, muscles and joints that result in a lowered head and gaze.<sup>76</sup> This can result in problems using shops:

- **Struggling to manoeuvre and reach** into large, deep trollies
- Shelves and **products on display are too high or low** – increasing the risk of falling
- **Struggling to bend down** at the till to pick up bags, as there's no convenient place to leave them

Noise can also be an issue. Noisy environments with lots of other customers can be too busy, confusing and stressful. Many of our participants preferred to shop during mornings to avoid this.

Access to toilets was another key issue for people with dementia, some of whom may need to visit toilets more frequently and with more urgency than most. Issues mentioned by our participants included:

- Inconsistent signage across different stores and leisure venues, making it harder to identify toilets
- Barriers to carers accompanying people to the toilet, leading to people getting lost
- Struggles in ensuring seating near enough to toilets, e.g. in cinemas or theatres

*“...my dad would sometimes have an urgent need to use the loo - on arrival to the shops. I think this was an anxiety thing... even if we made sure he went to the loo before we left – as soon as he got there, he would have to dash to the toilets. So clear signage of where the toilets are when you enter the supermarket could be really helpful – if you've got one - that would be really helpful.”*

(Interview participant: former carer for parent)

### **Good practice: dementia-friendly high streets**

A number of UK local authorities have undertaken initiatives to make their high streets dementia-friendly. In 2013, Fleet became North Hampshire's first 'dementia-friendly high-street'.<sup>77</sup> The launch involved a day of activities, information and displays at Hart Shopping Centre. Every business that had signed up to the Dementia Friendly High Street scheme displayed a sticker in their window to indicate staff had been trained on dementia awareness and how to support customers with dementia.

### **Existing solutions**

The Dementia Action Alliance (DAA) has established a checklist for public spaces and buildings that are open to the public, to help them become dementia-friendly.<sup>78</sup> Recommendations cover lighting and signage, as well as larger scale (and more costly) design issues.

Members of Local Dementia Action Alliances (LDDAs) can sign up to take action to meet the recommendations.

More formal assessments of a building's dementia-friendly design have been carried out by the University of Stirling's Dementia Services Development Centre (DSDC). DSDC has recently launched its Environments for Ageing and Dementia Design Assessment Tool (EADDAT) to replace its previous auditing tool.<sup>79</sup> The EADDAT has three tiers, ranging from entry-level changes for home spaces and small businesses, to advanced, inclusive changes for construction professionals, town planners and healthcare professionals.

### **Good practice: Great Sankey Neighbourhood Hub**

The Great Sankey Neighbourhood Hub in Warrington was the world's first public building to be certified 'gold' by the DSDC's auditing process. It was praised for its design, which included free-flowing reception pods, natural and artificial lighting, clear signage and floor finishes, and fully accessible toilets.<sup>80</sup> The accessible design allows those living with dementia in the community the opportunity to remain physically active and access vital wellbeing services.

Dementia-friendly design need not involve significant investment – a lot can be achieved by making small adaptations to the way in which services are provided in different environments. For example the Alzheimer’s Society published a guide for cinemas, providing tips on dementia-friendly screenings.<sup>81</sup> They highlighted key adaptations, including: the removal of advertisements from the start of films and offering a pre-show introduction; keeping lights on at a low level; providing break out rooms (or an interval) during the film; and offering a space where customers can socialise over refreshments before or after the film.

### **Good practice: The Castle Cinema, Hackney**

The independent Castle Cinema in Hackney<sup>82</sup> offers bi-monthly dementia-friendly screenings, selling tickets at a reduced rate with carers going free.

The cinema team have used guidance from the Alzheimer’s Society to inform their approach to screenings.



## Accessing and managing financial services

*“He’s got all these insurance policies coming out of his ears, you know, paying left, right and centre ... He’s got two policies, with two utility companies, both for the same thing...”*

(Interview participant: carer for parent and utility company employee)

To spend confidently, both online and in-person, customers must be able to access, manage and protect their personal finances. This means having access to banking services, managing their financial products (such as pensions and savings), and being able to manage bills and purchase products like insurance.

At different stages of dementia, people may need different levels of support:

1. For **those with mild impairments**, financial and essential services organisations can ensure that all customer-facing staff are well trained on the potential issues people with dementia may face; this can enable them to help people manage their finances independently for as long as possible
2. For **those who need help from carers**, financial services organisations can work with people with dementia and their carers to enable those people to get support when taking decisions
3. For **those who are no longer able to manage their own finances**, streamlined processes for activating and managing LPAs are vital

### Keeping track of finances and paying bills

Issues with financial management can be an early sign of dementia.<sup>83</sup> And struggling with money management can leave people with dementia vulnerable to falling into debt.

Common difficulties faced by people with dementia include:

- **Navigating bills**, especially complicated ones with lots of information, and communications, where they may struggle to determine which information is essential
- **Forgetting to pay bills** and not letting loved ones or carers know.<sup>84</sup>
- **Forgetting which letters they’ve read** or which correspondence is important

- **Continuing to pay unnecessary bills** due to memory issues or failure to understand communications from suppliers
- **Being unable to make changes** to financial policies and subscriptions
- **Signing up to multiple utility providers** or making multiple purchases/donations

*“People change their television, and their broadband and everything... I can’t do that. I just thought I’m paying too much. But it’s just beyond, you know, changing it. It’s just too difficult.”*

(Interview participant: living with dementia)

People with dementia can also face barriers to accessing their money and managing their financial services, including:

- Forgetting passwords and security details
- Finding it hard to fill out long telephone/online applications

*“She couldn’t remember her PIN or password - and because she hadn’t put in place power of attorney it was pretty hard to get somebody else to access the account... it was such a big battle”*

(Interview participant: former care worker in residential setting)

Other challenges include:

- Struggling with **technical jargon** when purchasing complex products such as insurance, making it difficult to identify the products that suit their needs
- **Impaired reasoning abilities**, which make it difficult to compare quotes and make good financial decisions
- **Buying products that they don’t need:** e.g. insurance for cars they don’t own or multiple products for the same purpose
- **Attraction to risky behaviour** that can result in unwise investments

## Online banking

The rapid move to online banking and digital payments in recent years has been particularly challenging for some people with dementia,<sup>85</sup> particularly those who didn’t use it pre-diagnosis.

***“They were not comfortable with online banking because it was an interface that neither parent could get used to or felt confident with. I think... they’d heard all this stuff about people being ripped off, so I think they were just angry...”***

(Interview participant: carer for parents)

Some of the people with dementia we spoke to had only basic phones and devices, making online banking impossible. In some cases carers told us that they had opted for these phones to protect their loved ones, but as a result their access to money was restricted.

As well as practical challenges accessing new technology, many of our participants expressed distrust for online banking, due to fear of online crime (see ***Avoiding scams on and offline***).

Many people with dementia told us they preferred going to a branch to manage their money. But recent branch closures are making this increasingly difficult.

***“My mum can’t look after her finances... there aren’t as many banks on the high street as there used to be... internet banking is easy... but not for people who have dementia.”***

(Interview participant: carer for parent)

***“Unfortunately my local bank branch has moved from being... 10 minutes’ walk away. It’s now a bus ride away. So, if I want to draw any money out from the machine, I’ve got to go get a bus and go for it. I couldn’t walk the distance.”***

(Interview participant: living with dementia)

## **Existing solutions**

While most financial services providers that we spoke to had support available for people with dementia, identifying those who need additional support can be challenging. For example, some professionals we spoke to noted that those with dementia may not be forthcoming about their financial difficulties:

***“A lady that I’ve been dealing with – who has dementia - she’s in financial difficulty... But when you ask at the start of the call... she was like, ‘No, everything’s fine. Everything’s fine.’ And you go into the call and we drill down... that’s when she told us that she was in financial difficulty.”***

(Interview participant: carer for parent and utility company employee)

Some of our participants with dementia and carers had accessed schemes available for 'vulnerable customers', but unfortunately others were not aware of the support available.

*"...I haven't found banks or utility companies that supportive... it's through sort of peer support that I've found out about the different things that you can apply to, in terms of reductions for the utility bills, your gas, electricity and TV license. Before that, no one is really forthcoming with information, and it can be so so, like, dead hard."*

(Interview participant: carer for parent)

Some of our participants with dementia expressed little trust in financial services companies, which discouraged them from communicating with staff.

*"Companies, what they're after is your money aren't they? They're not there to help you... And what would be helpful would be if, I think, that morally they had an obligation to customers who are vulnerable, to provide them with the best deal... It would be very good if I had somebody who could go through those options to find the cheapest one for me"*

(Interview participant: living with dementia)

In practice many people with dementia and their carers found ways to work around the barriers that they faced to managing money.

Some said that setting up direct debits for utility bills was a useful way of ensuring people with dementia didn't forget to pay important bills. But at the same time, we heard about the risks of direct debits leading to overspending – as people may forget what they've signed up to.

Many people with dementia rely on support from carers to manage their financial affairs. Unfortunately this can be challenging. A 2011 survey by the Alzheimer's Society<sup>86</sup> reported that 36% of carers experience problems managing finances for the person they care for. It also found that 90% of carers want better dementia awareness among bank staff. **They want companies to proactively ask if customers need support** as they suspect they're missing out on help.

Our participants told us that key issues for carers included:

- Suffering stress due to lack of time or skills in financial management, or simply disliking the role, especially if this is the first time they've taken on these tasks

- No centralised source for information about financial support and LPAs

*“...it's an area that I dislike anyway, I particularly hate numbers, I find them quite difficult to navigate – that's why my wife managed the finances... it's just yet another aspect of the household that I have to manage. And my natural tendency is to [say] I'll just put that bill on the side there.”*

(Interview participant: carer for partner)

Many of the carers we spoke to said that they want more support immediately, and to have the option of further help in the future, as they worried about their health going forward. This included most spouses managing their partner's finances.

### Good practice: money management services

The Money Carer Foundation is a daily money management and deputyship service, which provides clients with enhanced money management support that's independent and free from conflict of interest.<sup>87</sup>

The service can provide those with dementia the option to offload some of the monetary stresses that they may feel. For example, the foundation stepped in as an independent money manager to help a woman with early-onset dementia whose husband found controlling her finances was placing a strain on their relationship. The team took control of the bills for ongoing care contributions, along with transport and sundry costs.<sup>88</sup>

Our stakeholders agreed that enacting **a lasting power of attorney (LPA) is the single best thing that people with dementia can do to protect themselves financially** in the long term. Having an LPA in place lets family members or carers act on behalf of a person with dementia when that person no longer has capacity to make decisions for themselves.

*“It was all positive, because we were able to manage my family’s finances without any restriction. And it meant we were able to continue her lifestyle fairly seamlessly. So keeping up with her capacity, keeping up with how she would expect life to be in her own home, bills being paid, the shopping being done, and coming with us during the shop. And we constantly wanted to keep her involved - to keep her included. So if we were able to do that without any obstacles, it made it much more seamless.”*

(Interview participant: carer for parent)

*“I don’t think people properly understand the implications of not having a lasting power of attorney when they have financial products.”*

(Interview participant: manager for an investment company)

*“There are situations when you can’t help, because they lack a POA [power of attorney], that’s really hard. It’s like they’re in limbo. We apologise, but there’s nothing we can do.”*

(Interview participant: frontline staff member for a utility company)

However, we heard about a range of challenges when registering and using LPAs.

## Challenges with LPAs

The biggest challenges arise for people with dementia who don’t have an LPA in place when they lose the capacity to manage their affairs. Carers told us it was very distressing to find that they were unable to help their loved ones with their money when these situations arose. However, financial professionals we spoke to explained that they can’t deal with carers or relatives without an LPA in place, as they don’t have the tools to judge when someone lacks capacity and have no other means to avoid financial abuse. This caution is vital, given that 70% of known abusers of older people are family members, with financial abuse being the most common type of abuse.<sup>89</sup>

The best way to avoid this would be to make it easier for people to set up LPAs. Our participants reported a number of barriers:

- **It can take up to 20 weeks to register an LPA**, and it must be done while the applicant retains their mental capacity
- **It’s hard to determine the cheapest options:** using a solicitor

can be expensive for those who don't know about cheaper online alternatives

- It can be **hard to find current information** on LPAs
- Many felt there were **missed opportunities to recommend setting up LPAs** for example at the point of dementia diagnosis

Even once an LPA is in place, carers told us they had problems acting as attorneys:

- Carers found the **scope of LPAs** to be limiting – they can't set up direct debits or open new bank accounts for their loved ones
- Carers expressed frustration with the LPA **auditing process**: being obliged to keep receipts for all purchases, including very small ones, was stressful and sometimes not possible
- Some banks insist on **talking to customers with dementia rather than their attorney**
- **Inconsistent procedures** across different banks for implementing LPAs caused frustration for many:
  - o Some banks don't recognise multiple attorneys
  - o Some banks may be overly cautious and initially refuse to recognise LPA documents

The professionals we spoke to from the financial and utility sectors also described difficulties as there's no standard consistent practice on dealing with customers with LPAs across either sector.

***"I think it'd be good to have... uniformity across businesses as well as what we request from [LPAs]."***

(Interview participant: manager for a financial organisation)

## Paying for goods and services

***“People with dementia may struggle to get used to contactless payment (although once they are used to it, it can be beneficial).”***

(Focus group participant: Diversity and Inclusion manager for a high-street pharmacy)

For customers with dementia and cognitive impairments, making payments can be one of the most stressful parts of shopping and accessing leisure activities.

Key issues included:

- Struggling to pay using preferred methods – whether cash, chip and signature, chip and PIN, or contactless
- Confusion arising from changes in price, or misremembering the cost of items

Previous evidence suggests that a long-standing decline in the use of cash is creating difficulties for the many older people who rely on it.<sup>90</sup> Accessing cash has become increasingly difficult, and some retailers now refuse to take it. Age UK has called for the introduction of a Universal Service Obligation (USO) on banks to guarantee access to cash for everyone.<sup>91</sup>

***“Most people are used to using credit cards, but others may find it hard to assimilate... it's those changes in the way people operate... when the dementia kicks in.”***

(Focus group participant: Diversity and Inclusion manager for a pharmacy)

While a lack of access to cash, as well as decreasing options to use it, were a concern for some, many of our participants were positive about the shift towards using contactless payment over cash.

However, challenges arose when people faced different rules in different outlets and at different price points.

Having people available to help them make payments was a key issue for the people we spoke to.

### Paying at the till

People with dementia prefer to pay at a till with a cashier, rather than use self-service checkouts. Anchor, a housing and care charity,



reported that people with dementia found automated transactions intimidating, isolating and confusing, especially when having to complete a whole transaction alone.<sup>92</sup>

Specifically, customers can struggle to:

- **Understand the value of items** they're paying for and **how much they need to pay**
- Pay at the till without feeling **pressurised and rushed by other customers**: some need more time to insert their card and enter their PIN or count cash
- **Remember to take all their shopping with them**
- **Collect a receipt**, which can lead to confusion later when they try to remember how much they've paid, and for what goods

The interaction between cashier and shopper is critical to ensuring that people with dementia aren't overwhelmed by the process. Customers will also often need staff to help them pack. However, staff asking too many questions can be confusing, so this needs careful handling.

*"My mum would struggle if she was asked too many questions at the till... our team members ask a lot of questions. Like 'Oh, would you like a 10p carrier bag? Would you like an email receipt? Or a paper receipt?' Those kinds of things we need to be aware of... because it could make my mum feel very confused."*

(Interview participant: carer for parent and area manager for a large retailer)

Misunderstandings are avoided most effectively when staff can allow customers the time to move at their own pace.

## **Paying with cash**

21% of people aged over 65 prefer to use cash for all transactions.<sup>93</sup> However, many of our participants reported not feeling confident of handing over the correct amount.

*"Some customers, who may have dementia – but I can't be sure – are not sure of their change and stuff like that, e.g. the difference between a £1 or 50p coin, they need help to check they're paying the right amount of money... they get a bit confused with what money is what."*

(Interview participant: frontline staff member at a small shop).

This places responsibility on staff to ensure that they're returning the correct change to such customers, especially paying with large notes or a handful of coins.

## **Paying by card**

Paying by card allows customers with dementia to pay quickly, without worrying about finding the correct amount. Some large banks also have policies to retrieve unnecessary payments made by debit cards. However this may not be the case with some smaller banks and building societies, which makes it important to take precautions.

***"I'm not good with numbers so I always pay by cards because it's easier and I don't want to hold up the queues as people are impatient..."***

(Interview participant: living with dementia, without a carer).

However, paying by card can be challenging:

- Some people with dementia told us they struggled to use chip and PIN, whether through a lack of motor skills or memory
- People who had become used to paying by contactless payment found it particularly difficult to remember their PIN when asked for it

***"[My husband came out of the shop] brandishing his bank card, dropped it on the floor, shouting across the carpark asking what his PIN number was. I had to go back in and eventually got to the checkout... somebody said the trolley was used by the guy in the red coat and it was my husband. He'd got to the checkout but he hadn't been able to use his PIN..."***

(Interview participant: carer for partner)

Generally speaking, our participants were positive about contactless payments. However, contactless payment limits sometimes led to confusion and distress when PINs were suddenly required.

***"...he loved that... because he couldn't remember the PIN number - but [he could use contactless] quite often if we went out for coffee. 'Oh, I'll pay' - because he didn't have to worry about how much, getting change or anything else. So contactless really set him free..."***

(Interview participant: carer for partner)

At the same time we heard that contactless payments presented risks for some people with dementia, especially those who struggled with impulse control, as the lack of a visible transfer of cash could lead to excess spending.

## Existing solutions

Prepaid or restricted cards could present an effective way of helping people with dementia to shop more independently, while avoiding the risk of overspending. An attorney can issue them to a person who lacks capacity, to enable some continued independent retail activity, within careful boundaries. And if someone with dementia has capacity, they can issue these cards to trusted individuals to support spending on their behalf (see below).

### Good practice: Sibstar

**Sibstar** is a highly secure, prepaid card for people living with dementia.<sup>94</sup> The associated app allows carers to keep track of payments made by this card. Sibstar allows people with dementia to remain financially independent, while giving security not available from existing banks. It gives both parties a simple way of accessing and managing money every day, while making sure the user's finances remain protected and secure.

### Good practice: GuardianCard

**GuardianCard** is a debit card designed to give people with dementia or their carers a safe, simple and secure solution to managing day-to-day finances.<sup>95</sup> The account holder of the GuardianCard is issued with a card that has money loaded onto it, on a weekly or monthly basis. The user of the card can issue up to five physical or virtual cards to family members and friends so they can shop or pay bills on their behalf. The card offers financial security and flexibility, as you can restrict its use to certain retail outlets and set customisable spending limits.

## What could we do?

There are three key areas for action that we recommend to better support people with dementia so that they can continue retail and leisure activity for as long as possible. These are:

- **People:** we must ensure that people with dementia can access support from people who understand their condition, and who are equipped to help when they go out and about
- **Infrastructure:** we must build **physical and digital infrastructure** that's inclusive for the growing number of people living with dementia; we must also create the right **legal structures** to enable them to live well
- **Technology:** we must harness the potential of existing and emerging technology to make life easier for people with dementia and their carers

Below we offer some pointers for the future and recommend key areas for action.

### People

#### There are three key areas for action:

- Ensure staff in retail and leisure settings are available and equipped to support people with dementia
- Make it easier for people with dementia to find support
- Develop the future workforce (including volunteers) to be fit for a future where more people are living with dementia, including enabling more people with dementia to work and volunteer

### Equipping and enabling staff

We need to ensure more staff in retail and leisure environments are equipped and enabled to support customers with dementia. Our research suggests there's a need for enhanced training – going beyond existing Dementia Friends provisions – to equip retail staff to identify and support people with dementia. There's a gap in the market for such training, and a strong case for providing this free of charge to smaller businesses. It will also be important to ensure that *all* staff in retail and leisure environments are trained to understand and support people with dementia – with security staff being a key priority.

At the same time, we need to ensure that more staff are available, and explicitly encouraged, to provide sympathetic and responsive support. This would be similar to what many people with dementia told us they experienced most often in small, local shops. Some larger retailers – such as Timpson and John Lewis – already say that they encourage staff to “first be kind”. This approach should be encouraged across all retailers.

As more retailers move towards self-service checkouts, there’s an opportunity to redeploy checkout staff to play a more explicit role in supporting customers as they move around stores.

### **We recommend:**

- The Government should convene leisure and retail providers to work with dementia charities, to **develop enhanced training for staff who work with people with dementia**. This should include minimum mandatory training standards for customer-facing staff in regulated industries.
- Trade bodies, such as UKHospitality and the Confederation of Passenger Transport, should work with the Alzheimer’s Society to develop new **sector-relevant versions of their *Dementia Friendly Retail Guide***.
- The Federation of Small Businesses should work with trade bodies to develop **scenario-based training for small businesses** on supporting customers with additional needs.
- The FCA should require financial providers to **train staff working in customer-facing roles on the Mental Capacity Act and the use of LPAs** under the ‘Competent Employees Rule’ in the FCA handbook.<sup>96</sup>

### **Making it easier to find sources of support**

We need to make it easier for people with dementia and their carers to identify places where they can access the support they need. The Government should convene retail and leisure providers, regulators and dementia experts to **develop a ‘kitemark’ system to accredit those online and offline retailers and leisure providers who sign up to a minimum standard of support for people with dementia**.

We also need to make it easier for people with dementia and their carers to access existing support, such as assisted travel. A shift

towards proactively offering support – both in person and during online booking processes – will be important.

Leisure and retail providers, as well as financial services companies and transport providers, need to develop more effective ways of registering customers who need support so that people with dementia and their carers aren't forced to ask for it repeatedly. "Say it once" access to registers for 'supported customers' should become the norm.

### **We recommend:**

- **The Government should convene retail and leisure providers, regulators and dementia experts to develop a 'kitemark' system** to accredit those online and offline retailers and leisure providers who sign up to **a minimum standard of support for people with dementia.**
- **Larger online and offline retailers and leisure providers should work with experts to establish a Dementia-Friendly Kitemark scheme** for retailers who sign up to a code of conduct around dementia support; this should include enhanced returns policies for online purchases and the option to register for additional safeguards such as prompts.
- Retailers and hospitality venues should provide **'relaxed environments** days / showings' (drawing on the model of 'slow shopping') as a matter of course
- Retailers and leisure providers should train staff to proactively offer support to people in their stores as part of a **"first be kind" policy**
- Public transport operators **should proactively offer assisted transport options**, making it clear that support is available to people with hidden and cognitive disabilities, whether or not carers are with them, and without a requirement to prove need
- Ticket booking processes, online and offline, should include **prompts to request support** – with clear options to request human rather than digital support

### **Develop the future workforce**

We need to develop a future workforce that can support people with dementia as they go out and about in the community.

As digitalisation reduces the number of staff needed to run shops with facilities like self-checkout, pay-at-pump and automated stock management, we should think about the roles that leisure and retail staff will play in future. We need to equip more staff to offer personal shopping and supported access to people with dementia and others.

There's potential to develop new roles that join up across the retail environment. For example, managers of town centres and shopping malls could play a role in supporting people with dementia as they shop across whole retail areas.

In future, we could create new volunteer roles to offer support to people shopping in a particular high street or mall. This could mean that a customer visiting a particular mall could check in at the first store they visit and ask for support. This could trigger a call into a specialist team of supporters, including volunteers, who could then help that individual to navigate between and within the mall's shops and find what they want to buy.

Encouraging employers in the retail and leisure sectors to become dementia-friendly employers, and encouraging the employment of people with dementia in key roles, could improve awareness of, and support for, people with dementia in these settings.

Technology could also play a key role in enabling staff to more effectively identify and offer support to people who may need it (as discussed below).

### **We recommend:**

- Town and shopping centre managers should work with dementia experts to consider how to train **future staff and the volunteer workforce** to better support people with dementia
- Retail and leisure providers should proactively encourage the employment of people with dementia, working with dementia experts to understand how they can become **dementia-friendly employers**

## Infrastructure

### There are two key areas for action:

- Implementing dementia-friendly design across new retail and leisure environments, and adapting and retrofitting existing environments to be more dementia-friendly
- Getting the legal framework right to support people with dementia

### Dementia friendly design

We must ensure that dementia-friendly design becomes the norm across our communities, building in dementia-friendly features across our high streets, town centres, shopping malls and retail and leisure settings. These norms should also go beyond to include transport providers and web designers.

To do this we need a firm commitment to designing for dementia across all new developments. We also need to encourage planners and retail and leisure providers to take small steps to improve the design of existing online and offline environments, through retrofitting and adaptation. This could start with low-cost measures such as reducing background noise and improving signage.

There's potential to build on the existing work done by the University of Stirling and the DAA in developing a universal set of standards that could be adopted across sectors. Equivalent standards for online environments would also be needed.

### We recommend:

- Regulators should work with dementia experts **to develop and adopt standards for dementia-friendly design** as part of wider inclusive design principles. These should cover key issues including:
  - Toilet design and provision
  - Lighting
  - Flooring design
  - Signage
- When issuing new contracts for public transport operators, leisure provision, etc, national and local government should **favour providers and operators who sign up to dementia-friendly design principles** and train their staff on how to help customers with dementia.



## Getting the legal framework right

While it is right that the structures around LPAs are robust, it's clear that it's currently too difficult to register one, and that too many people only realise that they need an LPA when it's too late. We need to make it far easier for people to register an LPA well ahead of the point at which they may lose capacity.

People with dementia and their carers also told us that they found the current LPA structures too rigid. The all-or-nothing approach where either the person with dementia has capacity and retains sole decision-making power, or the attorney takes over completely, fails to reflect the reality of their lives.

In practice we saw that people with dementia and their carers wanted to share decision-making. This recognises that dementia often involves varying incapacity levels, as well as the fact that sometimes people with dementia can manage some decisions and not others.

We heard that carers and people with dementia wanted to be on more solid ground when acting in these ways. At the same time, retailers – and particularly financial services providers – reasonably told us that they can't operate in this grey area because of the significant and real risk of enabling financial abuse.

This is very difficult and complex territory, which requires careful consideration. However, as more people live with dementia, getting this right will be vital. Thinking carefully about how to enable people with dementia to share decision-making and to allow incursions into their freedom of choice should be part of a wider review of LPAs and how they are working.

### **We recommend:**

- The Government should conduct a **review of legislation surrounding LPAs** to consider whether procedures could be simplified, and to explore the potential for new processes which would enable people with dementia and their carers to share decision making.
- The Government should **simplify the process of setting up an LPA** – the Office of the Public Guardian should consult people with dementia and their carers to get insight into what would work best for them.

- The Government and NHS should work together with dementia experts to **identify effective ways to 'nudge' people towards setting up an LPA**. This should include providing information on LPAs when people are diagnosed with dementia, but could also include prompting people to consider LPAs when renewing passports or driving licenses, or when first receiving their state pension.
- Insurance companies and banking providers should work together to develop **more consistent approaches and procedures for working with attorneys**. This should include enabling attorneys to set up direct debits for their charges, etc.

## Technology

### There are three key areas for action:

- Making existing technology more accessible and useable
- Building on existing and emerging technology to support living well
- Encouraging innovation for the future

### Existing technology

Across all of the areas we discussed, we saw how people with dementia and their carers were already taking advantage of technology to enable them to live well. This might include using contactless payments, as well as booking tickets and shopping online. However we also saw ways in which rigid approaches to the use of technology could make life more difficult.

Being more flexible with how some technologies are used – for example allowing people to set their own contactless payment limits – could enable more people with dementia to use technology in ways that work for them.

For online shopping, consistent implementation of dementia-friendly design could help more people to shop and use online services such as booking tickets and price comparison sites. In future we should be able to support people with dementia with sites that meet high standards of design through the development of a 'Dementia-Friendly Kitemark.'

We can also harness technology to make it easier for people to navigate the offline environment. In one example, our proposed Dementia-Friendly kitemark could easily be linked to a website and app with information about accredited businesses in different market sectors. And a TripAdvisor-style interface could let real users share their experiences with different businesses.

We can also use technology to help businesses share data that has been volunteered by people, on an opt-in basis, who may need additional support. This could build on small-scale schemes where people with support needs register once with providers (such as theatres and cinemas) to be automatically offered more accessible seats when they book online.

### **We recommend:**

- The **Dementia-Friendly Kitemark should be linked to a digital database** that allows people to identify local businesses who meet minimum standards for dementia support, and which enables customers to rate their experiences
- Retailers, financial services providers, utility companies and others should **explore how data actively volunteered by customers with additional needs could be securely shared** to enable more proactive offers of support
- The UK Payments System Regulator should allow customers with dementia and other cognitive impairments to **personalise contactless debit card limits with all banks**, including setting their own payment limits

### **Building on existing technology**

We saw enormous potential in better harnessing existing technologies that can help people to live well with dementia, such as the trueCall call blockers.

Wearables and tracking devices, with suitable adaptations, offer huge opportunities to support people with dementia as they navigate retail and leisure environments.

We already have the technology to create a digital version of the current 'sunflower lanyard' scheme. This would remove the need for people with dementia to remember to wear a lanyard, and avoid the potential stigma of visible identification. Wearers could use a smart

wearable to identify themselves to staff at retail and leisure venues and retailers as requiring support without any extra action.

This technology would also offer the ability to create a network of kitemarked dementia-friendly businesses, who can consistently identify customers looking for support.

If the wearers understand and consent, these devices could also let family members, carers, or other trusted people track the wearer. They could help wearers navigate local environments. This might include being linked to 'virtual tours' that allow users to pre-plan routes, or being connect to local transport providers to allow users to get a notification when their bus is coming.

We could also potentially build on smart check-out developments, by companies like Amazon, to create 'single payment zones' that span entire high streets.

### **We recommend:**

- Developers should operate under a principle of **'accessible by default'**, adopting accessible design principles as a matter of course rather than using them for specialist products only. Interoperability should also be taken as the default.
- Developers should work with dementia experts to **develop a 'digital lanyard'** to help frontline staff identify customers with dementia and cognitive impairment, and to relieve those customers' concern over being visibly identified.
- Manufacturers of wearables should **expand the functionality of current personalised tracking devices** designed for those with dementia, to allow more personalised features and enable them to be linked to local services like transport.
- Individual retailers and shopping centres should provide **virtual tours** that allow customers to familiarise themselves with the store layout before leaving home and, where they choose to, programme a route to follow using a handheld/wearable device.
- Local authorities and town centre planners should work with banks and others to consider how technology could be harnessed to create **single payment zones** across whole shopping areas.

## Innovating for the future

While many technologies that could help people with dementia already exist, those innovators who are developing the technologies of the future should also be mindful of the enormous market for devices to support people with dementia.

In our conversations we heard about the potential of tech innovations, such as smart glasses to help people find their way around retail and leisure environments, and of financial technology developments that could offer people with dementia and their carers more secure ways to manage money together.

The recently announced Longitude Prize on Dementia<sup>97</sup> is therefore a positive development. However we will need to build on these investments to make progress faster. In particular we need to consider how to overcome the barriers to bringing new products for people with dementia to market. We need to powerfully make the case for the potential of selling new products that work for people with dementia to the wider market, and to overcome entrenched ageist and ableist attitudes among developers and investors.

### **We recommend:**

- The Government should use its convening power to **bring together technology investors and entrepreneurs** to consider the potential for new developments to support people with dementia
- The Government should consider how it can better **support innovators in the field of dementia to bring their products to market**, overcoming barriers of ageism and ableism.

## Conclusion

As more of us live with dementia, everyone will benefit if the Government, regulators and businesses work together to help customers with dementia to spend more easily. Making spaces and services more inclusive and accessible will make them more welcoming for all.

Over the past year, we heard from industry professionals, people with dementia, and their carers through interviews, focus groups and roundtables. All our stakeholders agree that action is lagging behind rhetoric.

We can improve the high street, and online retailers, for people with dementia by focusing on training and supporting people, improving and streamlining physical and legal infrastructure, and by building on a range of supportive technologies.

Many of these initiatives will require the Government, regulators and businesses to work with dementia experts to improve the use of data, create clearer standards, and develop shared infrastructure. The Government must use its convening and regulatory power to encourage these changes.

Making change now will allow people with dementia to spend independently for as long as possible, help them and their carers to live better lives, and make many physical and online spaces more welcoming and accessible for all. A dementia-friendly shopping and leisure environment is also one that encourages and supports the population as a whole to enjoy 'retail therapy'.

# Appendix

## About this report

For this project we conducted 44 interviews during the period from January to March 2022. Participants included people living with dementia, carers for people with dementia, and people from customer-facing retail professions, such as hospitality, leisure, transport and finance. We ensured that the participants who were living with dementia were diverse with regard to sex, age, type of dementia (including early-onset dementia) and socio-economic status.

We also conducted two focus groups with professionals in the field of diversity and inclusion, from small and large organisations working in a range of sectors. We conducted a roundtable with academics, charity sector professionals and representatives from relevant businesses, to refine the challenges identified in our interviews. This was the basis for an innovation forum with professionals from a variety of sectors.

We undertook analysis using data from Wave 9 of the English Longitudinal Study of Ageing (ELSA), a nationally representative sample of the population in England. We also used data from the Office for National Statistics (ONS) and the Alzheimer's Society. Our aims were to see if the reduction in spending identified in our qualitative research was notable at a national scale and, if so, to quantify the economic impact of this reduction.

To calculate how much those living with dementia and other cognitive impairments spent in relation to their age counterparts with normal cognitive function, we used the ELSA dataset. The variables used to measure whether an individual has dementia included "self-reported dementia diagnosis", "self-related-memory", "self-related other mental abilities" and "objective cognitive functions". We considered measures of cognitive impairment and ability alongside a diagnosis of dementia, as dementia is an ongoing cognitive impairment syndrome. Participants who had been diagnosed may have different levels of cognitive impairment; those that didn't report a diagnosis may have impaired cognitive functions. This made it necessary to consider subjective (self-reported) and objective (measured by a 27-point cognitive function scale<sup>98</sup>) measures of cognitive function. Participants

who scored between 0-6 on the cognitive function scale were classified as having dementia, those between 7-11 were classified as cognitively impaired and those scoring 12 or more were classified as cognitively normal.

Our spending variables were: "spending on food and groceries" and "non-essential spending" (food consumed out of the home, clothes, leisure activities). As the distributions of spending and income are often skewed, which would affect the model, we conducted natural logarithm transformations to all the spending variables when we included them in the model.

To calculate the economic impact of the potential additional spending of those with living dementia, we used data from the Alzheimer's Society and ONS to calculate the number of people living in the UK with dementia and other cognitive impairments.

We used the following equation to calculate the potential additional spending of our sample population: Estimated additional spending = population \* estimated additional spending per person \* 52 / 4. The reason we involve " 52 / 4" is that the spending data we received is the 4-week spending, and there are about 52 weeks a year, therefore we can get the annual spending.

The English Longitudinal Study of Ageing was developed by a team of researchers based at University College London, NatCen Social Research, the Institute for Fiscal Studies, the University of Manchester and the University of East Anglia. The data were collected by NatCen Social Research. The funding is currently provided by the National Institute on Aging (Ref: R01AG017644) and by a consortium of UK government departments: Department for Health and Social Care; Department for Transport; Department for Work and Pensions, which is coordinated by the National Institute for Health Research (NIHR, Ref: 198-1074). Funding has also been provided by the Economic and Social Research Council (ESRC).



## References

- <sup>1</sup>Alzheimer's Society. (2021). How many people have dementia in the UK. Available at: [How many people have dementia in the UK? | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/about-us/how-many-people-have-dementia-in-the-uk/)
- <sup>2</sup>Alzheimer's Society. (2018). *Dementia-friendly retail guide: A practical guide for shops and retailers to support people affected by dementia*. Available at: [AS\\_NEW\\_DF\\_Retail\\_Guide\\_Online\\_09\\_07\\_19.pdf \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/sites/default/files/2019-07/AS_NEW_DF_Retail_Guide_Online_09_07_19.pdf)
- <sup>3</sup>Alzheimer's Society. (2022). Facts for the media about dementia. Available at: [Facts for the media about dementia | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/about-us/facts-for-the-media-about-dementia/)
- <sup>4</sup>CEBR. (2014). The rising costs of dementia. Available at: [The rising costs of dementia - CEBR](https://www.cebri.co.uk/insights/the-rising-costs-of-dementia/)
- <sup>5</sup>Dimitriadis, S. (2019). *Maximising the Longevity Dividend*. The International Longevity Centre-UK. Available at: [Maximising the longevity dividend - ILCUK](https://www.ilcuk.org.uk/publications/maximising-the-longevity-dividend/)
- <sup>6</sup>Alzheimer's Society. (2018). *Dementia-friendly retail guide: A practical guide for shops and retailers to support people affected by dementia*. Available at: [AS\\_NEW\\_DF\\_Retail\\_Guide\\_Online\\_09\\_07\\_19.pdf \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/sites/default/files/2019-07/AS_NEW_DF_Retail_Guide_Online_09_07_19.pdf)
- <sup>7</sup>Alzheimer's Society. (2021). Young-onset dementia. Available at: [Young-onset dementia | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/about-us/young-onset-dementia/)
- <sup>8</sup>Alzheimer's Society. (2016). *Becoming a dementia-friendly retailer: A practical guide*. Available at: [https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia\\_friendly\\_retail\\_guide.pdf](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_friendly_retail_guide.pdf)
- <sup>9</sup>ILC-UK. (2016). *The Missing £Billions: The economic cost of failing to adapt our high street to respond to demographic change*. Available at: [ILC-UK-The-Missing-Billions.pdf \(ilcuk.org.uk\)](https://www.ilcuk.org.uk/publications/the-missing-billions/)
- <sup>10</sup>Alzheimer's Society. *Dementia-friendly retail guide: A practical guide for shops and retailers to support people affected by dementia*. Available at: [AS\\_NEW\\_DF\\_Retail\\_Guide\\_Online\\_09\\_07\\_19.pdf \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/sites/default/files/2019-07/AS_NEW_DF_Retail_Guide_Online_09_07_19.pdf)
- <sup>11</sup>ILC-UK. (2021). *Years lost: Boosting life expectancy through preventative health interventions*. The International Longevity Centre-UK. Available at: [ILC-Years-lost-Boosting-life-expectancy-through-preventative-health-interventions.pdf \(ilcuk.org.uk\)](https://www.ilcuk.org.uk/publications/years-lost-boosting-life-expectancy-through-preventative-health-interventions.pdf)
- <sup>12</sup>Department of Health and Social Care. (2015). *Policy paper: Prime Minister's challenge on dementia 2020*. Available at: [Prime Minister's challenge on dementia 2020 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/442212/prime-minister-s-challenge-on-dementia-2020.pdf)
- <sup>13</sup>The King Fund. (2019). *Cancer or dementia: the social care system is unfair to people with either condition*. The King's Fund. Available at: [Cancer or dementia: the social care system is unfair to people with either condition | The King's Fund \(kingsfund.org.uk\)](https://www.kingsfund.org.uk/publications/cancer-or-dementia-the-social-care-system-is-unfair-to-people-with-either-condition/)
- <sup>14</sup>House of Lords Library. (2021). *In Focus: All Party Parliamentary Group on Dementia report*. UK Parliament. Available at: [All Party Parliamentary Group on Dementia report - House of Lords Library](https://www.parliament.uk/business/committees/committees-a-z/all-party-groups/all-party-parliamentary-group-on-dementia/)

- <sup>15</sup>Alzheimer's Society. (2021). *How much does dementia care cost?* Available at: [How much does dementia care cost? | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/news-and-comment/charts-and-infographics/REAL-social-care-funding-gap)
- <sup>16</sup>The Health Foundation. (2021). *Social care funding gap: Our estimates of what it would cost to stabilise and improve adult social care in England.* Available at : <https://www.health.org.uk/news-and-comment/charts-and-infographics/REAL-social-care-funding-gap>
- <sup>17</sup>BBC News. (2021). *Boris Johnson outlines new 1.25% health and social care tax to pay for reforms.* Available at: [Boris Johnson outlines new 1.25% health and social care tax to pay for reforms - BBC News](https://www.bbc.com/news/health-58111111)
- <sup>18</sup>House of Lords Library. (2021). *In Focus: All Party Parliamentary Group on Dementia report.* UK Parliament. Available at: [All Party Parliamentary Group on Dementia report - House of Lords Library](https://www.parliament.uk/library/research-and-briefing/papers/2021/01/all-party-parliamentary-group-on-dementia-report/)
- <sup>19</sup>Alzheimer's Society. (2021). *Maximising the UK Dementia Research Moonshot for people affected by dementia.* Available at: [Maximising the UK Dementia Research Moonshot for people affected by dementia | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/news-and-comment/press-releases/maximising-the-uk-dementia-research-moonshot-for-people-affected-by-dementia/)
- <sup>20</sup>Alzheimer's Society. (Unknown). *Dementia Friends.* Available at: <https://www.dementiafriends.org.uk/>
- <sup>21</sup>Alzheimer's Society. (Unknown). *What is a dementia-friendly community?* Available at: [What is a dementia-friendly community? | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/news-and-comment/press-releases/what-is-a-dementia-friendly-community/)
- <sup>22</sup>NIHR. (Unknown). *Project AMM08: The DEMCOM study – A National Evaluation of Dementia Friendly Communities.* Available at: [The DEMCOM study: A National Evaluation of Dementia Friendly Communities | ARC East of England \(nihr.ac.uk\)](https://www.nihr.ac.uk/about/2018/07/26/the-demcom-study-a-national-evaluation-of-dementia-friendly-communities/)
- <sup>23</sup>Dementia Friends. (2018). *'We've reached 2.5 million Dementia friends!.* Available at: <https://www.dementiafriends.org.uk/WEBNewsStory?storyId=a0B-oJ00000rPGW5UAO#:~:text=Alzheimer%27s%20Society%20is%20proud%20to,the%20charity%27s%20Dementia%20Friends%20initiative.>
- <sup>24</sup>Longitude Prize. (2022). *Press release: Introducing The Longitude Prize on Dementia; the second instalment of the modern Longitude Prize.* Available at: [Introducing The Longitude Prize on Dementia; the second instalment of the modern Longitude Prize - Longitude Prize](https://www.longitudeprize.org.uk/news/2022/02/22/introducing-the-longitude-prize-on-dementia-the-second-instalment-of-the-modern-longitude-prize/)
- <sup>25</sup>Department of Health and Social Care. (2015). *Policy paper: Prime Minister's challenge on dementia 2020.* Available at: [Prime Minister's challenge on dementia 2020 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/442412/prime-ministers-challenge-on-dementia-2020.pdf)
- <sup>26</sup>Department of Health. (2016). *Prime Minister's Challenge on Dementia 2020: Implementation Plan.* Available at: [Prime Ministers Challenge on Dementia 2020 \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/524412/prime-ministers-challenge-on-dementia-2020-implementation-plan.pdf)
- <sup>27</sup>Alzheimer's Society. (2018). *Dementia-friendly retail guide: A practical guide for shops and retailers to support people affected by dementia.* Available at: [AS\\_NEW\\_DF\\_Retail\\_Guide\\_Online\\_09\\_07\\_19.pdf \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/news-and-comment/press-releases/dementia-friendly-retail-guide-a-practical-guide-for-shops-and-retailers-to-support-people-affected-by-dementia/)
- <sup>28</sup>Equality Act. (2010). Accessed at: [Equality Act 2010 \(legislation.gov.uk\)](https://www.legislation.gov.uk/ukpga/2010/15/section/1)

<sup>29</sup>Alzheimer's Society. 2015. *Alzheimer's Society's view on equality, discrimination and human rights*. Available at: [Alzheimer's Society's view on equality, discrimination, and human rights | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/about-us/news-and-views/2015/03/alzheimers-society-view-on-equality-discrimination-and-human-rights)

<sup>30</sup>Financial Conduct Authority. (2021). *Guidance for firms on the fair treatment of vulnerable customers*. Available at: [Guidance for firms on the fair treatment of vulnerable customers | FCA](https://www.fca.gov.uk/consumer-protection/guidance-fair-treatment-vulnerable-customers)

<sup>31</sup>Mental Capacity Act. (2005). Accessed at: [Mental Capacity Act 2005 \(legislation.gov.uk\)](https://www.legislation.gov.uk/ukpga/2005/9)

<sup>32</sup>Department of Health and Social Care. (2016). *Guidance: Care Act factsheets*. Available at: [Care Act factsheets - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/541222/care-act-factsheets-2016.pdf)

<sup>33</sup>Alzheimer's Society. (Unknown). *Driving and dementia*. Available at: [Driving and dementia | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/about-us/news-and-views/2015/03/driving-and-dementia)

<sup>34</sup>Musselwhite, C. (2011). *The importance of driving for older people and how the pain of driving cessation can be reduced*. *Signpost: Journal of Dementia and Mental Health*, 15(3), 22-26. 1. Available at: [Musselwhite - attitudes towards driving and giving it up\\_JoMHaD\\_pre\\_print \(1\).pdf](https://www.signpost.co.uk/pdf/e0111111.pdf)

<sup>35</sup>Alzheimer's Society. (2019). *How to apply for a blue badge for a person with dementia*. Available at: <https://www.alzheimers.org.uk/blog/how-apply-blue-badge-person-dementia>

<sup>36</sup>Alzheimer's Society. (2021). *5 simple ways to make public transport inclusive for people with dementia during coronavirus*. Available at: <https://www.alzheimers.org.uk/blog/dft-inclusive-transport-its-everyones-journey>

<sup>37</sup>O'Reilly, N. Shepard, H. Edwards, J. Franz, L. Willmott, E. Fielding, Biette, E.R. (2017). Aging in the era of air travel: Improving the accessibility of airports for travellers with dementia. *Innovation in Aging*. Available at: [AGING IN THE ERA OF AIR TRAVEL: IMPROVING THE ACCESSIBILITY OF AIRPORTS FOR TRAVELERS WITH DEMENTIA | Innovation in Aging | Oxford Academic \(oup.com\)](https://www.oup.com/academic/view/9780190854444/1-1)

<sup>38</sup>Network Rail Accessibility Team. (2020). *Design Manual NR/GN/CIV/300/04: Inclusive Design*. Available at: [Inclusive Design design manual NR/GN/CIV/300/04 \(networkrail.co.uk\)](https://www.networkrail.co.uk/~/media/NetworkRail/Accessibility/DesignManual/NRGN-CIV30004.pdf)

<sup>39</sup>Community Rail Network. (Unknown). *Leeds-Morecambe Community Rail Partnership, Northern and partners*. Available at: [Dementia and Community Rail - Community Rail Network](https://www.networkrail.co.uk/~/media/NetworkRail/Accessibility/DesignManual/NRGN-CIV30004.pdf)

<sup>40</sup>[Ibid](#)

<sup>41</sup>Heathrow and University of Plymouth. (2021). *Flying with Dementia: An informative guide*. Available at: [https://www.plymouth.ac.uk > uploads > production > document > path > 21 > 21319 > Heathrow\\_Dem](https://www.plymouth.ac.uk/uploads/production/document/path/21/21319/Heathrow_Dem)

<sup>42</sup>Andrews, M. (2021). *Trouble Managing Money May Be an Early Sign of Dementia*. *KHN*. Available at: [Trouble Managing Money May Be an Early Sign of Dementia | Kaiser Health News \(khn.org\)](https://www.khn.com/news/dementia/2021/05/04/trouble-managing-money-may-be-an-early-sign-of-dementia/)

<sup>43</sup>Bang, J. Spina, S. Miller, B.L. (2015). *Frontotemporal dementia*. *The Lancet*, vol 386 (10004). Pp 1672-1682. Available at: [Frontotemporal dementia - ScienceDirect](https://www.sciencedirect.com/science/article/pii/S0140673615004444)

<sup>44</sup>Lifted Team. (2018). *The GOOD and BAD news about shopping when you have dementia*. Lifted. Available at: The GOOD and BAD news about shopping when you have dementia - [Lifted \(liftedcare.com\)](https://liftedcare.com)

<sup>45</sup>[bid](#)

<sup>46</sup>Woo, B.K.P. (2020). *Dementia-Related Products on an e-Commerce Platform*. JMIR Biomed Eng. Vol 5(1). Available at: JMIR Biomedical Engineering - Dementia-Related Products on an e-Commerce Platform

<sup>47</sup>CPS. (Unknown). *Fraud and economic crime*. Available at: Fraud and economic crime | The Crown Prosecution Service ([cps.gov.uk](https://cps.gov.uk))

<sup>48</sup>Age UK. (2015). *Financial Abuse Evidence Review*. Age UK Research. Available at: [Financial Abuse Evidence Review \(ageuk.org.uk\)](https://ageuk.org.uk)

<sup>49</sup>[bid](#)

<sup>50</sup>AgeUK. (2022). *Staying safe online*. Available at: [Staying safe online - tips for older people | Age UK](#)

<sup>51</sup>Independent Age. (Unknown). How to avoid a scam. Available at: [How to avoid a scam | Independent Age](#)

<sup>52</sup>Bracknell Forest Council and West Berkshire Council. (Unknown). *No Cold Calling Zones*. Available at: No Cold Calling Zones - PPP ([publicprotectionpartnership.org.uk](https://publicprotectionpartnership.org.uk))

<sup>53</sup>Alzheimer's Society. (2011). *Short changed: Protecting people with dementia from financial abuse*. Available at: [Short Changed: Protecting People with Dementia from Financial Abuse \(alzheimers.org.uk\)](https://alzheimers.org.uk)

<sup>54</sup>Bracknell Forest Council and West Berkshire Council. (Unknown). *No Cold Calling Zones*. Available at: No Cold Calling Zones - PPP ([publicprotectionpartnership.org.uk](https://publicprotectionpartnership.org.uk))

<sup>55</sup>Prime Minister's Office, 10 Downing Street. (2017). Press release: *Government helps dementia sufferers in fight against nuisance calls*. Available at: [Government helps dementia sufferers in fight against nuisance calls - GOV.UK \(www.gov.uk\)](https://www.gov.uk)

<sup>56</sup>National Trading Standards. (2018). Successful project blocks over 100,000 nuisance calls. Available at: [Successful project blocks over 100,000 nuisance calls - National Trading Standards](#)

<sup>57</sup>[bid](#)

<sup>58</sup>Anchor. (2017). *£4.5bn annual high street losses predicted by 2030 as retailers fail to attract grey pound*. Available at: [£4.5bn annual high street losses predicted by 2030 as retailers fail to attract grey pound | Anchor](#)

<sup>59</sup>InformationNOW. (2021). *Dementia Space at The Grainger Market*. Available at: [Dementia Space at the Grainger Market - Information Now](#)

<sup>60</sup>Hidden Disabilities Sunflower. (2021). *The Sunflower is for people with non-visible disabilities*. Available at: [A symbol for non-visible disabilities \(hiddendisabilitiesstore.com\)](https://hiddendisabilitiesstore.com)

- <sup>61</sup>Alzheimer's Society. (2021). *Helpcards to support people with memory problems or dementia*. Available at: [Helpcards to support people with memory problems or dementia | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/helpcards-to-support-people-with-memory-problems-or-dementia)
- <sup>62</sup>Santander UK. (Unknown). *Dementia-friendly banking*. Available at: [Dementia | Santander UK](https://www.santander.co.uk/dementia-friendly)
- <sup>63</sup>[bid](#)
- <sup>64</sup>Santander UK. (Unknown). *Dementia Guide: Information for people affected by dementia*. Available at: dementia guide.pdf ([santandersustainability.co.uk](https://www.santandersustainability.co.uk))
- <sup>65</sup>NIHR. (Unknown). Project AMM08: *The DEMCOM study – A National Evaluation of Dementia Friendly Communities*. Available at: [The DEMCOM study: A National Evaluation of Dementia Friendly Communities | ARC East of England \(nihr.ac.uk\)](https://www.nihr.ac.uk/projects/the-demcom-study-a-national-evaluation-of-dementia-friendly-communities)
- <sup>66</sup>Salford Community Leisure. (Unknown). *Dementia Friendly*. Available at: [Dementia Friendly - SCL \(salfordcommunityleisure.co.uk\)](https://www.salfordcommunityleisure.co.uk/dementia-friendly)
- <sup>67</sup>PSNC. (2022). *Pharmacy Quality Scheme*. Available at: [Pharmacy Quality Scheme - PSNC Website](https://www.pharmacyqualityscheme.org/)
- <sup>68</sup>SozialMarie. (2018). *Mission Dementia*. Available at: [Mission Dementia | Sozial-Marie](https://www.sozialmarie.com/mission-dementia)
- <sup>69</sup>EIPA. (2021). *Mission Dementia – Knowledge in communicating with persons with dementia—an internet learning program for police officers in Austria*. Available at: [EIPA - EPSA Project - Mission Dementia - Knowledge in communicating with persons with dementia - an internet based learning program for police officers in Austria](https://www.eipa.europa.eu/eipa-epsa-project-mission-dementia-knowledge-in-communicating-with-persons-with-dementia-an-internet-based-learning-program-for-police-officers-in-austria)
- <sup>70</sup>Alzheimer's Society. (2015). *Dementia-friendly arts guide*. Available at: [AS\\_DF\\_NEW\\_Arts\\_Guide\\_Online\\_09\\_07\\_19.pdf \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/assets/Uploads/AS_DF_NEW_Arts_Guide_Online_09_07_19.pdf)
- <sup>71</sup>Alzheimer's Society. (2022). *What makes a dementia-friendly cinema?* Available at: [What makes a dementia-friendly cinema? | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/what-makes-a-dementia-friendly-cinema/)
- <sup>72</sup>Brosdahl, D. Edwards, K. Hughes, P. Rosenbaum, M. S. (2018). *Designing retail spaces for inclusion*. Journal of Retailing and Consumer Services. Vol 44. Pp 182-190. Available at: <https://www.sciencedirect.com/science/article/abs/pii/S0969698918302522>
- <sup>73</sup>Lord's. (2022). *Accessibility*. Available at: [Accessibility | Lord's \(lords.org\)](https://www.lords.org/accessibility)
- <sup>74</sup>[10 Lifesaving Location Devices for Dementia Patients | Alzheimers.net](https://www.alzheimers.net/10-lifesaving-location-devices-for-dementia-patients)
- <sup>75</sup>Sauer, A. (2018). *10 Lifesaving Location Devices for Dementia Patients*. Alzheimer's.net. Available at: [Article | A design assessment tool for layout planning in residential care for dementia | University of Stirling](https://www.alzheimers.net/article/a-design-assessment-tool-for-layout-planning-in-residential-care-for-dementia)
- <sup>76</sup>Fleming, R. Ostwald, M. Quirke, M. Taylor, M. Williams, A. (2021). *A design assessment tool for layout planning in residential care for dementia*. Architectural Science Review. Available at: [Article | A design assessment tool for layout planning in residential care for dementia | University of Stirling](https://www.alzheimers.net/article/a-design-assessment-tool-for-layout-planning-in-residential-care-for-dementia)

<sup>77</sup>Fleethants. (Unknown). *Fleet Becomes North Hampshire's First Dementia Friendly High Street*. Available at: [New Page 2 \(fleethants.com\)](#)

<sup>78</sup>Dementia Action Alliance (Unknown). *Making buildings easier for people with dementia*. Available at: [dementia-checklist-interactive.pdf \(fdean.gov.uk\)](#)

<sup>79</sup>University of Stirling. (2022). *Pioneering tool to support design of dementia friendly spaces*. Available at: [Pioneering tool to support design of dementia friendly spaces | About | University of Stirling](#)

<sup>80</sup>Warrington Borough Council. (2020). *Community hub becomes world's first public building to secure 'gold' dementia-friendly standard*. Available at: [Community hub becomes world's first public building to secure 'gold' dementia-friendly standard | warrington.gov.uk](#)

<sup>81</sup>UK Cinema Association. (2017). *Dementia Friendly Screenings: A guide for cinemas*. Available at: [Dementia-Friendly-Screenings\\_Guide\\_for\\_cinemas.pdf \(cinemauk.org.uk\)](#)

<sup>82</sup>The Castle Cinema. (2021). *Introducing monthly dementia-friendly screenings!* Available at: [Introducing monthly dementia-friendly screenings! · The Castle Cinema Blog](#)

<sup>83</sup>Whitehead, J. (2020). *Missing credit card or loan payments could be early sign of dementia, finds study*. The Independent. Available at: [Missing credit card or loan payments could be early sign of dementia, finds study | The Independent](#)

<sup>84</sup>Alzheimer's Society. (2019). *Living with dementia – Managing your money*. Available at: [Living with dementia - Managing your money | Alzheimer's Society \(alzheimers.org.uk\)](#)

<sup>85</sup>Age UK. (2021). *Age UK Behind the Headlines Short-changed: How the decline of cash is affecting older people*. Available at: [behind\\_the\\_headlines\\_shortchanged.pdf \(ageuk.org.uk\)](#)

<sup>86</sup>Alzheimer's Society. (2011). *Short changed: Protecting people with dementia from financial abuse*. Available at: [Short Changed: Protecting People with Dementia from Financial Abuse \(alzheimers.org.uk\)](#)

<sup>87</sup>[Ibid](#)

<sup>88</sup>The Money Carer Foundation. (Unknown). *A client with Early Onset Dementia*. Available at: [A Client With Early Onset Dementia | Case Studies | The Money Carer Foundation](#)

<sup>89</sup>Biggs, S. Constantine, R. Doyle, M. Erens, B. Hills, A. Manthorpe, J. McCreddie, C. O'Keeffe, M. Scholes, S. Tinker, A. (2007). *UK Study of Abuse and Neglect of Older People Prevalence Survey Report*. Prepared for Department of Health. Available at: [\(PDF\) UK Study of Abuse and Neglect of Older People Prevalence Survey Report \(researchgate.net\)](#)

<sup>90</sup>Age UK. (2021). *Age UK Behind the Headlines Short-changed: How the decline of cash is affecting older people*. Available at: [behind\\_the\\_headlines\\_shortchanged.pdf \(ageuk.org.uk\)](#)

<sup>91</sup>Age UK North Tyneside. (2021). *One in Five Older People Rely on Cash for Everyday Spending*. Available at: [One in Five Older People Rely On Cash For Everyday Spending \(ageuk.org.uk\)](https://www.ageuk.org.uk)

<sup>92</sup>Anchor. (2017). *£4.5bn annual high street losses predicted by 2030 as retailers fail to attract grey pound*. Available at: [£4.5bn annual high street losses predicted by 2030 as retailers fail to attract grey pound | Anchor](https://www.anchor.co.uk)

<sup>93</sup>FCA. (2021). *Financial Lives 2020 Survey: the impact of coronavirus*. Available at: [Financial Lives 2020 survey: the impact of coronavirus | FCA](https://www.fca.org.uk)

<sup>94</sup>Sibstar. (2022). *How it works*. Available at: [How it works — Sibstar](https://www.sibstar.co.uk)

<sup>95</sup>GuardianCard | [Secure Debit Card for Carers & Relatives](https://www.guardiancard.co.uk)

<sup>96</sup>FCA. (2022). FCA Handbook: SYSC 5.1 *Skills, knowledge and expertise*. Accessed at: [https://www.handbook.fca.org.uk > handbook > SYSC > 5 > 1.html](https://www.handbook.fca.org.uk)

<sup>97</sup>Alzheimer's Society. (2022). *Longitude Prize on Dementia*. Available at: [https://www.alzheimers.org.uk/longitude-prize](https://www.alzheimers.org.uk)

<sup>98</sup>ELSA. (2021). *The dynamics of ageing: The 2018/2019 English Longitudinal Study of Ageing (Wave 9) Technical Report*. Available at: [ELSA Wave 9 Technical Report \(ukdataservice.ac.uk\)](https://www.ukdataservice.ac.uk)

## About ILC

The International Longevity Centre UK (ILC) is the UK's specialist think tank on the impact of longevity on society. The ILC was established in 1997, as one of the founder members of the International Longevity Centre Global Alliance, an international network on longevity. We have unrivalled expertise in demographic change, ageing and longevity. We use this expertise to highlight the impact of ageing on society, working with experts, policy makers and practitioners to provoke conversations and pioneer solutions for a society where everyone can thrive, regardless of age.



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