

Hidden no more: Dementia and disability



All-Party
Parliamentary Group
on Dementia

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The information in this report, including reference to policies and Government status on issues, is correct at the time of writing (April 2019).

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Debbie Abrahams MP
Co-chair of the APPG
on Dementia



**Baroness Sally
Greengross OBE**
Co-chair of the
APPG on Dementia

Foreword

In 2018, the All-Party Parliamentary Group (APPG) on Dementia committed to adopt a rights-based approach to achieving change for people with dementia.

We also committed to use the Dementia Statements as a basis for all of our future work. The Dementia Statements reflect the things people with dementia and their carers say are essential to their quality of life. As Co-chairs of the APPG, we would like to take this opportunity to pay tribute to the important role of family carers. It is vital they are supported.

Grounded in human rights law, the Statements are a rallying call to improve the lives of people with dementia and to recognise that they shouldn't be treated differently because of their condition.

In legislation, dementia is a disability. Despite this, over the past year the APPG has gathered extensive evidence, driven by the voices of people affected by dementia, which has revealed that people with dementia are not having their disability rights met. People with dementia are losing out on the protection that legislation is supposed to provide, and this needs to change.

This inquiry is therefore closely aligned to the following Dementia Statements:

'We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.'

'We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.'



Debbie Abrahams MP
Co-chair of the APPG on Dementia

We use the social model of disability as the framework for this inquiry, which views people as being disabled primarily by barriers in society, not by their impairment or difference. Recognising dementia as a disability has been an important part of campaigning for change. It has received increased focus from people affected by dementia and organisations working in the field of dementia. When dementia is recognised as a disability, it helps to identify the societal barriers that prevent people with the condition living independently and it provides a framework for action based on disability rights.

We are not suggesting that dementia should only be understood in terms of a disability. People affected by dementia may prefer to describe it in terms of a condition, rather than a disability. However, we feel that this doesn't negate the need for social adjustments that enable people with dementia to continue to participate in their communities, and ensure social inclusion and change.

We want to raise awareness of the importance of recognising dementia as a disability and aim to bring about tangible changes, both nationally and locally, that will make a significant impact on the day-to-day lives of people with dementia.

'I want to live with dementia not exist with dementia.'

Person living with dementia

Our aim is nothing less than to ensure that the rights of people with dementia are finally recognised, just as all disabled people's rights should be.



Baroness Sally Greengross OBE
Co-chair of the APPG on Dementia

Executive summary

Dementia is a disability, according to domestic law and international convention. Thousands of people who responded to the All-Party Parliamentary Group (APPG) inquiry agreed that they see dementia as a disability. However, they told the APPG that society is lagging behind in this understanding and failing to uphold the legal rights of people with dementia.

This report aims to shine a spotlight on dementia as a disability, to enable people with dementia to assert their rights to services and for their rights as citizens to be treated fairly and equally.

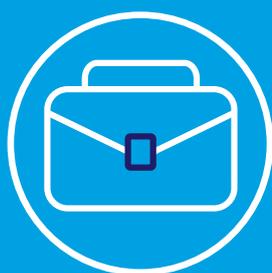
Evidence presented to this inquiry revealed that, across the country, people with dementia are not having their disability rights upheld. This report seeks to highlight the human impact this has on people living with dementia. It focuses on themes of equality, non-discrimination, participation and inclusion.

This inquiry also revealed the societal barriers that are preventing people with dementia from living independently. **Almost all (98%) of the 2,521 survey respondents thought that people living with dementia are treated differently to people with other health conditions or disabilities.** They believe that this is due to the progressive but 'hidden' nature of dementia, the individuality of dementia and its symptoms, and the stigma surrounding the condition.

The public, employers, organisations, governments and public bodies need to be more aware of, and recognise, the rights of people with dementia. This includes recognising dementia as a disability and upholding the relevant entitlements of people with the condition. These rights are enshrined under both the Equality Act 2010 and the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Submissions to this inquiry revealed that action needs to be taken across a number of key areas to make sure people with dementia receive the protections and safeguards that legislation and convention provides.

In this report we focus on six of these key areas which have a direct impact on people's daily lives. We identify opportunities for action, based on what respondents told us they found challenging in each area. These are listed below.



Employment

- There must be more awareness of the employment rights of people with dementia among both employers and employees.
- People need to feel empowered to tell their employers about their diagnosis.
- Employers should feel supported to fulfil their responsibilities to make reasonable adjustments to ensure people with dementia can continue to make a meaningful contribution in the workplace.



Social protection

- People with dementia and their carers often need support to know what financial help they are entitled to, as well as how to make a successful claim. They deserve to be assessed by professionals who understand the condition, without having to undergo unnecessary reviews or reassessments.
- Assessment processes must be clear and appropriate for people with cognitive impairments.



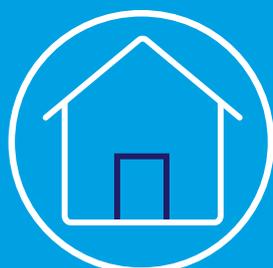
Social care

- The medical and social care support available to people with dementia is inadequate and inaccessible.
- The forthcoming Green Paper on social care reform must recognise and reflect the needs of people living with dementia, now and in the future.



Transport

- People with dementia face a lack of alternatives to driving. It is imperative that any changes to bus and community transport services are reviewed in the context of the Public Sector Equality Duty (PSED).
- Reasonable adjustments must be made that enable people to continue to use public transport.
- There must be an increase in societal awareness to reduce the stigma and discrimination that people with dementia feel while using public transport.



Housing

- People with dementia have the right to personal choice over where, and how, they live. Our evidence found that people want to live independently for longer, but limited availability of appropriate housing means they are faced with a lack of personal choice. They must have access to adaptable housing, trained home-care staff, and specialised supported housing schemes.



Community life

- Communities must increase their awareness and understanding of dementia and people need to be supported through the development of inclusive communities where no one is excluded or has to face dementia alone.

Throughout this report we make recommendations, calling on local and national government to take action in each of these areas of daily life. This will create meaningful change for people with dementia. The recommendations can be found at the end of each section, and in the summary of recommendations on page 43.

Collecting the evidence

The APPG on Dementia undertook an extensive evidence-gathering exercise to inform the contents of this inquiry. It achieved one of the largest responses to any APPG inquiry, highlighting the fundamental importance of the topic.

There was an online self-selecting survey open between May and July 2018, which received 2,521 responses. The respondents of the survey fell into the following groups*:



3% people living with dementia



80% people directly linked to people with dementia, such as carers, family and friends



18% people who knew a person with dementia (now deceased)



2% people with no direct experience of dementia



23% people working, or who have worked, in the field of dementia.

A further survey was conducted between April and May 2019 that looked specifically at how people with dementia feel about identifying dementia as a disability. This survey received responses from 168 people with dementia.

As well as the surveys, there were 14 focus groups, which consulted with 76 people with dementia and 11 carers. These were held across England, Wales and Northern Ireland between April and July 2018.

There were also 28 responses received to the written call for evidence, including responses from individual people affected by dementia, groups of people with dementia, professional bodies, independent consultants and third-sector organisations.

An oral evidence session was also held, which heard from representative organisations, people with dementia and carers.

For a more detailed breakdown of how we collected the evidence for this report, see 'Methodology' on page 46.

* Some respondents selected more than one identity profile, which is why the numbers do not add up to 100%.

Introduction: Dementia and disability



There are currently 850,000 people living with dementia in the UK¹.



Approximately 1 in 14 people over the age of 65 have dementia².



There are at least 40,000 people under the age of 65 living with dementia³.



By 2051, the number of people with dementia in the UK is set to rise to over 2 million⁴.

Dementia is a complex and progressive neurological condition which occurs when the brain is damaged by diseases (such as Alzheimer's disease) or a series of strokes. The symptoms of dementia can include memory loss and difficulties with thinking, problem-solving, language and physical function. The specific symptoms that someone experiences will depend on the parts of their brain that are damaged and the underlying cause of their dementia.

'It disables peoples' memories, choices, decisions and actions.'

Family carer

'If this isn't a disability then I don't know what is.'

Family carer

The cognitive and physical impairments caused by dementia are recognised as a disability both under domestic law⁵ and international convention⁶. This means that people with dementia have legal protections and entitlements which should:

- ensure laws and policies are applied in line with disability legislation
- remove barriers and develop inclusive practices
- establish financial and practical support
- tackle prejudicial attitudes and stereotypes⁷.

All of these steps would support people with dementia to continue to participate in their communities as full and equal citizens. We heard that, currently, people with dementia are facing significant challenges in having their disability rights recognised and upheld. This means that, too often, people with dementia are not benefiting from the protection these laws are supposed to provide.

'People give up what they are entitled to because they cannot fight the system while they try and fight the disease. It shouldn't be a fight.'

Person living with dementia

‘More education and training is required with young people, carers, people with dementia and professionals to move the discussion on rights and equality from rhetoric to reality.’

Tide – together in dementia everyday

The Equality Act 2010 and the United Nations Convention on the Rights of Persons with Disabilities (CRPD) are the basis on which this inquiry has determined whether people with dementia are having their disability rights met.

- The Equality Act looks to prohibit discrimination, including in the provision of goods and services, and by making ‘reasonable adjustments’.
- The CRPD is an international treaty passed by the UN in 2006 and signed by the UK in 2009. It exists to protect and promote the human rights of disabled people. Policies and practices at all levels of government in the UK must comply with the convention. The CRPD covers a wide range of areas, including health, employment, personal security, independent living, access to justice and access to information. It includes both negative rights (prohibitions) and positive rights (permissions and services).

The Equality Act 2010 states that: ‘A person (P) has a disability if –

- a P has a physical or mental impairment*, and
- b the impairment has a substantial and long-term adverse effect on P’s ability to carry out normal day-to-day activities.’

The Public Sector Equality Duty (PSED) was created by the Equality Act 2010. It applies to all nine areas of discrimination listed in the Act, including disability. It states that those subject to the duty must give due regard to the need to:

- eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act
- advance equality of opportunity between people who share a protected characteristic and those who do not
- foster good relations between people who share a protected characteristic and those who do not.

The CRPD defines people with disabilities as:

‘Those who have long-term physical, mental, intellectual** or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.

The widespread ratification of the CRPD demonstrates its increasingly influential role in raising the profile of human rights for people with disabilities. It gives important context to this inquiry as a tool to achieve change. Disappointingly, the CRPD Committee notes that there is no comprehensive UK-wide strategy to implement the CRPD Committee’s recommendations⁸.

Over the past few years there has been an increased focus on understanding dementia as a disability. This has happened in conjunction with the growing consideration of rights-based approaches in policy and practice for people living with dementia. The voices of people affected by dementia have been an important part of this change. Evidence of this work can be found in publications by the Mental Health Foundation⁹, Alzheimer Europe¹⁰ and the Voluntary Organisations Disability Group¹¹, as well as in reports produced by people with dementia about disability rights¹² and for the UN committee responsible for the CRPD^{13 14}.

* ‘Mental’ includes cognitive impairments, such as dementia.

** ‘Mental and intellectual’ includes cognitive impairments, such as dementia.

Dementia and the social model of disability

The framework for this inquiry is based on the social model of disability¹⁵, which views people as being disabled primarily by barriers in society, not by their impairment or difference. The social model, on which the CRPD is founded, suggests that there are a number of factors which create or contribute to the challenges, exclusion and discrimination faced by people with dementia. These factors are the social arrangements, behaviours, norms and practices in wider society. It is these environmental factors and personal attitudes that need to be addressed in order to tackle disability in society, and not the individual impairments related to dementia. Both the CRPD and the Equality Act use the language of ‘impairment’, not ‘diagnosis’, because of the prejudice, stigma and discrimination that medical diagnoses can generate (especially in psychiatry).

The APPG challenges the mainstream biomedical model of disability, which (in contrast to the social model) views disability as a product of an impairment or difference in the individual. The biomedical model looks at what is ‘wrong’ with the person, rather than what they might need to have independence, choice and control. Respondents to the inquiry also highlighted the ‘medicalised language’ which is often used in relation to dementia. This language can perpetuate the idea of something being ‘wrong’ with the person, and neglect the role that public services and society have in enabling people with dementia to live well.

‘Accepting dementia as a disability, and moving forward to learn how to manage it as such, rather than getting trapped in a medical route of gloom, medication, suffering and inevitable decline, has transformed our approach to this new and unsettling situation. It has enabled my mum and I to make radical changes in our approach to caring for my dad, resulting, most importantly, in a transformation in his quality of life.’

Family carer

‘While the search for a “cure” continues, people can forget that there are many non-medical approaches that can influence a positive adjustment for individuals and families.’

Survey respondent

The APPG understands that dementia is a multi-faceted condition which everybody will experience differently. Some survey respondents told us that they do not identify dementia as a disability because this does not focus enough on the medical needs of a person with the condition. Others prefer to think about the causes behind the symptoms of dementia, rather than ‘dementia’ as a single condition. The APPG recognises that there is still an overwhelming need to continue to search for cures and medical advances to provide treatments for all forms of dementia. However this should not be the only approach to helping people live well with the condition. The search for cures must accompany the push for social adjustments, to ensure social inclusion and change for people with dementia.

How do people feel about identifying dementia as a disability?

Our research revealed a very important finding: **81% of respondents to our online survey confirmed that they see dementia as a disability and that it should be identified as such.** This was confirmed by the majority of people in our focus groups and those who provided us with written evidence. However, it was clear that many respondents were still defining disability in terms of the individual’s challenges, rather than a wider social challenge. This indicates that the biomedical model of understanding disability is probably more common than a social model of understanding disability.

‘What does it matter how I or any of us feel about the label? Language is important, but this discussion is a “nice to have” topic for when the important issues that will make a real difference are sorted. Are we disabled? Of course we are. If you ever have to listen to me speaking about my life, you will consistently hear me asking for assistance to enable me to live as well as I can. My friends say the same.’

Person living with dementia

There were three main reasons why respondents viewed dementia as a disability:

① Dementia is progressive.

As a person's dementia progresses they will come to need more support with daily living. However, the 'hidden' nature of the diseases that cause dementia and its symptoms can make it difficult for others to recognise a person with dementia as having disabilities – even as their condition progresses.

Often, in the earlier stages of dementia, a person's symptoms can be quite mild. People may not understand that dementia is causing a person's behaviour or cognitive difficulties. This can lead to discrimination.

'Physically, they remain the same for most of their journey through dementia, which brings comments such as "well he doesn't look as though there is anything wrong". This masks the true depths of the disability.'

Family carer

'The progression of the disease robs [people] of the ability to reason out situations and their world is very different from ours.'

Family carer

② Dementia affects everyone differently.

This means that the public, employers, organisations, government and public bodies are not always aware of how best to support someone with the condition.

We need to put the person with dementia at the heart of this debate. Despite the UK having ratified the CRPD and legal requirements under the Equality Act (such as making reasonable adjustments) this inquiry has heard they are not common practice for people with dementia.

'Physical disabilities are easily seen and understood but cognitive problems are far harder to adjust to.'

Family member and healthcare assistant in a care home specialising in dementia

'I believe there is still a great deal of misunderstanding in general regarding dementia. People who have little experience tend to think everyone will follow the same pathway and are very blinkered to the uniqueness of the condition for each individual.'

Family member and third-sector professional

③ People with dementia face stigma and a lack of understanding within society.

Identifying dementia as a disability enables people to reinforce their rights to services and their rights as citizens to be treated fairly and equally.

More than a quarter of survey respondents (27%) stated that they faced stigma and negative attitudes. Some respondents reported that many people mistake the symptoms of dementia as a natural process of ageing. They also told us that people often think that dementia is only about having difficulties with memory.

These assumptions have a negative impact on people with dementia and their ability to live well. This demonstrates the need for people with dementia to be recognised as having a disability, and for their disability rights to be upheld.

'People associate dementia with old age and attitudes are patronising as a result.'

Carer

This report has been shaped by four key themes that resonated throughout the vast evidence received for this inquiry:

- equality
- non-discrimination
- participation
- inclusion.

The following sections go into more detail on specific challenges identified by respondents. They look at how these challenges are evidence that people with dementia are not having their disability rights consistently met.

In this report we set out our recommendations in order to change the way government, the public and organisations think about dementia. These recommendations will detail how social change and inclusion can become a reality for people with dementia in six key areas of daily life: employment, social protection, social care, transport, housing and community life.

The APPG recognises that the realisation of disability rights for people with dementia should not be limited to these six areas. The CRPD covers a range of other issues – some of which were referred to by respondents to the survey. These include issues with using new technology, which can be challenging to people whose symptoms make it difficult to follow sequences or remember passwords or PINs. These challenges could be removed or limited by the technology industry being inclusive in their design and manufacture. The APPG does not consider these issues any less important than the areas on which this report focuses. It seeks to ensure that people with dementia have full recognition under the law and have their rights upheld in all aspects of their life.

‘Current support is often non-existent, inconsistent, unintegrated, overly-traditional, rigid not flexible, task-based not person-centred, unimaginative, inappropriate for age, a “postcode lottery”, unaffordable, “gate-keepered”, stigmatising, [based on a] medical not social model, poorly publicised, hard to get to, anti-couple and deficit rather than asset-focused.’

Innovations in Dementia and DEEP – The UK Network of Dementia Voices

Dementia and disability: Recommendations

- The Government should incorporate the CRPD into UK law and report to Parliament on its progress in implementation.
- The Office for Disability Issues should ensure that people with cognitive impairments, including dementia, are represented on their Regional Stakeholder Networks.

Equality and non-discrimination

Employment

‘Dementia has taken a big chunk of my life. Working was part of me and then to try and find something else to fill your life is difficult.’

Person living with dementia

‘I applied for so many jobs and I just got rejections. I used to lecture at a university and now I can’t get a job collecting trolleys. Any job is worthwhile. [Not having a job] destroys self-esteem.’

Person living with young-onset dementia

Both the Equality Act 2010 and the CRPD acknowledge the rights of people with disabilities to work on an equal basis with others. Despite this, remaining in employment can be a significant challenge for people with dementia, both prior to, and following, a diagnosis.

We heard about the specific barriers faced by people affected by dementia in the workplace. These include:

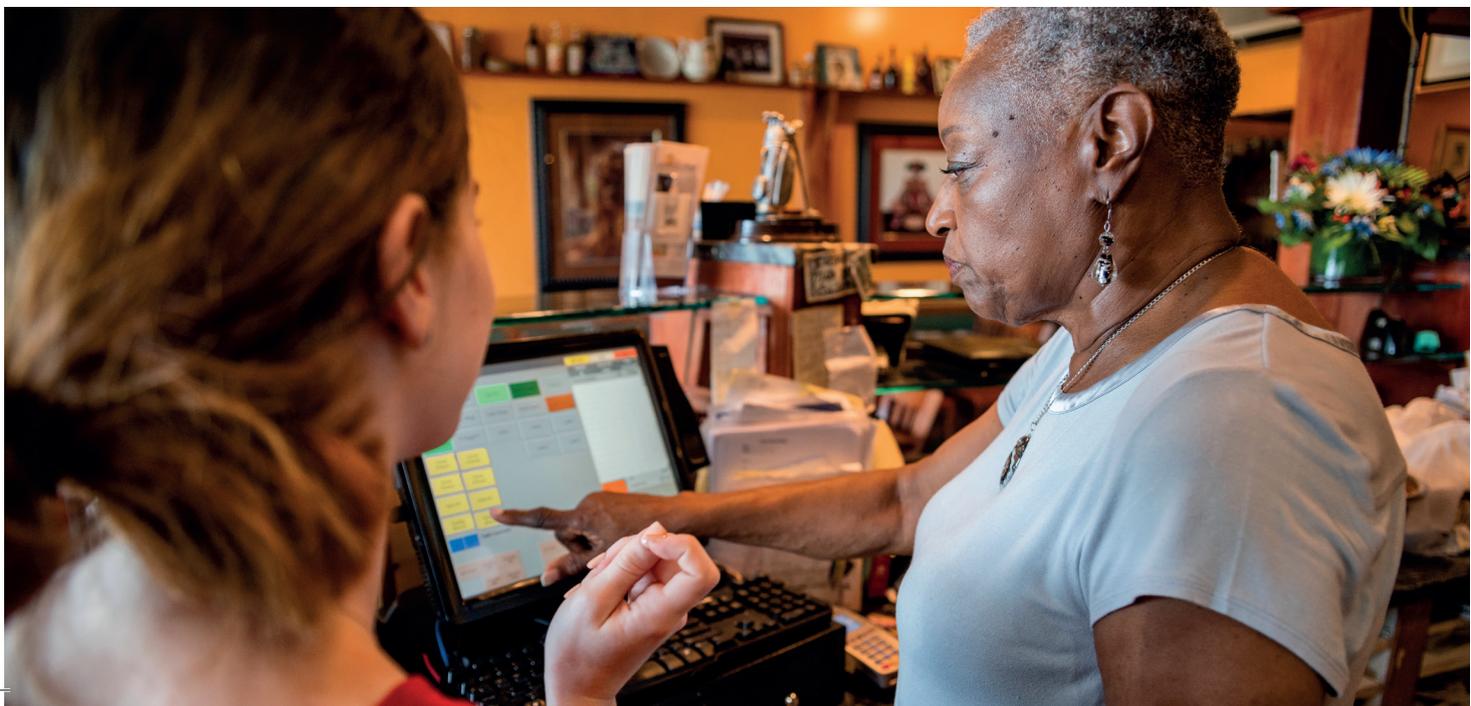
- people in the workplace lacking understanding about dementia
- people not knowing their rights in the workplace
- carers struggling to manage their caring responsibilities alongside a job.

This could particularly affect the 40,000 people under the age of 65 living with young-onset dementia, who are more likely to be in full-time employment¹⁶. This inquiry heard evidence about how these barriers often mean that people can no longer continue to work.

The impact of people with dementia and carers leaving the workforce can be felt financially by individuals, families and employers, but it also has a significant human and emotional impact on the people who are affected. It is therefore crucial that employers feel supported to understand dementia in order to support employees living with the condition.

‘Employers are increasingly taking action to ensure other disability groups are recognised within their workforce and are expanding their understanding of different disabilities, resulting in positive changes to promote equality and inclusivity. Although many other conditions like dementia are “hidden” disabilities, there is less acceptance and understanding of dementia, often resulting in a negative response. People with dementia and their families face inequalities because of their disability. There is a tendency for a more risk-averse approach and there remains much work to be done to reduce stigma, increase independence and change perceptions in the workplace.’

Dementia UK



Understanding rights and responsibilities

An important theme identified from the inquiry feedback was that many people felt unable to tell their employer about their condition. This is because people were not aware of their employment rights, and because they didn't know that dementia is a disability. Employers, Human Resources (HR) departments and employees must be made more aware of the employment rights of people with dementia.

Having to leave work has major financial implications for a person affected by dementia. It can often be an abrupt process that someone isn't prepared for, particularly if the person is not yet entitled to draw their pension. Employers must, therefore, handle leaving work carefully and sensitively. This inquiry received a lot of evidence from people voicing concerns about the critical financial challenges of the loss of employment and related income. This often affects people's families or their financial ability to continue to live independently. This highlights the inequity that people affected by dementia can face as a result of the condition.

'People talk about a "dementia tax" for the elderly, or that the elderly should expect to pay for their care. My husband had to stop working at the age of 53. This means he has not paid fully into his pension and is not saving money for the future. Additionally, the money he has inherited from his parents, who worked hard all their lives, will be spent on care and he cannot even allocate some of that money to our daughter to support her through university, as his brother is doing for his sons, as that will be classed as deprivation of assets. We are penalised all ways round.'

Family carer

Employment can give people a sense of purpose, self-esteem, status, companionship and income. It can also provide a routine, which can be vital to someone living with dementia. Without this, people can feel a loss of identity and their sense of purpose. This can lead to depression and feelings of exclusion and isolation.

It is therefore imperative that employers understand their responsibility to accommodate the needs of people affected by dementia. Action must also be taken to ensure that people are aware of their rights and feel empowered to inform their employers of their diagnosis.

'Employment is very rarely flexible enough to maximise the usefulness of people with dementia. Often they are squeezed out of employment too early, if not sacked prior to diagnosis. Once out of employment the main challenge is useful occupation, such as voluntary work. Feeling useless is a major cause of frustration and in my view causes people to decline faster.'

Spouse and carer

'Employers frequently do not make allowances for staff that develop cognitive impairments and (later) symptoms of dementia. As dementia is a disability, the Equality Act applies, but it is hard to make this work for you when you are losing your abilities to organise your thoughts and cope with everyday living. Good employers will refer you to occupational health and find ways of keeping you employed, perhaps in a different role, or part time, or provide you with assistive technology such as an iPad or tablet. In this way, you can remain active, engaged and with your colleagues.'

3 Nations Dementia Working Group



Receiving a diagnosis of dementia

Receiving a diagnosis of dementia from a healthcare professional can be a gateway to accessing support, medication and information. All these things can help people to live well and plan for the future. Because of this, it can enable people to stay in work for longer. It can also be a helpful explanation for the person themselves, and for those around them (including employers), to understand the changes they have been experiencing. However, diagnosis rates vary regionally and some regions still do not meet the Government's target rate of two-thirds¹⁷. We know that many people delay visiting their GP due to the stigma attached to dementia¹⁸.

'My husband was working and took early retirement because he was finding things difficult in work. If we had been given a proper diagnosis he could have worked longer with the right support and not have thought he was just becoming "stupid".'

Spouse and carer

According to the Equality Act, an employer only has to make reasonable adjustments when they are aware, or reasonably aware, that someone has a disability. This is why it can be vital for a person to receive an official diagnosis of dementia in a timely manner.

Making reasonable adjustments

'We are in a blind spot people don't want to see. I had to retire as a stressful middle manager. Took on another role for two years, but then realised I'd need to stop. Direct boss was helpful but HR was not. Boss was happy for me to go part time and helped me but HR said absolutely not. They needed a letter from the doctor, who confirmed mild cognitive impairment and recommended three days a week. HR said "you're the healthiest person I've ever seen" and refused, so I quit as I couldn't carry on full time.'

Person living with dementia

The Equality Act imposes a duty on employers to make 'reasonable adjustments' to ensure that someone is not disadvantaged because of their disability – for instance because of a 'provision, criterion or practice'¹⁹. Reasonable adjustments could include making changes to a person's:

- responsibilities
- working environment
- working hours
- management support.

As a minimum, employers must make adjustments for someone to carry on doing their job, or offer them to move roles if that is more appropriate. In reality, however, people with dementia are having these important rights infringed upon. This inquiry heard evidence that employers do not understand dementia and therefore do not always make the necessary reasonable adjustments to ensure that someone can continue working.

Failing to make reasonable adjustments is one of the most common types of disability discrimination²⁰. Of those we surveyed:



Nearly 1 in 5 (19%) reported people with dementia are unable to find or stay in work.



Nearly 1 in 10 (7%) reported discrimination at work.

‘There is a lack of understanding from the public, employers and employees working from an assumption that it is an all-or-nothing problem so the assumption would be that someone with dementia would have NO ability to work thereby preventing thought going into designing solutions.’

Retired geriatric psychiatrist

Dementia affects everybody differently, and there is no single way to support everyone with the condition. This can mean that employers are unsure of the best way to support someone in the workplace. We heard evidence during the inquiry that a disclosure of dementia was met by employers with an awkward silence, offering sympathy and apologies but with no questions asked about how the person could be best supported. This was in contrast to a disclosure of epilepsy, which prompted reasonable adjustments to be made. This is a clear example of the effects of dementia not being recognised as a disability in the workplace. This must change.

‘At the point of diagnosis people are often in a very difficult place. Leaving work seems the easiest solution. Employers need education and expert guidance if they are to work with employees and make appropriate adjustments. This takes time, as the best balance of medication might take a while to identify. My husband was in a much more employable position three to six months after his diagnosis but by then he had lost his job and had no prospect of finding another.’

Carer

In 2018, the Department for Work and Pensions (DWP) published guidance for employers to increase their understanding of disability, and to enable them to recruit and support disabled people and those with long-term health conditions. It is a complete oversight that this guidance makes no reference to dementia, but does for a range of other ‘hidden’ impairments²¹.

It is integral to future planning that employers are prepared to address the needs of people with dementia who are still in work. This is particularly important given the abolition of the default retirement age, and the raising of the age at which people can collect their state pension. Official statistics for December 2017 to February 2018 show that nearly 1.2 million people over the age of 65 were in work²². This is the age group most likely to have a diagnosis of dementia. As well as this, there are an increasing number of people under the age of 65 receiving a diagnosis of dementia.

‘I supported a woman with dementia at an early age, who was still working as a classroom assistant. As soon as her employers realised it was dementia they risk-assessed her out of work. A preferable strategy would have been recognition of the personal skills she still had and adapting her role to those.’

Family carer and Nurse Manager of care home for people living with dementia

Case study: Chris

‘In 2016, I was diagnosed with vascular dementia when I was 60. It was subsequently agreed with my doctor that I would do a phased return to work, however I was told that my work was not ready for my return. I went back to work anyway and I found that my desk had been moved to the corner. I felt wholly unsupported. I was told to re-read policies and procedures which weren’t making sense to me anymore. I was put on a disciplinary process for people who underperform at work and eventually I retired on ill health. I would have carried on working in a different role however this wasn’t even an option. Within three months of my diagnosis I lost my job and I got depression.’

Access to Work

A person with dementia must be at the centre of any decisions about their employment. This may include employers agreeing to support or adaptations that are beyond the scope of reasonable adjustments required by law. For example, they may benefit from support with communication or travelling to work. The Government's Access to Work programme provides a grant to reimburse the costs of such support, yet is relatively unknown. In 2011, the Sayce review highlighted the effectiveness of the programme but found a lack of awareness, recommending that the DWP 'transform [Access to Work] from the Government's best-kept secret to a recognised passport to successful employment'²³. In December 2014, the House of Commons Work and Pensions Committee came to the same conclusion²⁴.

Given the additional support needs of people with dementia, the Access to Work programme could go some way to address unmet needs for people in employment. A concerted effort must therefore be made to ensure that people know about, and can benefit from, the scheme.

Carers in employment

Employment is not only an issue for people with dementia – it is also a concern for many family carers who are in work. The APPG recognises the crucial role of family carers. It is essential that they are supported in their caring role. However, the inquiry revealed that carers often felt they had no choice but to leave work or cut down their working hours to provide care. This was mainly a result of the inadequate or unaffordable social care available. Carers also cited the lack of opportunities for flexible working or paid carers' leave (which allows time off for dependents) as a reason for having to leave work.

'Because social care does not even begin to meet the needs of people with dementia, partners are unable to work and forced into poverty.'

Former carer

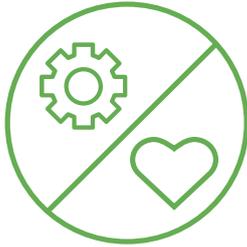
Unpublished data from a current UK study suggests that carers spend an average of 36 hours per week caring for individuals with 'mild to moderate' dementia, which is a high proportion of their time²⁵. Carers told us that they want to be supported in the workplace through flexibility that accommodates their caring responsibilities. They also told us they want to be supported emotionally by employers who understand and recognise their caring responsibilities.

'I am a carer for my husband, aged 64, who has mixed dementia. I am aged 57. I work because I have to, but after a 30-year career, these days I have to take more flexible work which I can fit in around caring, and pay is much poorer, less than a third of what I earned previously, and this is on top of the loss of my husband's earnings.'

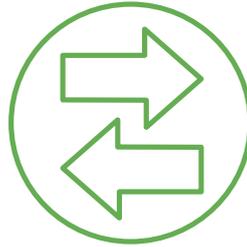
Family carer

All employees have a right to request flexible working after they have worked for the same employer for 26 weeks²⁶. This can be a lifeline for people who have caring responsibilities. However the significant financial implications of flexible working can affect a person's current circumstances as well as their income in retirement (if they are under retirement age).

Family members are also entitled to time off to deal with unforeseen matters and emergencies relating to dependents. This could include needing to find alternative care arrangements at short notice, or dealing with establishing longer-term care.

According to Carers UK:

1 in 7 of all workers are juggling work and care



38% said their employer offered flexible working...



... but only 12% said they had paid care leave²⁷.

‘Carer’s Allowance, and what I am allowed to earn in order to claim it, is just too low to meet the financial demands of day to day living, let alone the idea of paying for him to go to dementia day care centre, while I work. It is impossible.’

Family carer

Employment: Recommendations

- The Government should mandate the DWP to revise its guidance to employers about their responsibilities to support people with disabilities. The guidance should include explicit reference to cognitive disabilities, including dementia. This guidance should cover reasonable adjustments, information on the Access to Work programme and how to support employees with dementia.
- As part of the 2019 Spending Review, the Government should consider the adequacy of the Access to Work programme to ensure that people with dementia benefit from this.



Social protection

‘People with dementia are effectively ignored by the disability benefits system.’

Family member

‘Social protection’ in the CRPD refers to systems that prevent, manage or overcome social and economic situations that have a negative effect on people’s wellbeing, such as poverty and disability. In the UK, this is our social security system, which is mainly administered through the Department for Work and Pensions (DWP). Early access to financial support in the form of disability benefits can significantly improve the quality of life for someone living with dementia.

Article 28 of the CRPD describes the responsibilities of governments and public bodies to ensure an adequate standard of living and social protection for people with disabilities. Moreover, the Special Rapporteur recently released a report on the rights of persons with disabilities. This described the role of disability-inclusive social protection systems in ensuring income security and access to social services. The report found that these systems can contribute to reducing deprivation of liberty of persons with disabilities²⁹.

However, this inquiry heard about the hurdles faced by people affected by dementia trying to access financial support. These challenges range from not knowing what is available to them, to experiencing difficulties with making a claim and undergoing reviews.

The cost of living with a disability can be devastating. Being able to access extra financial support can provide a lifeline for people with dementia. It can help people to continue getting out and doing the things they enjoy. People with dementia often report that it can feel like the physical world around them becomes smaller, as they lose touch with activities that are important to them and form part of their identity³⁰. As a person’s dementia progresses, financial support can help with extra costs, such as for additional care, foods that are easier to eat or assistive technology devices.

Awareness of entitlements

‘There is very little help available and on diagnosis we should be signposted instead of being left to “walk through treacle”. Once you get a diagnosis it is a minefield trying to get any information.’

Former carer

One of the key challenges for people affected by dementia is knowing what financial support is available to them. Too often people affected by dementia are left with no formal support after a diagnosis, and can struggle to find out about and access critical social protection. This means that people are missing out on the financial support they are legally entitled to.

‘It would be helpful if the [person with dementia] and their family were automatically given pointers on where to get help and specifically what benefits are available. We have been left floundering from first diagnosis.’

Family member

The DWP deals with most benefits entitlements. However, local authorities also have a duty under the Care Act 2014 to provide information relating to care and support. This should include information about how to access independent financial advice on matters relevant to meeting needs. They also have a duty to help people to benefit from this advice³¹. Despite this, the information and advice available from local authorities is inconsistent. This means that people affected by dementia are not getting the support they need to find out what is available and how to claim effectively.

‘Support appears to be at best patchy and at worst non-existent around the country. There needs to be a thorough review of the needs of people with dementia.’

Retired mental health specialist

Local authorities are meeting their duty in the Care Act to provide information online. However people with dementia often need more support to access information this way. They may also need more specialised support to ensure they can access the financial support they are legally entitled to.

Information from Alzheimer's Society was cited as a major source of help for people with dementia and their families. The APPG also commends the work of Citizens Advice and local charities such as Age UK, who provide support to help people to claim effectively. We heard evidence from people affected by dementia that support from these organisations was often the only reason they were able to make an effective claim. However, we also heard evidence that support from the voluntary sector isn't available everywhere and that while these services are filling some of the gaps, this should be a supplement to statutory services, not a substitute for them. Local authorities need to do more to ensure that appropriate services exist, particularly when the voluntary sector is at capacity.

'Support is patchy in many areas. Provision must be person centred. More awareness of benefits is very important and legal advice is vital at an early stage.'

Retired social worker and former carer

Local authorities need to:

- create or commission connected services
- work with partner organisations that have an understanding of dementia, to provide information on what is available
- improve signposting to the different services that are available locally.

'There should be a support team ready to tell you what you need to do next, and also if there are any benefits you can claim such as Attendance Allowance. This helped to pay for mum's medication, extra incontinence pads, special foods and extra care relief for Dad who, at 92, was Mum's main carer.'

Family member

The council tax discount is one example of financial support which has been inconsistently applied. The Local Government Finance Act 1992 states that a person who is severely mentally impaired (SMI) is entitled to a council tax discount if they meet certain criteria³². The APPG heard evidence that this benefit was incredibly helpful for people affected by dementia. However, we were disappointed to also hear evidence of the lack of clarity and awareness of this crucial entitlement in England. This evidence is supported by Money Saving Expert who revealed up to 100,000 people are missing out on the SMI council tax discount³³.

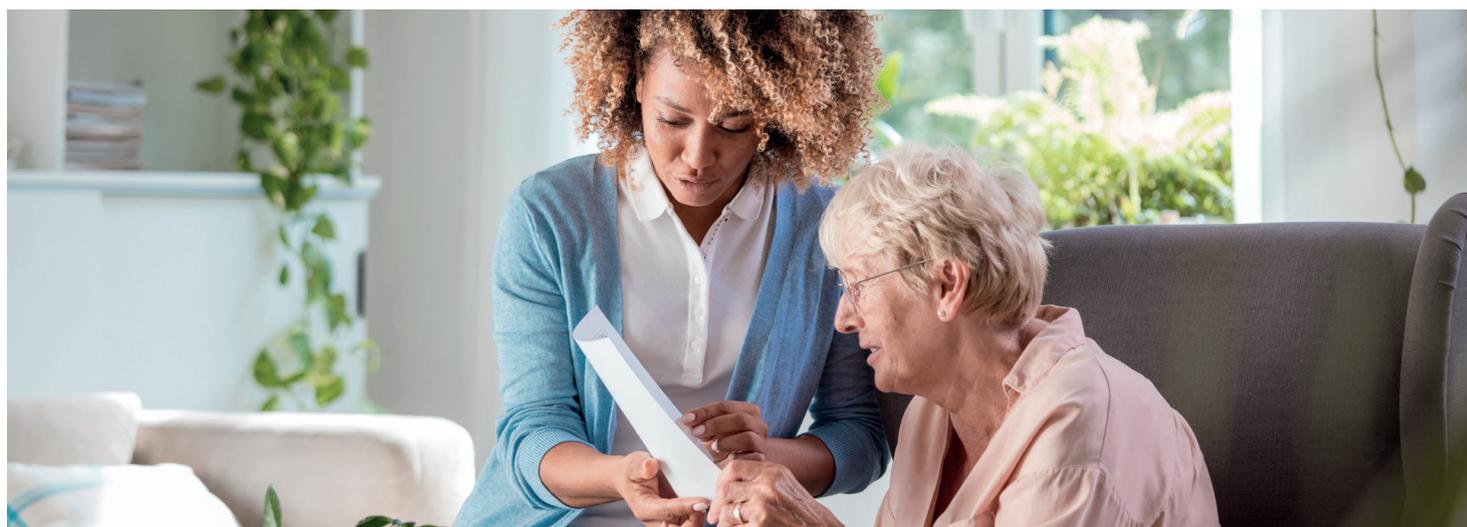
'We were not told about things my mother and father were entitled to, but had to find out by accident as we went along. This added unnecessarily to the stress we were already experiencing. For example, we were not told about Attendance Allowance or reduction in Council Tax until some years after diagnosis.'

Family member

'My GP has helped me to get the council tax disregard in place but I only found out about this by accident. I think it should be advertised on prime time TV so that everyone knows.'

Family member

The APPG commends the action taken in Wales to introduce a standardised application procedure and form for all councils and to allow every council to backdate payments³⁴. England must do the same to ensure that people with dementia can benefit from the financial help they are entitled to.



Case study: Halton Borough Council's Welfare Rights Service

Halton Borough Council provides a free Welfare Rights Service which offers local residents advice, information and representation on all aspects of welfare benefits and debt problems. They actively seek to promote social security to ensure that residents are aware of their rights. The service provides:

- an advice line where residents are able to get directly through to a specialist who can do a benefits check either by phone or in person. This check can either be done at someone's home or at one of Halton's 'one-stop shops' which offer support with a range of council services
- support with completing forms to make sure residents are able to claim their entitlements
- representation at Social Security Appeal Tribunals.

The service works in partnership with other local services, including the local Citizens Advice and Age UK, to ensure that everyone in the area can access support. This is particularly useful where some local services only provide certain types of support, or when services do not have the capacity to provide support.

Support with making a claim and the assessment processes

Making a claim for social protection can be incredibly complicated because of the difficult processes involved. People affected by dementia told the APPG that they often felt like they were not given sufficient opportunity to explain their needs during the claims process. We also heard about a lack of awareness of the condition and how it can impact people. This had an effect on people with dementia accessing the support they need.

For example, Personal Independence Payment (PIP) assessment processes look at 12 activities that a person would do in their daily life, such as preparing a meal and washing and dressing. People told us that this process often doesn't allow them to sufficiently describe the impact that their dementia has on their lives. A person with dementia may struggle with any number of things leading up to, or following, the tasks that are assessed, even if they appear capable of the task itself. We would like the assessment process to include more examples of cognitive challenges and increased awareness of the associated impact that people with dementia face.

'Forms are written from an implicit assumption that any disability will be physical and it takes a lot of thinking outside the box to make it fit for a person disabled with dementia. I feel that many people are likely to miss out on benefits to which they are entitled because their carers or advocates are not as capable of filling in forms in the correct way, which is unfair and discriminatory.'

Family member

'The [benefits] assessor looked at the body – focused on the arthritis but didn't want to hear about the mental problems. They ignored what I said I found difficult.'

Person living with dementia

It is essential that people with dementia are supported to complete applications for financial support.

'I would like to see the Prime Minister have a go at contacting the DWP by phone she would see what a mess they are in. When you are faced with dementia it is now you need help not 10 months down the line.'

Family member

A report from Demos in March 2019 revealed that only:

20%

of public survey respondents think the DWP understands the concerns of ill and disabled people

21%

believe that local councils understand the views and concerns of ill and disabled people³⁵.

The DWP should consider how the current application processes are working in practice for people with cognitive impairment. For instance, we heard a range of evidence describing the length of the Attendance Allowance (AA) form:

'Having seen how long and complicated the AA form is, I think it is challenging for a person with "normal capacity" to understand and complete, let alone a person with dementia. It is difficult to find time to apply on a family member's behalf, when you spend most of your time caring for that person or if you are helping with this care and also working full time. Eventually we had help from an Admiral Nurse who kindly completed the application form. By the time the first AA payment was received my mother had passed away. The rules and application process for AA need simplifying.'

Family member

'There needs to be much change in the forms used when applying for benefits. They are an absolute nightmare for a person with dementia. They are not laid out in a way that you can start at page one and work through to the end. A person has to hop about from one page to another, all over the place. It is tiring, difficult and extremely complex to complete. It takes me a whole week to complete one. Remembering all my difficulties when completing the form is almost impossible. One slip up and you have lost your benefit. Dementia does not go away, it is with us for life.'

Person living with dementia

People also spoke extensively about the face-to-face part of the assessment and reassessment processes for PIP. Both of these experiences can be extremely stressful for a person with dementia.

'Lack of understanding of the impact and the restrictions the condition imposes. People confusing memory loss or confusion with stupidity. PIP assessors asking my husband to stand on one leg to assess him for the mobility element of his PIP award. What hope does the general public have when the professionals can't deal with it?'

Family carer

Reviews and reassessments

The APPG recognises the Government's intention to reform the social security assessment processes by 2021³⁶. It is imperative that they openly consult with those who will be affected during implementation. The Government has also confirmed that PIP claimants at, or above, State Pension age will no longer have to undergo regular reviews. While this is a welcome move, it is important to note that in January 2019 official statistics revealed there were 6,865 people with dementia under the age of 65 receiving PIP³⁷. These people should also be exempt from regular reviews due to the progressive nature of their condition.

Assessment guidance is clear that decisions on reviews must take into account whether someone has a progressive condition³⁸. However, the APPG heard evidence that this isn't always the case. With the State Pension age rising, more and more people with dementia will be entitled to PIP. It is therefore crucial that assessors have the training they need to make informed decisions. This is even more important to ensure that new rules on reassessments and light touch reviews can have a positive effect.

Currently, 91.8% of people living with dementia have another health condition³⁹. Moreover, people with dementia have complex and fluctuating needs. Assessors need to understand the impact and restrictions of the condition. It is important that providers are transparent about how the Condition Insight Report for dementia (which provides detail and insight to professionals) is used and monitored in order to ensure the training is effective. We heard examples of observations made by health professionals carrying out assessments, claiming that someone was 'dressed nicely', 'well-groomed' or 'had painted nails' with no further questions asked. These sorts of observations are irrelevant to the person's level of impairments and demonstrate a lack of understanding of the realities of dementia and its symptoms.

'At the point of diagnosis we should begin to receive disability benefits without the need for degrading assessments, which in mine, and many others, cases didn't bear any resemblance to my challenges with dementia.'

Person living with dementia

When assessors and health professionals do not have appropriate training to enable them to understand dementia and its challenges, incorrect decisions can be made about their disability benefits. The process of appealing a decision can be extremely stressful for a person with dementia, and the experience can vary regionally. We heard evidence that in one large urban local authority it takes a year on average to appeal a decision – from applying for reconsideration through to tribunal. This evidence emphasises the importance of getting decisions right in the first instance.

Evidence from DWP in November 2017 stated that half of PIP decisions are changed after mandatory reconsideration or an appeal to a tribunal⁴⁰. The most recent data shows that 73% of PIP tribunals were found in favour of the claimant⁴¹. Despite low numbers of claimants appealing decisions, such a high rate of overturn indicates that initial decisions are inaccurate. Where reconsideration requests are made, it is because they were felt to be unfair or due to a lack of regard for the evidence submitted⁴². Furthermore, research from DWP shows that many people do not make an appeal due to ill health, stress or lack of faith in a positive outcome⁴³. Clearly, the current situation cannot continue.

Case study: Tracey

'I was diagnosed with dementia in December 2015 and I was lucky I had a good consultant who told me what I was entitled to access. I applied for PIP and took a friend to the meeting with me and then I was awarded the daily living component. I had my diagnosis for three years and my mobility was getting worse. I had two walking sticks so my Occupational Therapist said to get reassessed due to my mobility problems. Three people had to help me fill in the form. An assessor then came to my house. Assessors don't understand that the brain affects the whole body – it's hard to be honest about the bad days when I can't walk or talk. I would rather go without than get reassessed again. The health professional doing the reassessment couldn't understand how I had gone downhill so fast and thought I was pretending. I fought the system, I complained, I met with Atos and I got the mobility [component] in the end. But we shouldn't have to keep fighting.'

Case study: Chris

'After being made to retire on health grounds by my employers, I claimed Employment and Support Allowance (ESA). I attended a face-to-face meeting with a DWP health professional, after which I received a letter stating that DWP would not pay me ESA. This was despite the fact that I had two knee replacements and mobility issues. I had suffered three minor strokes and was given a diagnosis of early-onset vascular dementia. I formally appealed the decision and again was not granted ESA. I had scored zero points on their scoring system and you needed to score a minimum of 15 points to be eligible for ESA.

With the help of Alzheimer's Society Cymru I sought a tribunal hearing and my case was heard before a judge and a doctor. At this hearing the decision was overturned and I was awarded 30 points and awarded ESA.

I had a similar experience whilst applying for PIP. I strongly feel that when a person receives a life-limiting diagnosis of dementia that ESA and PIP should automatically be awarded for life. We all know that dementia is going to get worse and not better. Why is it that we have to reapply and be reassessed for these allowances every three years? A total waste of money and immense stress caused to the applicants.'

Social protection: Recommendations

- All local authorities should use a single, standardised form for the SMI council tax discount, and all claims should be backdated to the point of diagnosis.
- The Government should mandate the DWP to convene an expert group to review access to social protection for people living with dementia and their carers, recognising their specific needs. This must include those who are experts by lived experience.
- The Government should mandate the DWP to exempt PIP claimants below the State Pension age and with a dementia diagnosis from reassessments.
- Alongside local health providers, local authorities should set out an accessible offer for people with a dementia diagnosis. The offer should give information about available services and support, including any financial entitlements.

Social care

The focus of this report is on the barriers faced by people with dementia to fully participating and feeling included in the community and society. However, it is important to make reference to the considerable amount of feedback we received about inadequate or inaccessible social care for people affected by dementia living in England.

The Equality Act 2010 prohibits discrimination in the provision of health and social care services. Articles 25 and 26 of the CRPD require the provision of services to meet the health and social care needs of people with disabilities. These should maximise independence, and support community participation and inclusion of people with dementia. It is vital to consider both health and social care to ensure that these services are non-discriminatory against people with dementia, and are helping people to fully participate in society.

Almost all survey respondents (98%) thought that people living with dementia are treated differently to people with other health conditions or disabilities. According to 44% of respondents, this is because of inadequate medical and social support. The Royal College of Speech and Language Therapists echoed this, highlighting widespread differences in access to, and support from, speech and language therapy which can enable someone with dementia to live safely and well⁴⁴.

‘Much more planning, money and support needs to be put into social care. It’s no use just applying a sticking plaster approach. At the moment, it’s a lottery. It really is a completely unacceptable approach for a so-called caring society.’

Family member

Evidence to the inquiry showed the perceived inequity facing people with dementia in the current social care system in England. We heard about people paying for their own care in the majority of circumstances, and about issues around accessibility and quality.

‘My mother is now in a care home which has resulted in having to sell her home and she is now spending her life savings on her own care.’

Family member

‘[There should be] no more “dementia tax” causing money to haemorrhage from families affected by dementia, creating additional worry and making it impossible to survive for some families.’

Former carer

Under the current system publicly-funded social care is limited according to severity, need and financial eligibility. This means that large numbers of people affected by dementia find themselves having to arrange and pay for care themselves (including residential care). This can affect other people with long-term conditions and disabilities but the negative impact is disproportionately felt by people affected by dementia. This is because of the progressive nature of the condition, which can mean people rely on social care and support for decades. Due to the strict eligibility criteria for publicly-funded care and a ‘cliff-edge’ means test, people are forced to spend vast sums on providing care.

The social care system in England needs reform. It is a widely-held view that the current system is unsustainable. Two-thirds of people using homecare, and 70% of people in care homes, live with some form of dementia⁴⁵. Clearly, the social care crisis is a dementia care crisis.

Having said this, we felt that these issues fell slightly outside of the scope of this report. We also felt that the issues with the system are well known by the public and Parliament. There is recognition of the need to address these issues in a long-awaited Green Paper on social care reform. We are greatly disappointed that the publication of the Green Paper has been consistently delayed. It is essential that these issues are finally addressed and national action is taken to tackle the crisis.

‘The Government should find a more efficient solution and ensure that people living with dementia are given the treatment and respect they deserve. People are having to sell their homes to pay to go to care homes. It is disgusting and ageist and wrong.’

Family member

Social care: Recommendation

- The Government must publish the Green Paper on social care reform as soon as possible, to set out proposals for a fairer, more accessible and inclusive system of funding for social care. It should recognise and reflect the needs of people living with dementia, now and in the future.

Participation and inclusion

Transport

‘Just about everything about travel has become problematic with my dementia: remembering when to go, where to go and what for, remembering to buy and bring a ticket, remembering when and where to get on, where to get off [the bus], and where to go after that. Travel becomes a very anxious affair.’

Person living with dementia

Access to public transport can have a huge impact on the lives of people affected by dementia. It can help to reduce loneliness and social isolation by linking someone to their community, and it can provide links to essential services such as necessary respite care. Access to public transport is therefore critical to maintaining someone’s quality of life.

Poor or inaccessible transport – physically or financially – can compound issues with a person losing their sense of identity. This could happen if it means that a person is unable to continue doing things they used to enjoy, such as shopping, meeting friends, attending religious services or going to the theatre.

The rights of persons with disabilities with regards to public transport are enshrined in the Equality Act 2010. The Act requires transport providers to provide accessible services and make reasonable adjustments. Article 9 of the CRPD is also intended to enable people with disabilities to live independently and participate fully in all aspects of life – this includes access to transportation.

In this inquiry, **36% of survey respondents expressed concern about transport.** The APPG heard a substantial amount of feedback on the lack of availability of local transport, particularly if a person with dementia no longer had their driving licence. We also heard evidence that pointed to the stigma and discrimination that people face while using public transport, which can often act as a deterrent to continuing to use services.

Loss of driving licence

‘The most serious consequence of receiving the final diagnosis was that I had to surrender my driving licence which obviously took all my freedom away. I am now reliant on my wife to take me mainly to medical appointments. I endeavour not to call on her for unnecessary outings and I have found as time has gone on I have become more content to be at home.’

Person living with dementia

A diagnosis of dementia doesn’t mean that people have to stop driving. However, people must contact the relevant licensing agency (DVLA/DVA) about their diagnosis and follow professional advice⁴⁶. A time may come when a person with dementia can no longer drive safely – a point we heard from family members as part of this inquiry – and it is important that people with dementia are aware of their rights.

If a person with dementia wants to continue driving, they are entitled to a full assessment, which would include a questionnaire from the relevant licensing agency. The agency will also

request permission to obtain their medical reports. We found that people are not fully aware of their rights in relation to driving and would rather follow ‘doctor’s orders’, before a proper assessment has been undertaken.

We know that people can continue to drive safely for some time after diagnosis. It is therefore important that people are empowered to make a decision themselves regarding their ability to drive, taking into account medical advice. However, we heard examples of GPs contacting the DVLA automatically following diagnosis. We heard one example where someone’s GP



wrote to the DVLA confirming the diagnosis, without having seen the person in 14 months. The person with dementia was subsequently instructed to stop driving.

People can be significantly impacted by losing their driving licence. We heard evidence that people felt depressed after losing their licence, feeling a sense of loss and anger due to the impact it has on their independence. Giving up driving can worsen someone's anxiety about leaving the house, and be a key cause of isolation, reducing access to their usual activities.

'Every year I have a wrestle with the DVLA to get his driving licence renewed even though he is physically fit to drive with someone to guide him back home but they make assumptions about the decline and progression of dementia which don't apply in his case.'

Family carer

'My father had vascular dementia. Until he lost his driving licence he coped OK but got very depressed once he lost his independence. Getting this recognised and getting help was a real struggle.'

Family member

Stigma and lack of understanding

This inquiry heard about the stigma people with dementia face when using public transport and reported a lack of support to enable them to continue to use local services.

Case study: Amanda

'I often feel anxious when I use public transport. Recently, I was travelling with my daughter and the train before mine had been cancelled so by the time I arrived on the platform, it was extremely busy and I was panicking. Fortunately, we had reserved seats but when we got there people were sitting in them. These individuals refused to move and started to abuse me verbally when my daughter told them I had dementia. They said I should be on a different carriage, I should be locked up, I shouldn't be allowed out in society and that I am a danger to myself and others. I was devastated. I felt dirty. I felt like I wasn't any good. The guard was on the carriage but he didn't feel confident to support me so I was told to find another seat. My journey back couldn't have been more different. I asked for assistance and a member of staff took me to the platform before it was announced and I got on the train – even before the driver! The journey was lovely. Just one understanding member of staff can make all the difference.'

The APPG heard about the difficulties faced by people with dementia when using public transport. These challenges are compounded by a lack of understanding and patience from fellow passengers and staff. People spoke positively about the difference Alzheimer's Society's Dementia Friends programme is making by tackling stigma and discrimination, but more needs to be done.

In evidence to the House of Lords Select Committee on the Equality Act 2010 and Disability, Andrew Jones MP, Parliamentary Under-Secretary of State at the Department for Transport, acknowledged the 'fundamental importance' of taxis, private-hire vehicles (PHVs) and buses to disabled people⁴⁷. However, only just over one-third of licensing authorities require disability awareness training for taxi and drivers⁴⁸.

'I have rung the bell too early before on the bus because I feel anxious about when I need to get off and I panic. The bus driver told me I had pushed it too early and when I told him I had dementia he said I still shouldn't do that next time. People don't understand that it can be a struggle to even walk out of the door sometimes.'

Person living with dementia

The Equality Act 2010 should protect against discrimination on the grounds of disability across transport services. Public authorities should consider the needs of people who are disadvantaged or experience discrimination when they make decisions about how they provide services and implement policies. These may include, for example, decisions about the use of different types of technology on transport. People affected by dementia told us how much of a challenge using new technology can be.

'My dad uses public transport but is increasingly confused by modern technology like swiping train tickets. It is an alien concept to him especially as his memories regress to when he was younger and commuted by train.'

Family member

Businesses must have a responsibility to consider the impact such changes have on people with dementia and their ability to continue to use a service. The Public Sector Equality Duty (PSED) aims to ensure that this

happens. Currently there is low awareness among industries and businesses of their obligations under the PSED, particularly for people with dementia. This must be rectified during an Equality Impact Assessment.

A significant part of the PSED process is ensuring that organisations make reasonable adjustments. We know, however, that organisations can find it difficult to make reasonable adjustments for people with dementia. This can in part be due to the 'hidden' nature of dementia. This inquiry heard evidence that organisations often refer to processes for other more 'visible' disabilities, for example suggesting someone with dementia goes in a wheelchair when they don't need to just to make their disability visible. This demonstrates the gulf of understanding between visible and non-visible conditions.

NatCen carried out some qualitative research as part of their independent review into the PSED. This research identified a variation in people's knowledge of the duty⁴⁹. The PSED is an important way of ensuring progress on the realisation of rights for people with disabilities. It is therefore imperative that the PSED is understood by public sector staff at all levels. This will enhance awareness of how the duty applies to their day-to-day work, and the changing needs of the public, including people with disabilities. It is also important that there is an awareness of the duty and its benefits amongst the public. This will help to ensure that people can continue to use public transport.

The APPG was pleased to note that the Government's Inclusive Transport Strategy⁵⁰ highlighted the need to ensure that all public transport bodies understand their obligations under the PSED. However, more needs to be done to ensure that service provision is genuinely meeting the needs of people living with dementia and that actions are being taken to address this.

As part of the Strategy, the Government committed to developing a training package to help transport operators to train their staff. The number of people with dementia is set to rise, and the Government has made commitments to reducing loneliness and social isolation. We therefore expect dementia to be a key part of the development of this training package.

'In the early or mid-stages there are no outward indicators that the person has dementia and many in our society don't recognise the symptoms and react rudely when an instruction can't be followed. I have witnessed this with my wife on public transport when drivers have raised their voices because she couldn't put her bus pass on their card reader.'

Family carer

In 2017, people affected by dementia participated in a campaign that successfully persuaded the UK Government to review the criteria for blue badge parking permits. People with cognitive impairments had experienced difficulties in getting blue badges despite

clearly needing them. The challenges they faced depended on how individual local authorities chose to administer the scheme and assess eligibility. The campaign was a significant step towards developing a more inclusive environment for people living with dementia, with a subsequent policy change announced in July 2018 that the scheme would be extended to people with 'hidden' disabilities⁵¹. However, since the announcement, there appears to have been a lack of progress in ensuring widened availability is rolled out. Councils must be given clear, robust and prompt guidance on eligibility – including an explicit reference to the newly-included conditions, such as dementia.

Availability of public and community transport

This inquiry heard evidence that many people with dementia are faced with a lack of alternatives to driving. They therefore struggle to access social activities, as well as care options and crucial services that would make a real difference to their day-to-day lives.

'The bus services do not run regularly and many people rely on volunteer services and family. The cost of volunteer services can be 44p a mile and when you live in the country and have to travel 30 miles for a hospital appointment several times a month this can be very expensive. Volunteer transport is only available for hospital appointments: if you want to go to a social activity they may not be available particularly in the evenings.'

Third-sector professional and former carer

Community transport, such as dial-a-ride or volunteer schemes, provides an alternative to mainstream public transport. It can therefore enable people to access their local communities. We found that community transport can be a lifeline for people affected by dementia. However, we also found that increasingly tight local authority budgets are having an impact on the availability of transport.

While the APPG recognises the significant financial challenges that local authorities are facing, reduced funding for bus routes and community transport mean that vulnerable

people are struggling to remain connected to their communities. In 2018, the Local Government Association reported that from 2013–14 to 2017–18 there were 297 million fewer journeys over all bus routes across the country – a decrease of 6.4%⁵². It highlighted the increasing risk facing nearly half of all bus routes in England that receive partial or complete subsidies from councils. The loss of these could have a considerable effect for people with dementia. It's also important to note the variation in public transport fares across the UK, which puts people in certain areas at more of a disadvantage than others⁵³.

It is essential that local councils are consistently looking at the PSED when developing local transport plans, and when making decisions on changes to bus and community transport services, including service tenders. The report of the House of Lords Select Committee on the Equality Act 2010 and Disability said that in one local authority area, urban buses have been cut without full public consultation or an Equalities Impact Assessment. This would therefore arguably contravene the PSED⁵⁴.

The inquiry has revealed that the availability of transport and support can depend on where someone lives. One person with young-onset dementia told us he moved from a rural town to an urban town, 90 miles away, so that he could access more support to use

transport. People with dementia have a right to live in a community that makes reasonable adjustments, rather than having to move to an entirely new area that they don't know or recognise, just so that they can continue to participate in community life.

Local authorities should encourage innovation to combat unmet need in relation to transport provision. These considerations should take into account the need for a personalised service

where passengers can benefit from increased autonomy. It is important that local areas feel empowered to make changes to benefit the community. With this in mind, the APPG was pleased with the progress made in the Bus Services Act⁵⁵. The Act sought to strengthen powers of local leaders to improve bus services. It is important that all Mayors of combined authorities are able to assess the provision of transport locally and make changes to ensure people's needs are being met.

Case study: Greater Manchester

Greater Manchester is leading the way on bus reform, as they are the first mayoral combined authority seeking to make use of new powers in the Bus Services Act 2017. On behalf of Greater Manchester Combined Authority, Transport for Greater Manchester is looking to reform bus services to create a more coordinated transport system, which could be widely beneficial to people with dementia.

We would like to see this work rolled out more widely to ensure local transport networks are benefitting passengers with dementia, for example through Total Transport schemes⁵⁶. These schemes integrate transport services that are commissioned by different agencies and delivered by different operators. Any service redesign must involve consultation with disabled people, as intended in the Bus Services Act, including people with dementia.

'Our bus service is limited and so we are prisoners in our own home.'

Person living with dementia

'I believe more community transport will give people with dementia the freedom they crave to continue living their lives independently for longer than they can at the moment.'

Professional

It is important that local communities are able to manage and support the demand for transport. Ample consideration must also be given to the choice available to older people and those with disabilities about when and how they travel.

Transport: Recommendations

- Every Local Transport Plan should include a section on how local transport is meeting the needs of disabled people, including people with dementia. The Plan should clearly outline how they are meeting their obligations under the PSED. This should refer to planning and delivering transport, taking into account spending reductions to buses and community transport.
- Metro Mayors should make use of new powers within the Bus Services Act to assess local need. They should reform bus services to ensure transport remains accessible for people with physical and cognitive disabilities.
- Licensing for taxis in local authorities should include provision for dementia awareness and wider disability training.
- The Department for Transport should publish clear and robust guidance on eligibility for the Blue Badge scheme – including an explicit reference to the conditions newly included, such as dementia, by Autumn 2019.
- The Department for Transport should report to Parliament on how many driving licences have been voluntarily surrendered and the reasons given, and on the mandated surrender of driving licences and the reasons given.

Housing

Part 4 of the Equality Act covers discrimination in housing, meaning that people with dementia should not experience any form of discrimination and that there are requirements for landlords to make 'reasonable adjustments'⁵⁷. For example, a person with dementia might benefit from replacing signs or notices, changing taps or door handles, replacing bells or entry systems and changing colours of walls or other surfaces.

Article 19 of the CRPD is a cornerstone for ensuring the right of people with disabilities to live independently. It stipulates that any state parties recognise the equal right of people with disabilities to live in the community and to facilitate effective and appropriate measures to full inclusion and participation in the community⁵⁸. In practice, this should mean that people with dementia are entitled to live independently in their own homes. They are also entitled to receive good quality, affordable supported housing, adaptations and technology.

However, people with dementia are being denied their right to live independently in their own homes where they are able to make their own choices. It is important that people with dementia are supported as much as possible to stay living in their own home or are able to access suitable housing.

A care home is often presented as the only option, when there may be more appropriate choices. Data from Public Health England reveals that nearly 60% of people with dementia die in a care home⁵⁹, despite 85% of people saying if they developed dementia they would want to stay at home for as long as they want to or feel able to⁶⁰.

'Greater funding is needed to support families looking after any member of their family with dementia, so they get the right support and help so the person with dementia can continue to live in their familiar comfortable surroundings without having to be put in a care home.'

Family carer

Accessible and adaptable housing

The symptoms of dementia are not limited to memory loss. People with the condition can have difficulty with sensory impairments and mobility that make perception and navigation challenging. This can mean that people with dementia have complex cognitive and physical needs. People with dementia are also more likely to be affected by other health conditions. Adaptations to the home can help to meet these needs and can help people to continue to live independently. Adaptations can range from installing grab rails, adding signs to help with navigating around the house, to redesigning rooms entirely to make them easier to use. The type of adaptations somebody makes to their home will depend on their individual needs.

It is disappointing that the Equality and Human Rights Commission (EHRC) found that it took, on average, 22 weeks from application to installation of adaptations. Some local authorities have waiting times of a year or more⁶¹.

'People with dementia need housing assistance, including the installation of ramps, showers with seating, grab rails and emergency call buttons.'

Family member

Survey respondents spoke about the need for extra resource to make adaptations. They also told us about the need for resource to fit assistive technology, such as devices that remind someone to take their medication.

This can be integral to supporting independent living for people with dementia.

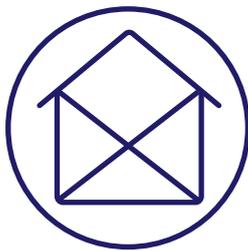
'Housing associations often lack the appropriate training when dealing with the elderly in general, who often have multiple health issues. This can make for a very anxious tenant, less likely to attempt contact trying to get help and therefore a spiral of deterioration in both mental and physical health results.'

Family carer

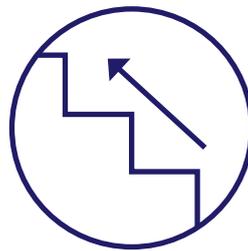
The National Planning Policy Framework specifically outlines that the size, type and tenure of housing needed for different groups, including people with disabilities, should be assessed and reflected in planning policies⁶². Governments at national and local level have a responsibility to ensure there is adequate supply of accessible housing, which supports independent living for people with dementia. The planning and development processes of local authorities should be informed by what people need, now and in the future.

An ageing population and growing numbers of people with dementia will continue to add pressure on policy makers, housing providers and care providers. They must meet people's needs and ensure that people with dementia are protected by their rights as enshrined in the PSED. It is estimated that the number of specialist homes for older people will need to increase by 400,000 units in less than 20 years⁶³. This must be recognised in Councils' Local Plans.

However, research shows that currently:



20% of UK homes failed the Decent Homes Standard.



93% of homes lack even basic accessibility features such as level access to the entrance.



One-third of houses with a 'category 1 hazard' (a serious threat to the health or safety of people living in or visiting a home) were occupied by people aged 55 and over⁶⁴.

These statistics are due in part to the lack of targets for accessible homes from local authorities. Similarly, local authorities are often too stretched to take legal action against developers who do not comply with accessibility regulations. Nearly two-thirds of local authorities reported that developers did not always comply with accessibility requirements. Despite this, only 3% of local authorities took formal or informal action against developers on accessibility grounds between 2015 and 2018⁶⁵.

The effects of not reaching targets for accessible homes will continue to be felt strongly by people with dementia. Many people with dementia receive care and support from their children. However, the number of people aged 65 and over without children is set to rise to 2 million by 2030⁶⁶. As household composition changes, more people will be living independently without support from children. Women's life expectancy is still on average 2.5 years longer than men's⁶⁷. Moreover, a quarter of women born in the 1970s will not

have children. This means that there will be an increase in women living in isolation and needing support at home. Equally, as society becomes more mobile, children are less likely to live near to their parents. This means they are less able to provide care and support at home. The need for accessible homes will therefore increase, and a growing number of people with dementia will be directly impacted by a lack of action on this matter.

'My current challenge is trying to get the local council and housing association where my relative lives to provide disabled access so that we can get them out of the house to attend social activities. This needs to be a priority or people with dementia will become prisoners in their own homes.'

Carer

Getting the right support at home

It is estimated that two-thirds of people with dementia live at home⁶⁸. This is around 560,000 people. The APPG heard that for people living in their own homes, care and support at home was crucial.

‘Often the most difficult times for families are in the early hours of the morning from midnight to 5am. This can be very distressing and very exhausting for carers. I feel if there were peripatetic teams to support families in crisis at these key times, more people with dementia could be supported to live within their own homes.’

Family member and health and social care professional

People with dementia represent 60% of homecare recipients⁶⁹ and yet often receive poor quality care. This is partly because the majority of homecare staff do not have access to accredited dementia training⁷⁰.

Effective homecare can enable people to remain independent for longer. It can include:

- support with administering medication
- support with personal care, such as washing
- support with eating
- supporting someone to go out or attend an appointment or social activity
- identifying changes in a person’s symptoms (including behaviour and general condition)
- signposting to other sources of support
- supporting family carers.

Homecare is often one of the first formal care services accessed by people affected by dementia, and can be vital to providing the early support needed to prevent an issue escalating to the point of requiring hospital admission.

Access and availability of specialised supported housing

Many of the respondents reported that they didn’t feel able to continue living at home but they were not at a stage where they wanted to live in a care home. The rights of people with dementia to have personal choice and control over where they live are being curtailed due to a lack of specialised supported housing.

Specialised supported housing (often called ‘sheltered housing’) for people with dementia is typically a residential complex or community where people can live independently, with varying degrees of support and care options on-site. Enabling people with dementia to live in specialist supported housing could delay their need to go into residential care. This can increase their independence, and reduce costs for families and public services.

The APPG was pleased to hear of the benefits such housing has for people with dementia. However, many survey respondents spoke of a shortage of specialised supported housing having an impact on their ability to live independently. The availability of such housing can vary locally. It is essential that housing is

considered as part of proposals to reform care and support in the upcoming Green Paper on social care.

‘I live in sheltered housing. The best move I ever made. If you are as fortunate as me you have a small network of fellow residents and support staff around to encourage me to socialise, go out on coach trips, join in social activities and generally keep active. I believe following a good diet and walking everyday helps. It is very easy to slip into a slew of despair, if left alone. I actively seek out friends and family in order to feel connected.’

Person living with dementia

There has been some work to create initiatives and guidance on this topic. The following resources can help to improve new and existing supported housing for people with disabilities, including dementia:

- The Guinness Partnership Dementia-Friendly Environment Guide⁷¹
- design criteria for ‘Lifetime Homes’⁷²
- Alzheimer’s Society’s Dementia-friendly housing charter⁷³.

It is vital that this guidance is widely promoted so that local authorities and organisations have more awareness of the problems someone with dementia might face.

'There is a lack of adequate 24-hour social support to deal with a progressive incurable condition. Families can only do so much and need to be able to have regular sleep-in help and respite time for carers. When care at home becomes impossible we need supported living.'

Family member and retired professional

The APPG heard a number of shocking stories about the lack of personalised support for people with dementia. Training and awareness about the condition is currently lacking amongst supported living scheme providers. Dementia-friendly training must be an essential minimum requirement for all staff in supported living schemes to make sure that people receive the right support.

'Dad moved to an independent living development, where care to remind him to do everyday tasks, including taking medication, was available at a cost. This was the worst thing we could have done. He was vilified by other residents and the owners of the development considered him to be a nuisance. No one other than the carers cared and the carers are underpaid and over worked. My father needed conversation and stimulation but there was none.'

Family member

Housing: Recommendations

- Councils' Local Plans should include targets for accessible and adaptable housing which enables independent living. The UK Government should report annually on these local targets, including on if appropriate levels of funding have been made available to support plans.
- All applications for adaptations should be assessed by local authorities and other social housing providers within 20 working days.
- All home and residential care staff should receive mandatory training. This should be equivalent to Tier 2 of the Department of Health and Social Care-backed Dementia Core Skills Education and Training Framework, provided by Health Education England.



Community life

Article 19 in the CRPD describes the rights of people with disabilities to be included and supported in community life in general. Articles 29 and 30 describe their rights to be able to participate on an equal basis with others in the political, civic and cultural life of a community, and in recreation, leisure and sport.

‘Much more awareness is needed in transport, shops, banks, and web-based activities. Charities can do a lot, but legislation needs to catch up with the needs of people living with dementia.’

Family carer

The Prime Minister’s Challenge on Dementia 2020⁷⁴ (launched in 2015) states the Government’s vision for widespread awareness and understanding of dementia. However, the evidence submitted to this inquiry revealed that people with dementia are not benefiting from increased awareness and understanding in their daily activities, such as shopping, meeting friends and doing the things they enjoy.

‘Most of the occasions when I was with my mum in a public space (restaurants, shops, garden centers), and her illness was making her conversation confusing or abstract, or she displayed anxiety-induced erratic behaviour (wringing her hands, shredding tissues), we were treated with confusion and questions from staff, a lack of support and occasionally were asked to leave as my mum’s behaviour was “upsetting” for others.’

Family member

The evidence to this inquiry revealed the importance of supporting people with dementia to continue to lead full and independent lives. This means creating communities where no one is excluded or has to face dementia alone. The meaningful involvement of people with dementia in society is integral to ensuring that inclusive communities become a reality, and that stigma is tackled. This must be a joint effort from people and organisations across different areas of society.

The APPG praises the work of networks such as the Dementia Engagement and Empowerment Project (DEEP) in supporting people with dementia to have their voice heard and to influence local and national policies.

‘Sometimes the emphasis is solely on memory problems and little awareness of the feeling of panic when in strange places or excessive surroundings.’

Spouse and carer

‘Very few places make adjustments for people with dementia so that they can live normal lives. For example, you see wheelchair ramps everywhere but dementia-friendly signage is almost non-existent.’

Former family carer

Survey respondents spoke about how the Alzheimer’s Society Dementia Friends programme is making great progress in ensuring that the public are more aware of the condition. The programme has created almost three million Dementia Friends in England, Wales and Northern Ireland.

The APPG also notes the work of local governments, the national and local dementia action alliances and many other organisations in creating inclusive communities. The work of Alzheimer’s Society is particularly commendable. They have created hundreds of communities across the UK working towards becoming recognised as Dementia-Friendly Communities. They aim to support people with dementia to live well locally and remain a part of their community⁷⁵. A Dementia-Friendly Community is a city, town or village where people with dementia are understood, respected and supported. It is vital this becomes widespread practice. A representative from each local authority should sit on the steering group of each Dementia-Friendly Community in England in order to encourage businesses and organisations to become involved.

Case study: Wigan Borough Council Dementia-Friendly Communities

The Borough of Wigan received dementia-friendly recognition in June 2015. It is undertaking a number of activities to create a dementia-friendly town, raise awareness of dementia to reduce stigma and increase diagnosis rates.

There are now 13 Dementia-Friendly Communities in the Borough. They host a number of dementia-friendly activities that attract over 500 people each month. Examples of activities include active cafés, reminiscence sessions, vintage tea parties, dementia-friendly dog walking, music and singing groups, dementia-friendly swimming, yoga for carers and befriending services.

Families and carers who attend the sessions regularly say that they enjoy the variety of activities that come from the Dementia-Friendly Communities project. They feel that they are meaningful, and that they enable them to make new friends and improve their wellbeing.

The project also works closely with local organisations to support people living with dementia. For example, it referred many people living with dementia who didn't have smoke alarms to Greater Manchester Fire and Rescue Service for a 'safe and well' check.

Wigan has over 100 Dementia Friends Champions who have created over 4,400 Dementia Friends, raising awareness within local communities, businesses, and workplaces.

Wales is leading the way by committing to become the world's first dementia-friendly nation. Both national and local government have a role to play in championing dementia-friendly policies and considering dementia in all policies and procedures.

We therefore call on Westminster to become the world's first dementia-friendly parliament which:

- recognises dementia as one of the key issues of our time
- considers people living with dementia when making policy
- ensures that all MPs and Peers know how to support people affected by dementia in their constituencies and local communities
- ensures that the parliamentary estate is a safe and welcoming place for people affected by dementia to visit and to work.

Locally, Health and Wellbeing Boards are crucial forums to improve the health and wellbeing of their populations. It is therefore essential that the needs of people with dementia are recognised as part of strategic needs assessments and health and wellbeing strategies. All members of the boards should be Dementia Friends.

'The dementia-friendly shops and other public places mean that the person with dementia can feel comfortable going into them because they know that they will be treated with patience and consideration. This kind of thing should be much more widespread than it is. This boils down to education of the public at large.'

Former carer

Community life: Recommendations

- The UK Parliament should show enhanced leadership on the issue of dementia as a disability through its work towards becoming the world's first dementia-friendly parliament.
- A local authority representative should sit on the steering group of each dementia-friendly community.
- All members of Health and Wellbeing Boards should become Dementia Friends.

Conclusion

Legislation is clear that dementia is a disability. Through this inquiry, the APPG found 81% of respondents identified dementia as such. Despite this, people with dementia are not having their disability rights upheld.

Almost all (98%) respondents felt that society treats people with dementia differently to people with other health conditions or disabilities. This significantly impacts on the ability of people affected by dementia to participate in their communities. This will continue unless we take action to ensure people with dementia can access the legal protections they are entitled to.

This report focused on the importance of promoting disability rights for people with dementia in six areas: employment, social protection, social care, transport, housing and community life. However, these rights should not be limited to these areas – it is vital they are embedded in all areas of society.

Focusing on the themes of equality, non-discrimination, participation and inclusion, this report has shone a spotlight on the societal barriers people with dementia face. We have made recommendations throughout that will help to tackle these barriers. Each recommendation is designed to increase awareness of the disability rights of people with dementia, as enshrined in the Equality Act and CRPD, and identify ways people can be supported to participate as equal citizens in society.

Central and local governments have an integral role to play in making sure these rights are upheld. Both have a duty to support public bodies, employers, organisations and the public to fully embed these rights across society. In doing this, we can achieve positive change for people with dementia.



Summary of recommendations

Dementia and disability

- The Government should incorporate the CRPD into UK law and report to Parliament on its progress in implementation.
- The Office for Disability Issues should ensure that people with cognitive impairments, including dementia, are represented on their Regional Stakeholder Networks.

Employment

- The Government should mandate the DWP to revise its guidance to employers about their responsibilities to support people with disabilities. The guidance should include explicit reference to cognitive disabilities, including dementia. This guidance should cover reasonable adjustments, information on the Access to Work programme and how to support employees with dementia.
- As part of the 2019 Spending Review, the Government should consider the adequacy of the Access to Work programme to ensure that people with dementia benefit from this.

Social protection

- All local authorities should use a single, standardised form for the SMI council tax discount, and all claims should be backdated to the point of diagnosis.
- The Government should mandate the DWP to convene an expert group to review access to social protection for people living with dementia and their carers, recognising their specific needs. This must include those who are experts by lived experience.
- The Government should mandate the DWP to exempt PIP claimants below the State Pension age and with a dementia diagnosis from reassessments.
- Alongside local health providers, local authorities should set out an accessible offer for people with a dementia diagnosis. The offer should give information about available services and support, including any financial entitlements.

Social care

- The Government must publish the Green Paper on social care reform as soon as possible, to set out proposals for a fairer, more accessible and inclusive system of funding for social care. It should recognise and reflect the needs of people living with dementia, now and in the future.

Transport

- Every Local Transport Plan should include a section on how local transport is meeting the needs of disabled people, including people with dementia. The Plan should clearly outline how they are meeting their obligations under the PSED. This should refer to planning and delivering transport, taking into account spending reductions to buses and community transport.
- Metro Mayors should make use of new powers within the Bus Services Act to assess local need. They should reform bus services to ensure transport remains accessible for people with physical and cognitive disabilities.
- Licensing for taxis in local authorities should include provision for dementia awareness and wider disability training.
- The Department for Transport should publish clear and robust guidance on eligibility for the Blue Badge scheme – including an explicit reference to the conditions newly included, such as dementia, by Autumn 2019.
- The Department for Transport should report to Parliament on how many driving licences have been voluntarily surrendered and the reasons given, and on the mandated surrender of driving licences and the reasons given.

Housing

- Councils' Local Plans should include targets for accessible and adaptable housing which enables independent living. The UK Government should report annually on these local targets, including on if appropriate levels of funding have been made available to support plans.
- All applications for adaptations should be assessed by local authorities and other social housing providers within 20 working days.
- All home and residential care staff should receive mandatory training. This should be equivalent to Tier 2 of the Department of Health and Social Care-backed Dementia Core Skills Education and Training Framework, provided by Health Education England.

Community life

- The UK Parliament should show enhanced leadership on the issue of dementia as a disability through its work towards becoming the world's first dementia-friendly parliament.
- A local authority representative should sit on the steering group of each dementia-friendly community.
- All members of Health and Wellbeing Boards should become Dementia Friends.

Appendix

Methodology

In May 2018, the APPG launched an inquiry into dementia and disability – the subject of this research. The inquiry included a call for evidence from anyone with an interest in dementia – personal or professional.

The APPG received an unprecedented amount of feedback via an online survey, focus groups, written evidence and an oral evidence session. The amount of feedback received was one of the largest responses to any APPG inquiry, highlighting the importance of this issue.

The Group extends their most grateful thanks to everyone who gave evidence to this inquiry, including all those who submitted stories via the online surveys and written evidence, and everyone who participated in the focus groups and the oral evidence session.

Online surveys

These were the questions asked in the online self-selecting survey:

- Please tell us about yourself.
- Please describe your views on dementia being identified as a disability.
- Do you feel that people with dementia are treated differently to people with other health conditions or disabilities? Please expand on your answer.
- How have people with dementia been supported to live well and what else do people need in order to continue to live well?
- What do you think are the main challenges that people affected by dementia face in day-to-day life (for example using transport or in employment)?
- What support currently exists to address these challenges and what future action do you think needs to be taken to address these challenges?

There were 2,521 responses to the online survey, which was open between May and July 2018. The respondents fell into the following groups*:

- 3% people living with dementia
- 80% people directly linked to people with dementia, such as carers, family and friends
- 18% people who knew person with dementia (now deceased)
- 23% people working, or who have worked, in the field of dementia
- 2% people with no direct experience of dementia.

All of the responses received through the consultation were in the form of open text. In order to analyse the findings, each response was read and assigned a code or codes. A code frame was designed to cover each of the six questions. The code frame developed as coding progressed. An overview of the code frame is shown in the table on the next page.

* Some respondents selected more than one identity profile, which is why the numbers do not add up to 100.

Question	Analysis requirements
<p>1. Please tell us about yourself.</p>	<p>Responses were gathered under the following headings to permit a comparison of findings by different groups of the consultation participants:</p> <ul style="list-style-type: none"> ■ People living with dementia ■ Carers ■ Professionals ■ Other groups.
<p>2. Please describe your views on dementia being identified as a disability.</p>	<p>Responses were reviewed, coded and gathered under the following themes:</p> <ul style="list-style-type: none"> ■ How dementia manifests itself ■ The impact of dementia ■ What is needed for dementia.
<p>3. Do you feel that people with dementia are treated differently to people with other health conditions or disabilities? Please expand on your answer.</p>	<p>The responses of participants were reviewed, coded and gathered into four themes:</p> <ul style="list-style-type: none"> ■ Health and social care services ■ Funding ■ Society/community experiences ■ Miscellaneous.
<p>4. How have people with dementia been supported to live well and what else do people need in order to continue to live well?</p>	<p>Responses were reviewed and answers to the two parts of the question were coded separately:</p> <ul style="list-style-type: none"> ■ Those describing how people with dementia are supported to live well ■ Those describing what else people living with dementia need in order to continue to live well. <p>In a number of cases, participants chose to describe problems faced by people with dementia. Where possible support needed to live well were interpreted from these statements.</p> <p>The views expressed in questions 4 and 6 were found to be similar and the reporting considered them together.</p>
<p>5. What do you think are the main challenges that people affected by dementia face in day-to-day life (for example using transport or in employment)?</p>	<p>Views on the challenges were identified, coded and gathered into the following themes:</p> <ul style="list-style-type: none"> ■ Every day challenges ■ Physical health challenges ■ Cognitive challenges ■ Work challenges ■ Social challenges ■ Carer challenges ■ Emotional challenges ■ Public services challenges ■ Health and social care challenges ■ Funding challenges.
<p>6. What support currently exists to address these challenges and what future action do you think needs to be taken to address these challenges?</p>	<p>Responses were reviewed and answers to the two parts of the question were coded separately:</p> <ul style="list-style-type: none"> ■ Current support to address challenges ■ Future action needed to address challenges. <p>The views expressed in questions 4 and 6 were similar and the reporting considered them together.</p>

The APPG commissioned Accent to undertake the analysis and reporting of the consultation responses. A second survey was conducted between April and May 2019 that looked specifically at how people with dementia feel about identifying dementia as a disability. This survey received responses from 168 people with dementia.

Focus groups

76 people with dementia and 11 carers attended 14 focus groups, which were held across England, Wales and Northern Ireland between April and July 2018.

Written call for evidence

Below is a list of respondents to the call for written evidence:

- 3 Nations Dementia Working Group
- Action on Hearing Loss
- Alzheimer's Society Memory Café, Omagh
- APPG on Deafness
- Contented Dementia Trust
- Dementia United
- Forget-Me-Nots DEEP Group
- Go-Ahead Group
- Goal-oriented Cognitive Rehabilitation in Early-stage Alzheimer's and Related Dementias: Multi-centre Single-blind Randomised Controlled Trial (GREAT) Programme Research Team
- Improving the Experience of Dementia and Enhancing Active Life (IDEAL) Programme Research Team
- Innovations in Dementia and DEEP (The UK Network of Dementia Voices)
- Irish in Britain
- Laverstock Memory Support Group
- National Housing Federation
- Neil Crowther, independent expert on equality, human rights and social change
- Professor Linda Clare PhD ScD CPsychol FBPsS FAcSS, Professor of Clinical Psychology of Ageing and Dementia, Centre for Research in Ageing and Cognitive Health, University of Exeter
- Professor Peter Mittler CBE FRSA, Human Rights Consultant to ADI and DAI, Member of International Development and Disability Consortium
- SUNshiners DEEP Group
- The Royal College of Speech and Language Therapists
- The College of Optometrists
- The Guinness Partnership
- Tide – together in dementia everyday
- Toby Williamson, Toby Williamson Consultancy
- Worcester DEEP Group

The APPG also received written evidence from four people affected by dementia.

Oral evidence session

We held an oral evidence session on 27 November 2018. The following people were witnesses at this session:

- Sally Copley, Alzheimer's Society
- Hilary Doxford, 3 Nations Dementia Working Group
- Philly Hare, Innovations in Dementia and DEEP – the UK Network of Dementia Voices
- Emily Cook, Alzheimer's Research UK (talking on behalf of the 356 survey responses collected by Alzheimer's Research UK)
- Lena O'Connell, Tide – together in dementia everyday
- Cecilia Toole, Tide – together in dementia everyday

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The All-Party Parliamentary Group (APPG) on Dementia is a group of cross-party parliamentarians with an interest in dementia. It was created to build support for dementia as a publicly stated health and social care priority, in order to meet one of the greatest challenges presented by our ageing population.

The APPG prides itself on remaining at the forefront of debates on the future of dementia care and services. Over the past ten years we have run parliamentary inquiries into key issues affecting people with dementia, their families and carers.

This year, our report looks at dementia as a disability.

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