

Our Lived Experience

Current Evidence on Dementia Rights in the UK

An Alternative Report to the UNCRPD Committee



Co-produced by:

The Dementia Policy Think Tank
The DEEP Network
Innovations in Dementia CIC

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Executive summary

This alternative report has been co-produced by the *Dementia Policy Think Tank*, founded in 2016 by eight people with dementia in the UK. The group is the first dementia group to be recognised by Disability Rights UK as a Disabled People's User Led Organisation.

The report is a direct response to issues identified by our contributors. All the examples fall under one of five themes:

<u>Section</u>	<u>Theme</u>	<u>UNCRPD Articles</u>
1	Stereotypes & prejudices	8
2	Accessible transport	5, 9, 20, 21, 23, 28
3	Independent living & community inclusion	9, 12, 19, 21, 28, 30
4	Accessible healthcare	5, 8, 9, 12, 25, 26
5	Work	27, 28

Alongside examples of abuses or ignorance of rights, we include examples of good practice, and of how groups are trying to challenge the barriers they face through using a rights-based approach. We hope that these examples offer an optimistic context for the future.

Our evidence includes:

- Individual submissions

- Quotes from the audio diaries project 'Dementia Diaries'

- Quotes from blogs and booklets written by people with dementia

- Group submissions from a range of DEEP network groups

Notes of three recent Scottish DEEP Gatherings
The DEEP Yorkshire project 'Our Right to Get Out & About'
Film 'The Power of Words'
The Welsh Government: The Record of Proceedings of the Health,
Social Care and Sport Committee 09/03/2017

Almost all of the quotes come from people living with dementia, with a few from carers/supporters. Names have only been used when the quotes are already publicly available e.g. on blogs or films.

The devolved authorities

There is different legislation impacting on rights in the four devolved authorities of the UK, and differences in the way services are delivered. However, we suspect that many of the issues raised apply to a greater or lesser degree across the UK.

As the DEEP network covers the whole of the UK, we have included contributions from all the devolved authorities. Whenever possible, these are indicated by a flag.



England



Scotland



Wales



Northern Ireland

Note

Think Tank members have also contributed to the report sent to the Committee by the Alzheimer's Society, in conjunction with the new Three Nations Working Group and Young Dementia UK. The two reports, while separate, complement each other.

Together they bring a wealth of experiential knowledge to the Committee.

Foreword

*For the past few years much has been written, and even more said, about 'person-centred care', 'living well with dementia' and 'dementia friendly communities'. This is almost meaningless without greater emphasis and attention being paid to the **human rights** of those affected by dementia [including] our ... partners, family and close friends, each of whom shares the caring role and the impact of the dementia.*

For too long, older people have been too compliant and accepting of their lot. For too long this has been the same for people living with... dementia, because they were only diagnosed when they could no longer take up the challenge of advocacy. We feel part of a movement.¹

Keith Oliver



Keith and Rosemary Oliver at Hampton Court Flower Show.
Keith lives with dementia and is a member of East Kent Forget me Nots.

¹ Symposium on Human Rights and Dementia - UKDC Brighton (3 November 2016)

The Dementia Policy Think Tank

This alternative report has been co-produced, and is submitted, by the *Dementia Policy Think Tank*, a group founded in 2016 by eight people with dementia in the UK, committed to change dementia policy in the UK, and recognised by Disability Rights UK as a Disabled People's User Led Organisation.

The members of Think Tank are: Dr Jennifer Bute; Hilary Doxford; Larry Gardiner; Nigel Hullah; Wendy Mitchell; Prof Peter Mittler; Keith Oliver; Chris Roberts.

It is supported and facilitated by the UK-wide Innovations in Dementia CIC, a social enterprise organisation, but all decisions are made by its members living with dementia.

Think Tank is also a member of DEEP², a UK wide network of over 85 groups of people with dementia. It has drawn on the experiences and contributions of its fellow member groups in producing this paper.

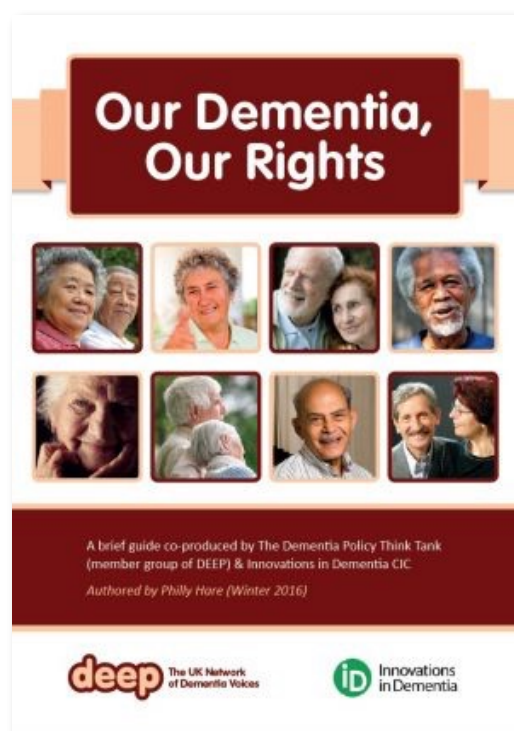
It is only very recently that people with dementia and their advocates have started waking up to the fact that they are 'persons with disabilities' under the United Nations Convention on the Rights of Persons with Disabilities and associated UK legislation.

Scotland was the first country to include people with dementia in its implementation of the Convention. In Great Britain and Northern Ireland, the Prime Minister's Challenge on Dementia 2020 commits to 'a greater understanding and protection of the human rights of those living with dementia around the world'. The new 'We Statements' from the Dementia Action Alliance are all overtly rights-based. Wales has human rights principles embedded in legislation and its Declaration of Rights for Older People, and a draft Wales Dementia Strategy also reflects this position. The dementia rights movement in Northern Ireland is also gathering pace.

² <http://dementiavoices.org.uk/>

Think Tank has produced a booklet '*Our Dementia, Our Rights*'³ and has also contributed to the *Alternative report - Great Britain* (Jan 2017), led by Inclusion Scotland, Disability Rights UK and Disability Wales, which was submitted to the UNCRPD Committee. This was the first report submitted to the UNCRPD Committee by people with dementia. The UNCRPD Committee's first List of Issues submitted to the UK government in March 2017 included a specific mention of dementia and also noted that many of the other items were relevant to people with dementia.

The Think Tank is committed to ensuring that the rights of people with dementia are an integral part of the universal discourse about social justice and that they are accepted as rights-bearers on the same basis as people with other disabilities.



Think Tank booklet published 2016

³ <http://dementiavoices.org.uk/deep-groups-news/our-dementia-our-rights/>

Section 1

Stereotypes & prejudices

Article 8 – Awareness raising

The List of Issues asks for answers to specific questions and information on measures taken by the national government across the whole of Great Britain and Northern Ireland under each of the substantive Articles.

Article 8 on Awareness Raising address prejudices and negative attitudes towards people with disabilities, in particular people with those with age-related conditions *such as dementia* and intellectual disabilities.

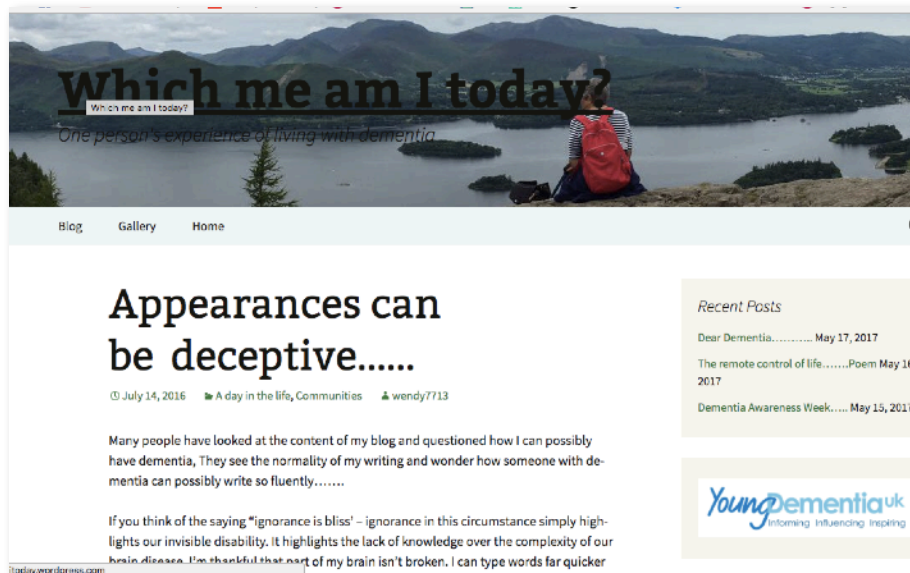
Not being believed

Wendy Mitchell has written extensively about this aspect of discrimination in her blog⁴.




Many people with dementia experience attitudes of disbelief. The 'invisible disability' doesn't help in our favour. I have had many comments and expressions of disbelief because I'm capable of writing a blog and speaking in public. For example; 'It's not real dementia though is it, otherwise you wouldn't be able to write as you do'.

⁴ <https://whichmeamitoday.wordpress.com/2016/07/14/appearances-can-be-deceptive/>




'Which Me am I today?' Wendy Mitchell's blog

A person from Kent who has young onset dementia agrees:

 *I have more problems with my age and dementia, rather than just dementia. Many people find it hard to believe such a young person can have a dementia (especially when in their forties or fifties).*

Several others reiterate the point that, on telling people their diagnosis, the response has been 'Well, you look alright'. There is a strong stereotype of how a person with dementia 'should look'.

 *What concerns and disappoints me, are the number of people with experience of dementia who, at conferences, will say that the person with dementia speaking does not in fact have dementia. It has happened to many of my friends and myself. Very few people will say it to our faces, but [they] will say it to our friends and family members. If they have the knowledge they proclaim, do they not understand the progression of this disease? The early stages are not visible. But for every 15-minute presentation we give, we have done many hours of preparation to try and be as good as we can be... I try not to take it personally, but feel I am being told I am a fraud and a liar.*

Lack of training of clinical and other professional staff, and discriminatory attitudes by public sector staff

We were given many examples of discrimination arising from lack of awareness by those in the caring professions. In one case, in Kent, the person with dementia shared their diagnosis with a professional – who then asked where their carer was and if they were allowed to be out on their own! This person comments:



It highlights that old fashioned attitudes are still around.

In another example, a person with dementia attending a hospital eye clinic wanted to check in at the desk. She was repeatedly refused and told by the receptionist that ‘there is a machine for it now’ – even when she shared her diagnosis and said that many people with dementia may struggle with using [the machine] too. It was only after she said she was part of a group which is trying to change these things that she was assisted at the desk. (On a positive note, there was no problem with checking in at the desk the next time she came for an appointment.)

Several others said they had experience of doctors talking to their spouse or whoever was with them, rather than to them, once they saw their diagnosis of dementia.

Failure to listen to a person with dementia (whatever their skills and expertise) can have very serious consequences, as one story illustrates. This lady, who has dementia, used to be a doctor:





When my husband was taken ill with a sudden severe headache, I told the hospital staff it was serious. I was a doctor and wanted a referral to a neurology department They wrote in the notes that I had dementia, so did not know what I was talking about, and that my husband had a headache due to the stress of having a wife with dementia. I insisted he had a CT scan and they said yes, it showed something, but was an old injury that I had forgotten about as I had dementia and could not remember!!...He died a few days later!! It was a treatable condition. When there was an inquiry they told me I could


not remember anything as I had dementia. They had written a load of lies in the notes, but had forgotten my son was with me the second time!! I had a written apology, admission of negligence etc. etc. but I do not believe in suing, and I just have to live with the guilt that if I had not had dementia he could have lived! [Think Tank member]

Lack of awareness in the general public


Lack of awareness amongst families and the general public can have a big impact on how people with dementia are treated by those around them:

 *Ooh yes - my daughter, as soon I was diagnosed, believes I'm incapable of doing anything for myself any more. [York Minds & Voices]*

 *When I was first diagnosed, my son asked 'so when are you going into a home?' [York Minds & Voices]*

 The Lewisham DEEP group recently discussed stigma and attitudes. The group feels that, in general, awareness is better now than when they were young, but that there is still work to be done. Most members don't discuss their diagnosis much outside of the group and feel there is a stigma to dementia. They feel that, while awareness-raising has helped, it is not necessarily *awareness of rights*... and tends to focus on people with more advanced dementia. Therefore, people don't expect there to be people in the community living independently with dementia.


A woman from Dementia NI confirms the same⁵:


 *We're not here to be felt sorry for, we don't want that. All we need is for people to know that we are people here.*


How it can be better?


Others have more positive comments which show how things can, or could, be:

⁵ <https://audioboom.com/posts/4586055-co-chair-john-mcerlane-talks-to-sarah-travers-about-living-with-dementia> May 2016

 *Although I have only been diagnosed recently, so perhaps have not had too many experiences, all those I had so far have been very good... But maybe that is because most people I know are quite good people.*


 *[A friend said] I am so pleased you told me (of having a diagnosis of dementia), it meant a lot.*

 *... I manage my condition with the support of family and friends, it's an amazing structure... My wife is very supportive; she might roll her eyes but it's all in good humour. [Buddies group]*

 *I live a fantastic life because of my support network, which is my family and friends. I do not have any support from health or social professionals. [Buddies group]*

Members of Kent group SUNshiners think the new Alzheimer's Society message/advertisement helps, by emphasising young onset dementia and 'All races, all ages'. They comment positively on the effort to target young audiences, children and schools – and find advertisements that focus on the message 'You can do anything' very helpful, including for example encouragement to join marathons or walking challenges.

However, many think there is much more to be done:

 *Awareness of dementia is improving, but we have a long way to go, it's a first step but we need more information out in the public arena. [Buddies group]*


The power of words

Many people with dementia are offended by the continuing use of terminology which they consider disempowering and outdated – words such as 'sufferer' and 'victim'. In 2015, DEEP and the Dementia Action Alliance launched a Call to Action to challenge such language. DEEP members also made a short film to illustrate the Power of Words⁶ - this contains these testimonies:

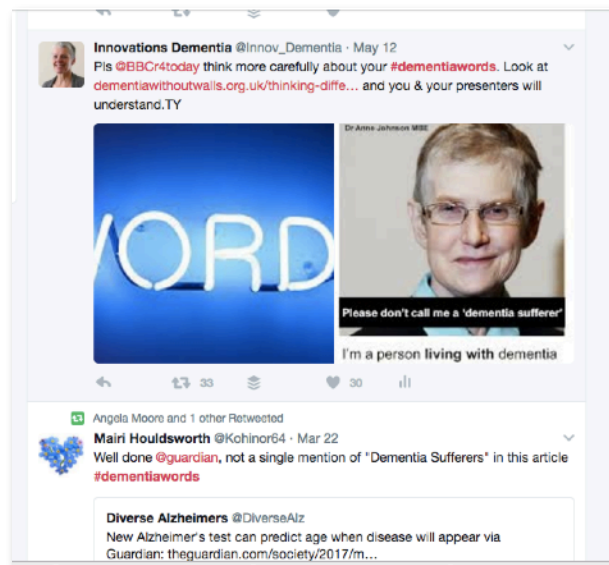
⁶ <https://vimeo.com/122528299>



Clip from the film The Power of Words

 *Since my diagnosis of dementia, words hurt more than they did before. It's like prodding a wound. They should choose their words with care...To build people up with dementia and help them live well is what the government and everybody else want to do. Words can empower people to live well. [Agnes Houston]*

 *I'm not suffering; I'm living well with dementia. [Gina Shaw]*



Twitter hashtag #dementiawords is being used to challenge stigmatising terminology

There are now around 440 signatories⁷ – **though no Government departments**. The hashtag #dementiawords is used by many Twitter users to

⁷ <http://www.dementiaaction.org.uk/dementiawords/signatories>

challenge via social media – and to reinforce good practice. However, the media in particular still routinely uses ‘sufferers’. Much more leadership is needed from Government.

Section 2

Accessible transport

Article 5 - Equality and non-discrimination

Article 9 – Accessibility

Article 19: Living independently and being included in the community

Article 20 - Personal mobility

Article 21 - Freedom of expression and opinion, and access to information

Article 23 - Respect for home and the family

Article 28 - Adequate standard of living and social protection

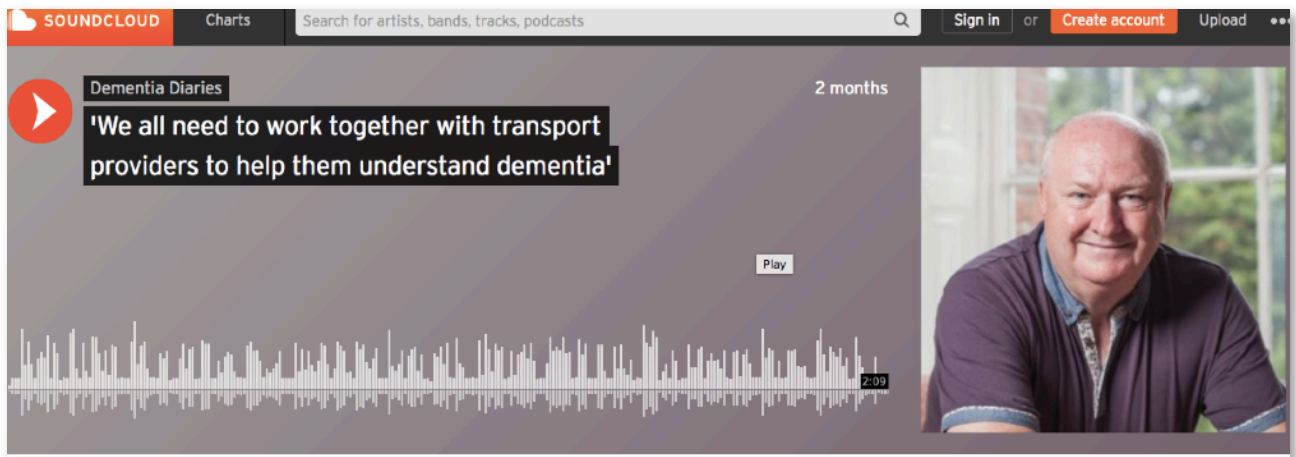
We have received many comments on buses and trains, parking, taxis, driving, and airports. The way in which these are organised – and staff attitudes - can present huge barriers to independent living (Article 19) and access to the community – as Tommy Dunne (an ex-rail employee now living with dementia) explains in his audio diary⁸:



Access to reliable, affordable and safe transport is important to people with dementia to maintain contact with friends and family...or just going to the shops or appointments. That helps avoid loneliness and isolation...


Every time I get on the bus, the driver can make or break my day. We all need to work with transport providers to help them understand dementia. Their most valuable asset is staff... It's no good giving them a 45-minute Dementia Friends session and calling that training...

⁸ <https://soundcloud.com/dementia-diaries/we-all-need-to-work-together-with-transport-providers-to-help-them-understand-dementia>



Tommy Dunne on Dementia Diaries

Wendy also explains the importance of travel to her⁹:

 *If I didn't have coping strategies to remain independent and mobile, I'd be very lonely and soon sink into depression. Travel brings normality to an otherwise abnormal life. The main barriers are often other people...thinking you can't, instead of helping you to find other ways to remain independent ... I also find websites quite difficult and have to resort to others doing it for me...I wish there was a middle ground between travelling unaided and using Assisted Travel.*



Wendy Mitchell on Dementia Diaries


Driving


Driving is often a lifeline for people, especially those living in rural areas (of which there are many in the UK). One in three people with dementia still

⁹ <https://soundcloud.com/dementia-diaries/my-thoughts-on-continuing-to-travel>

drive¹⁰, but many feel the loss of their license very keenly, and feel that the procedure for assessing ability to drive should be better communicated and more sensitively administered.


Driving issues were discussed in detail recently at two Scottish DEEP Gatherings:

 *When you have the right to drive taken off you, it can affect your whole life, very suddenly, and you can lose your right to a family and community life. We have the right to be enabled to get about and remain a part of our family and community.*

 *There is a lack of information about getting about and your right to drive. Who makes the decision? There should be info in a pack given to you when you are diagnosed, because the effect can be immediate.*

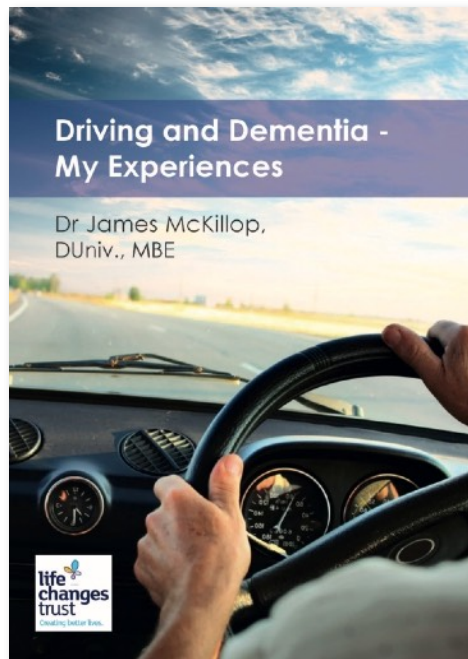
 *Can you appeal against your [driving] assessment?*

Dr James McKillop, who has been living with dementia for 17 years, has published a booklet¹¹ ‘*Driving and Dementia: my experiences*’. Here he proposes:

 *If someone responds to treatment and medication, they should be allowed to sit a further driving test, and the result should be abided by. I also strongly feel that in appropriate cases there should be a restricted license available. For example, you could be restricted to, say, daylight only; A or B roads, not motorways; your local town; X miles from your home; or so many hours a day.*


¹⁰ https://www.alzheimers.org.uk/info/20030/staying_independent/27/driving

¹¹ <http://www.lifechangestrust.org.uk/sites/default/files/publications/Driving%20with%20Dementia%20website.pdf>




Dr James McKillop's booklet

One contributor drives and owns her own car. This is what she has to say about the cost of being retested every 6 months:

 *I think it is most unfair to be charged £50 for the review assessment. It is a discrimination for drivers affected with dementia. It was not our decision to be given a diagnosis of dementia so we are being penalised for this condition. On assessment day, which is every six months, I have to make arrangements for someone who is a car driver to accompany me to the centre, as you cannot use your own car. This is an added cost to the nominated person that accompanies you.*

Many people have also recently lost the right to a government-funded Motability car (Article 28):

 *Without the Motability car [that was taken away] I am unable to make the bus journey (with 3 changes) to get to hospital in town.*

Parking


Whether you drive or are driven, you need to park. Like other disabled people, people with dementia often need to park very close to where there are going.

In the UK, the Disabled Persons Parking Badge Scheme, often referred to as the Blue Badge scheme, allows people who have disabilities various concessions and privileges relating to parking. The eligibility rules vary depending on whether you live in England, Wales, Scotland or Northern Ireland.



The 'Blue Badge'

Many people with dementia feel they are discriminated against in terms of eligibility for the Blue Badge (apart from in Wales).

 The Scarborough group, DEEP Vibes, identified a number of problems this unsatisfactory situation causes for people with dementia. These include risks to the person left on the pavement while their carer parks - risks of abduction, getting lost, or getting panicky. If the person with dementia is the driver, they may have to park far away and have more difficulty navigating to where they need to go – as well as forgetting later on where they parked. In addition, the application forms are very complex, you have to supply a range of documents, and the cost is prohibitive to some.

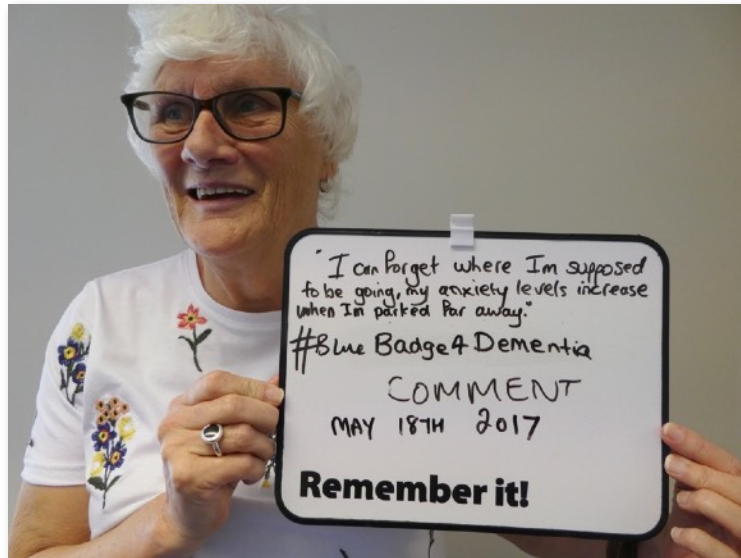
The group set up a petition in May 2017 which is currently ongoing¹². Here are some of the comments of the signatories:

My father had Lewy Body dementia and Parkinsons... he was 84...we were refused a disabled parking space as he was not the driver... red tape and rules and [regulations] in this country are archaic and need a massive overhaul.


¹² <https://you.38degrees.org.uk/petitions/blue-badges-4-dementia-1>


My husband has no road sense now due to his dementia and just steps out without looking, we have had a few near misses!!!!

Dementia is not all about memory, there is also spatial awareness.




Scarborough DEEPVibes member launches their campaign

 *The forms are too complicated. I gave up.*

 One woman, who does have a Blue Badge, finds that having to park in a bay marked with a wheelchair symbol causes her problems. She said that people look at her as if she shouldn't have a Blue Badge when she walks away from her parked car, and even question her need of the space.

Taxis


Those who cannot drive often have to depend on taxis. Taxi issues were discussed in detail recently at the Scottish DEEP Gatherings:

 *Taking taxis means you have to be able to trust the driver, to feel safe.*

 *In Liverpool they have the "Pink Ladies Taxis" just for women. Can't we?*




Scottish DEEP Gathering Spring 2017 Hawick

 A few members of the Lewisham group said their transport costs have increased because they can't drive and have to get taxis. Many use the bus, but some people don't feel confident to do that, so pay for taxis. They acknowledged they are lucky to be able to afford this - and that, if they couldn't, their lives would be very limited.


Buses and trains

Public transport presents a range of hurdles to people with dementia. Both train and bus services are provided by networks of different companies, who often have different rules for concessionary travel, and different ways of providing and presenting information. Both bus and train travel are often hindered by inaccessible information.

Many people struggle with poorly designed online train booking systems:

 *Difficulty booking tickets on my own on-line. The complexity of multi changes is difficult for anyone, but is more confusing when you can't remember the last thing you clicked. [Wendy Mitchell]*

People with dementia find the way information is presented and provided on trains and in stations difficult too:

 *Finding the right seat on the train can be very stressful, depending how they display the reservations. Cross Country are particularly stressful. [Wendy Mitchell]*



I got off one train and had no idea where the exit was, so spent the next half an hour or so wandering up and down the platform and over the bridge to the platform on the other side and back again. The railway staff just ignored me until the person meant to be picking me up came looking for me!

Assistance Travel is available for people with disabilities, but Wendy finds that it is very much oriented towards those with physical disabilities, and has yet to grasp the problems faced by people with cognitive impairments:



*Assistance Travel does not work when you're not in a wheelchair.
[Wendy Mitchell]*

In many areas of daily living, people with dementia will need to make plans, and will often struggle most when plans go awry. This is particularly acute when travelling, as people are often alone and can feel very vulnerable:



Confusion when trains are delayed and you need help working out what to do. [Wendy Mitchell]




Another time I was on a through train (carefully chosen!), having been put on into a reserved seat. I was due to be collected by someone from the numbered seat at my destination (they had the number), when there was a crisis on the line and an announcement was made for us to get off (I did not understand the message) and to find our own way to our destination! Only when the blind man in the seat in front started shouting for help and he was just told to 'be quiet and 'shut up' by the staff member who was going through the carriages told us to get off... When my daughter wrote to them later we were told as I had not registered for help in an emergency none would be provided.





The consequence of this was I now NEVER travel alone!

As for bus services, whilst they are often cheaper than trains, (and in Scotland carers can travel free), services are in short supply and have been cut in many areas.


Buses are usually staffed by a single person, and so there is a lot that can be done to make sure that staff awareness and attitudes do not present barriers:


 *I got on the wrong bus and did not realise until it turned right instead of left at a crossroad, and the driver just shouted at me, although I had told him when I got on where I wanted to go!*


 *Another driver shouted at me when I forgot how to use my bus pass.*

 *Another driver told me to get off the bus, as it was not yet 9.30 in the morning (the time when the bus pass is eligible). It was by my watch though, and the bus was almost empty. Again I ended up in tears at the roadside.*

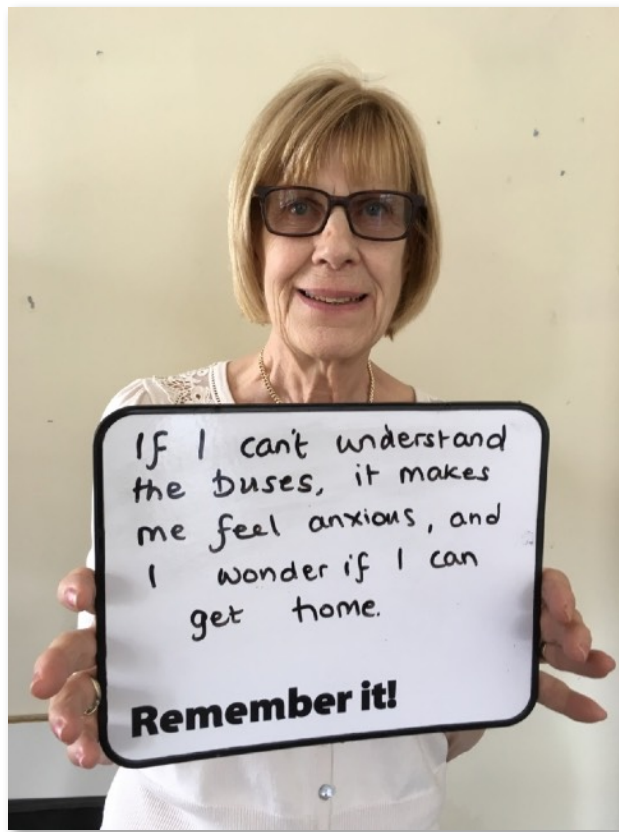
Bus timetables are notoriously difficult to understand. There are examples of people getting the wrong bus or being put off travelling at all because the inaccessibility of the information makes them feel confused, embarrassed and stupid.

 The York event identified that bus travel is difficult because different providers and route changes make it very confusing. Some display information screens and some do not. Some use colour coding, but this is often not followed through to the colours of bus stops or buses – it would be helpful if it was comprehensive and consistent.

 The Bradford FIT group have since made a short iPhone film about bus information, and are calling for clear route maps and colour coding at every bus stop, as well as personalised timetables. One member feels that, as a bus user, his right to go further than his immediate locality is denied:

 *If you don't limit yourself to your immediate area, then you don't understand the bus rules of that area. You don't know whether to put*

your hand out, how to use the timetables etc. This limits my freedom.
[Bradford FIT member]



Bradford FIT group member gets her message across

Airports

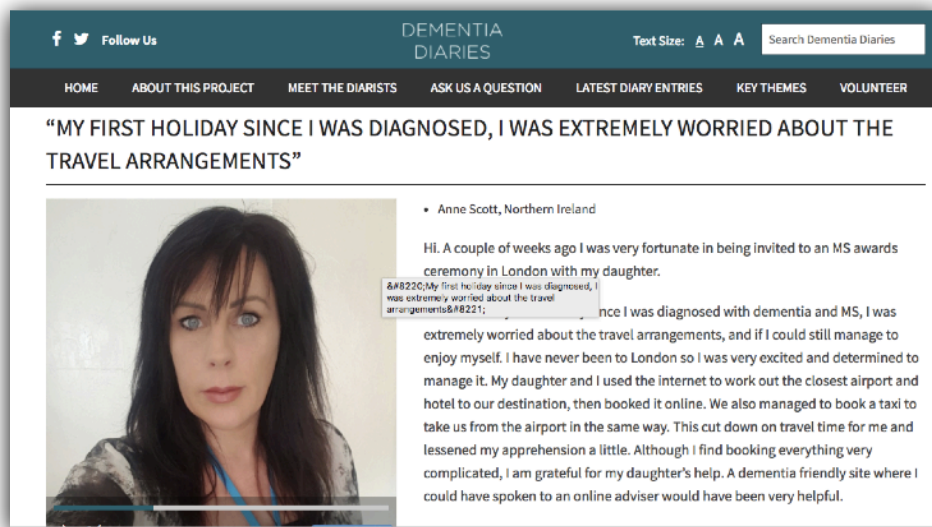
Anne Scott from Northern Ireland used her audio diary¹³ to describe her experience using airports. Although some of it was positive, she says:



Apparently not all airports supply wooden walking sticks. Once again I did not pass security and was not allowed my own stick. I asked if I could lean against the wall while being searched and was told no. I was shocked at this and I had a hard time trying not to collapse. I was given my stick back halfway through the search by another attendant and received an apology, but for me my stress level had now reached a high level, and by the time I got to the plane I was panicking and

¹³ <http://www.dementiadiaries.org/entry/4784/my-first-holiday-since-i-was-diagnosed-i-was-extremely-worried-about-the-travel-arrangements>

exhausted. This all could have been avoided and my journey much more pleasurable if the London airport had taken the notification they received about my travel requirements.



Anne Scott's audio diary on Dementia Diaries

Alzheimer Scotland's Positive Dementia Group in Aberdeen (members of the DEEP network) have recently been working with Aberdeen Airport to improve access issues.



Aberdeen group working directly with airport staff

Section 3

Independent living and community inclusion

Article 9 - Accessibility

Article 12 - Equal recognition before the law

Article 19 - Living independently and being included in the community

Article 21 - Freedom of expression and opinion, and access to information

Article 28 - Adequate standard of living and social protection

Article 30 - Participation in cultural life, recreation, leisure and sport

The UN Committee asks the UK government to identify the legal protection of the right to independent living and the means by which disabled people can enforce it. It also asks about sufficiency of budget allocation (Article 28) to ensure realisation of the right to live independently and to be included in the community, and about the legal mechanisms to ensure the availability of support based on choice, control and inclusion (Article 12).

All these are very relevant to the lived experience of people with dementia.

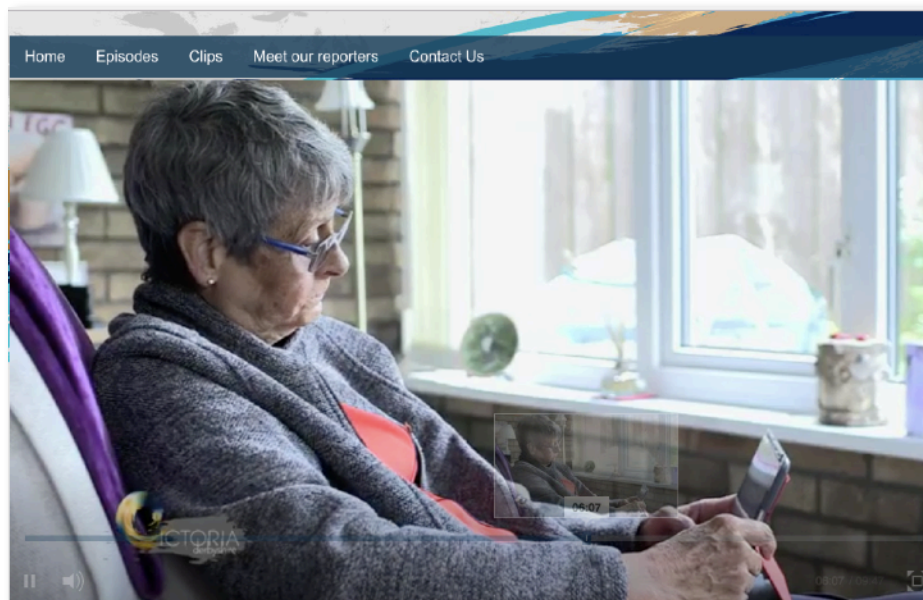
Benefits and other entitlements (Article 28)

On a recent BBC programme¹⁴, Wendy Mitchell explains the impact of losing benefits under the Government's reforms:




For 18 months I was entitled to PIP (Personal Independence Payment). After a reassessment I was suddenly deemed as no longer requiring this help to keep me independent. In the written explanation I was told I could now do things I clearly can't. Having clearly deteriorated since being entitled, I don't understand a system that now says I'm no longer in need. The assessor did not understand dementia.

¹⁴ <http://www.bbc.co.uk/programmes/p04hb0hw>




Wendy Mitchell on the BBC

In her blog, Wendy Mitchell also explains why she feels unable to challenge the review:

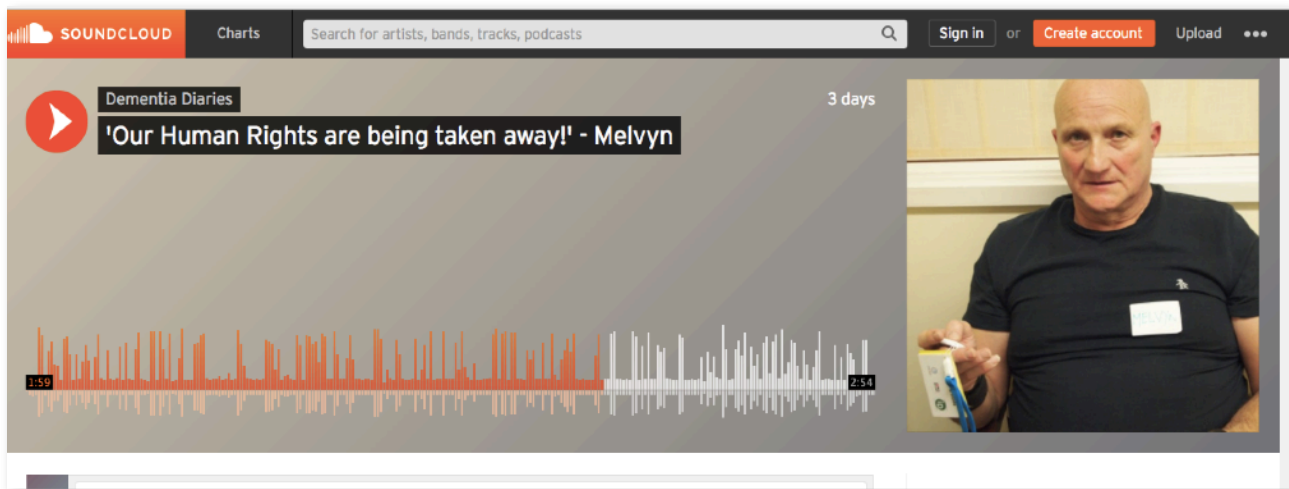
 *Watching the [BBC] programme brought back all the sadness once again, which just reiterated for me that I'd made the right decision not to take it to the tribunal. Life is a daily struggle as it is, without being continually brought down by the system. It doesn't just affect me, it affects my daughters as well and their well being is first and foremost in my mind. All I hope is that this brings those that can influence, to their senses, and that people with with incurable conditions that can only get worse, become exempt from the demoralising assessments.¹⁵*

Melvyn Brooks explains what he thinks about PIP, using an audio diary:

 *Our human rights are being taken away... there is an agenda that is taking the rights of people away with a disability... The people who are making the assessments are not medics, not qualified going against the reports and words of the doctors. I expect care, love and*

¹⁵ <https://whichmeamitoday.wordpress.com/2016/11/23/victoria-derbyshire-programme-highlighting-pip-fiasco/>

*compassion at the end of the day ... we need to challenge these politicians who are a disgrace*¹⁶



Melvyn Brooks using Dementia Diaries to make his point

Others also feel very strongly that the PIP assessment process does not give them the support they need.



Every day I have to prove I can live well with dementia, then I go to the PIP assessment and I have to try and prove that I don't.


For her assessment, one person had to find an unmarked office with very poor parking facilities.




Another had to take the DWP to tribunal after he scored 0 points on his PIP assessment. The tribunal found in his favour, and he was told he would now get both parts of the PIP payments until a reassessment in 2018. But in the last few weeks, he has been contacted again to say that he needs to reapply by completing the 40-page form again.


The Kent Forget Me Nots group sent in their views on the right to independent living:

¹⁶ https://soundcloud.com/dementia-diaries/our-human-rights-are-being-taken-away-melvyn?utm_source=soundcloud&utm_campaign=share&utm_medium=twitter


 *Paradox: the concept of independent living is still about [getting] people dependent on the support provided. The UN needs to look at the human rights rather than the help to support people with their sickness, the right to get help to live independently.*


 *My PIP assessment takes away my independence. There is no allowance for independent living for older people with dementia.*

 *No support at all when living alone – all too expensive to afford.*


 *There is no care in the community, nobody to remind me to take pills, cook. [We are] stuck with 15 minute calls that we [have no use for].*


Issues around living independently and benefit entitlements were discussed in detail recently at two Scottish DEEP Gatherings. These were some of their comments:

 *If you do learn to adjust and travel independently you can have your benefits cut!*


 *In the Western Isles there was 0% post diagnostic support provided in 2015. This was because there were no link workers but that didn't mean the need wasn't there. In 2017 a part time 7 hours a week post was put in place for the whole of Uist and Barra. It would take 7 hours to drive to one appointment.*


 *Link workers' posts are temporary, short term, part time. This makes me feel more lost.*

 *[We are in] what we call "The Black Hole": this is the long time between post-diagnostic support and end of life, when we are expected to "self-manage" our dementia.*

 *Who is actually supposed to be supporting us between the [Scottish Strategy's] 5 and 8 Pillars? If we are supposed to be self-supporting and supported by our families, how do we do that?*

 *There should be support for couples and supportive relationships.*

 *People living with dementia have the same right to supported independent living as other groups of people, e.g. people with learning disabilities/physical disabilities/mental health problems.*


 *There must be a link made between our right to independent living with PIP (Personal Independence Payment) and SDS (Self Directed Support).*



Scottish DEEP Gathering Spring 2017 Inverness

Comments from the Kent group show how things can be very different in another area:

 *In the area where we live, I feel we have a pretty good support.*

 *My journey is just starting, but so far we are managing with everything quite well. Good support from the family helps to maintain my independence (e.g. my organisational skills), and support from additional services has not much been needed yet.*

One person from Kent has had very good support to live independently. She has always enjoyed cooking, but stopped doing it due to struggling with recipes. However, her Occupational Therapist helped her to make meals and simplify recipes, include a list of the equipment needed, and to use various strategies to help her achieve her goals (such as putting a laminated sheet over the top of a recipe so she can tick off each stage as she has done it). She still uses these strategies and is now also adjusting some aids as the time goes on and some things get more difficult. She also uses other strategies such as a checklist by the front door with essential items to remember (e.g. key, phone, handbag), a tick-list on the fridge for somebody else to help encourage them to drink frequently, how to cope with depth perception changes etc.


In Kent, some people said they attended Cognitive Stimulation Groups which encourage them to go back to some of their activities, to exercise their brain.


Access to community services

The Committee asks the UK government to explain what steps are being taken to implement, coordinate, monitor and sanction in relation to advancing accessibility (Article 9).

Accessibility is an important component and arguably the underlying principle behind the notion of dementia friendly communities, which has been at the forefront of much UK dementia policy in recent years.

Although many towns and cities are now signed up to becoming dementia friendly communities, people with dementia have different views as to what impact this has had, as the York Minds & Voices group discussed:

 *Well I'm not really aware of it.*

 *But there's more attention to it now. Everything you touch is 'dementia friendly'.*


 *It's been milked but has still not really been taken in.*


Here we offer comments about the difficulty that many people with dementia still face in accessing their community, its services and resources.

The most obvious manifestation of accessibility for people with dementia is in the physical environment - the building and places we use and the materials we encounter within them.


Kent Forget me Not group members raised the issue of poor signage which complicates access to public spaces:

 *We need large signs in public building, large font toilet signs sticking out from the wall.*


 *Supermarkets (could have) a plan of where things are so we can take it home and plan our shopping. And a person available to help.*

 *[In the bank] I have no idea where to go or how to ask if I need help once I get there. [Think Tank]*

Our society's reliance on the written word excludes some people:

 *If I lived alone, I don't know how I would manage. If I had a bill in, I wouldn't be able to pay for it, also not be able to read the bill or deal with the money, and I wouldn't know where to go to get some support. Simple solution: partner people up. [Buddies group]*

But there is still much that can be done to make written material more accessible without resorting to solutions like this:

 *[In the restaurant] I told them I could not read the menu easily, and so they gave me a Kids' Menu!! [Think Tank]*

For most people with dementia though, people are a more important determinant of accessibility than the material environment, and their attitude and awareness can make a lot of difference:



I couldn't find where to pay in a shop. When I asked, I was given a general waft of a hand 'over there'. It's really about good customer service. [York Minds and Voices]



I once took a lot of coins into my bank (from selling my DVD's and USB sticks at a conference) as I could not count them, and I handed them over at the counter in various bags (there were 3 ladies behind the screens and no other customers in the building). They refused to count them for me and told me to fill in a form once I had counted them. I had no idea which form and where to find it 'Over there' was not helpful. It was only when I sat down and started crying did one of them come out and say she wasn't allowed help me as she might add them up incorrectly. Well, I said, through my tears, I would be none the wiser, and left.

(I then got involved in another bank's dementia awareness to try and do something positive with it!) [Think Tank]

One Think Tank member articulates the importance of attitude in creating accessible communities:



...more distressing was the realisation I was viewed as a lesser person. It was obvious that institutions such as banks, employers, statutory bodies favour a complete cognition as opposed to my now altered one. And I was slowly being denied the rights and responsibilities of being a fully recognised member of civil society and being denied self determination. Until recently people with dementia were assumed incapable of making any decisions simply because of the presence of dementia. There remains a lack of recognition that people with dementia should also have a right to independent living.

Section 4

Accessible care

Article 5 - Equality and non-discrimination

Article 8 - Awareness-raising

Article 9 - Accessibility

Article 12 - Equal recognition before the law

Article 25 - Health


Article 26 - Habilitation and rehabilitation


The Committee has asked the UK government how health inequalities are monitored and eliminated.


Diagnosis

There are numerous issues about the timing and manner of diagnosis.

Many younger people in particular experience problems getting a timely diagnosis:


 *Misdiagnosis is very common among younger people. This can lead to wrong treatment and medication, to a loss of job and even your home and can impact your medical records.*

 *I was misdiagnosed with bi-polar disorder, and then had a breakdown.*

 *Three years ago I was diagnosed with early-onset Alzheimer's. I was 51. First of all, when I saw the GP, they said yes, there were memory problems. Then I had to see a psychiatrist nurse who thought maybe I was going through the change, but I'd had a hysterectomy at the age of 42. Then I had to see a psychiatrist because they thought I was depressed, which was a waste of time, because they said to me, 'You're not depressed'. I said, 'I know'. Eventually, then, I got to the*


memory clinic, and was told that I had Alzheimer's. Because I'm young, people automatically think that I've got something else.¹⁷

There is also concern about the lack of specificity in diagnosis:


 *It is important to get the correct diagnosis. "Dementia" is not enough, there are many kinds of dementia, which can benefit from different medications. They wouldn't just say "You have cancer" and send you away. We have the right to more specific information.*


Continuity of healthcare (Article 26)

When Wendy Mitchell moved house from York to the East Riding, she experienced many problems in continuity of care. She explains:

 *It took me months to access any services in the East Riding. After my CPN (Community Psychiatric Nurse) from York referred me to services, I was discharged, as I didn't fit into the appropriate age group. I wasn't told I'd been automatically discharged without anyone seeing me – it was after many phone calls and emails that I was told this.*

Lack of understanding of dementia can be a significant barrier to continuity of care, especially when dealing with other health conditions, as can be seen from Wendy's experience:

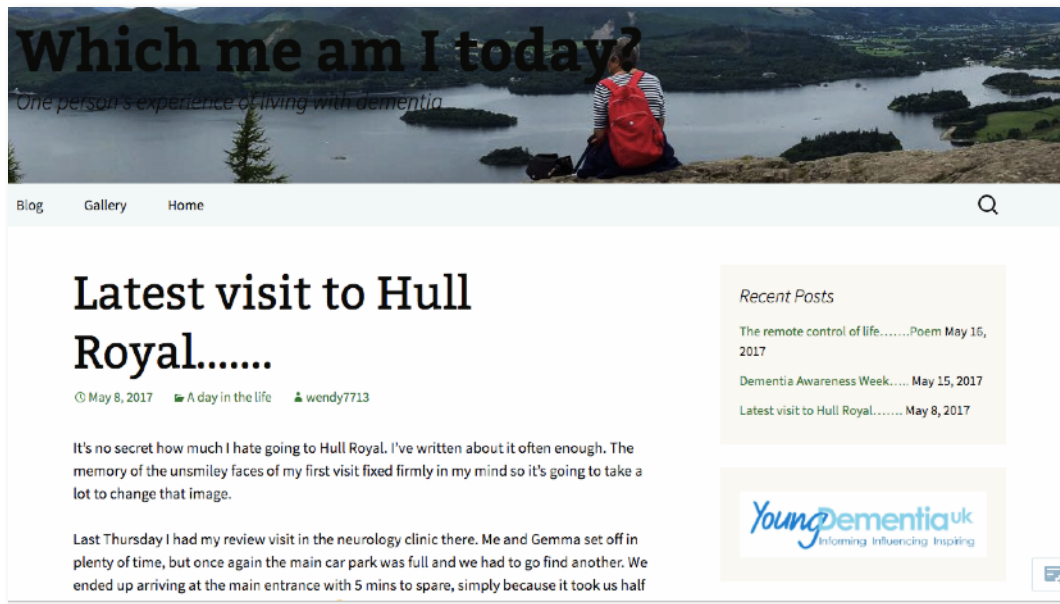
 *My District Nurse and OT (Occupational Therapist) both had little or no knowledge of Young Onset Dementia, so, each time, there was a look of surprise as I answered the door, and then the usual conversation had to take place to educate them before we could start on why they were there.*

 *Whilst being treated as a day patient for an eye operation, I was asked important questions several times – by nurse, then anaesthetist, then doctor – even though it clearly said I had dementia on my notes. Yet they were relying on my memory for important information.*

¹⁷ The Welsh Government The Record of Proceedings The Health, Social Care and Sport Committee
09/03/2017



Attitudes of staff at Hull Royal Infirmary were less than helpful. No smiley faces; a Consultant who spoke quickly and threw questions at me; and healthcare professionals who addressed my daughters when I'm stood next to them.



Wendy Mitchell writes in her blog about healthcare accessibility issues

A member of the Buddies group gave another good example of the lack of understanding among some health professionals:



Sadly, I have just today had a bad experience [of] a professional's understanding of dementia. [I was] seeing a (non-dementia) consultant today and I explained that I was living with dementia, however he [did] not remember that I had a cognitive impairment and still asked me questions like, "Can you remember when it started?", "Do you know the date?", time / incidents. I couldn't answer his questions, and I felt sorry for him.

There are many access issues which could easily be resolved, as Wendy Mitchell points out:



We were called straight in for me to be weighed, but then had to wait another 90 mins before seeing a registrar. I don't mind waiting to be seen at all, what I do object to is not being told why. Anxiety is high

enough without having the worry of when you'll be seen. They have on the wall beside each consulting room the ideal solution – a board telling you how late they're running... but it's such a shame they don't bother to use it. They really don't help themselves.

Post-diagnostic support

Many contributors criticise the quality of post-diagnostic support, or its absence:



*...It was eight years before we had any support at all. At the beginning, when he was first diagnosed, we were lucky, he was put on a drug trial, so for about two years, we would go back to the memory clinic every two months or so and we felt very supported and very safe. But after that, when that drug trial came to an end, we were left. And it was only last year when the crisis point came and the GP contacted social services...*¹⁸

Lack of information can send the message that you are no longer valued, as a member of York Minds & Voices points out:



I found people very dismissive. You've got lots of questions yourself but you feel as if you are an inconvenience. I feel written off.

In contrast a member of the Buddies group explains how one supportive health professional can make all the difference:



My own GP at my local surgery is a lovely doctor. She is absolutely wonderful, no lip service there, she will do what she can.

Peer support is still undervalued as a source of post diagnostic support:



The early days are days of confusion. You pinball from one agency to another. You don't know what's going on. Things are happening to you. There is a tendency, I think, for people to drop though the net, and the tighter the net is, of course, the less likely it is that people will drop

¹⁸ The Welsh Government The Record of Proceedings The Health, Social Care and Sport Committee
09/03/2017

through it. One of the innovations we're hoping for is more dementia support workers, and more peer support. Peer support, we've found, is the best kind of support. It's other people who have been on the journey and are in a position to help.... We're hoping that every memory clinic will have a cup of tea, a packet of biscuits and somebody like me in the room when the diagnosis is given, as they do with any other disease. So, we're hoping that becomes a national standard.¹⁹ [Think Tank]



A DEEP member group highlights what matters to her post-diagnosis
(DEEP Gathering, Edinburgh 2017)

Accessible Healthcare (Article 9)

As has been noted above, lack of awareness of dementia on the part of health professionals can impact on continuity of care, specially when it involved other health conditions. It can also impact on access to primary care too:



Doctors' appointment systems are very inconsistent across the country. It can be very difficult to get to see a doctor.



My doctor's surgery has just implemented a system where you can only get an appointment by phoning on the day. I never remember to phone and, when I do, all of the appointments for that day have

¹⁹ The Welsh Government The Record of Proceedings The Health, Social Care and Sport Committee
09/03/2017

gone.



When I see my doctor, he always tells me I need to see him again in 6 weeks. I walk out of the consultation room and go and ask the receptionist if I can make an appointment in 6 weeks and she always says “you can only book 4 weeks in advance”. I then have to try and remember to book later on.

Quality of care in hospitals and care homes

A number of people gave evidence about poor quality care in hospitals or care homes, and a lack of understanding about dementia:



Tommy Dunne explains in a ‘Dementia Diary’ (audio diary) how poor care is a rights issue²⁰:

We know there a variable standards of care in care homes. Owners and staff do not have the specific skills and knowledge required to understand the particular needs of people with dementia. So in many cases, services for people with dementia are nonexistent. People with dementia face widespread discrimination for a number of reasons. There remains a significant misunderstanding and a stigma attached to dementia that manifests itself in widespread discriminatory attitudes. Abuses and serious infringement of our human rights have serious impact on our quality of life. Poor quality care in itself is a breach of human rights act for people with dementia. Therefore, poor quality care ought to be recognised as a form of abuse. The wide-spread over-prescription of anti-psychotic drugs to treat the behavioural symptoms of dementia is a serious breach of these rights. Anti-psychotic drugs have serious risks for people with dementia, including excessive sedation, exhilarated cognitive decline, and increased mortality.

Tommy’s comments reflect the concerns of others about the use of anti-psychotic medication:



We believe that the pharmacological approach is the wrong one and that it really should be the last one. We’ve had conversations with the older persons’ commissioner on this and she’s quite concerned, particularly about the use of anti-psychotics in nursing homes in

²⁰ <http://www.dementiadiaries.org/entry/2151/poor-quality-care-ought-be-recognised-as-a-form-of-abuse>

particular and whether or not it's always the appropriate response to somebody's behaviour. You know, how many other things have been tried before they decide on medication? I understand why it's done because it's an easy answer. If you're in a situation where you've got three or four people caring for 10 or 15, it may be the swiftest answer. But they really need to look at themselves... [Think Tank]



I had a personal experience where I was threatened with a section...because I was presented as being very aggressive... [If] every other avenue has been explored and there is good, clinical justification for using anti-psychotics or, in some cases, worse, then fine, but I think that our experiences are that, very often, that is not the case. [Think Tank]

One contributor, who has a cluster of disabling conditions and cognitive impairments, also frequently acts an advocate for others. He has given evidence of the hostility he experiences when asking for issues to be investigated:



I live in a sheltered housing scheme comprising 21 dwellings. During a 12-month period, 5 of my neighbours died... Not unreasonably, I asked the CCG [Clinical Commissioning Group] how unpredicted and unexplained deaths are investigated ...[but] instead of specific answers to specific questions, the responses have been platitudes accompanied by very thinly disguised hostility and threat. [Think Tank]

This man also has views on how the internal market in health and social care operates - to the detriment of service users, including people with dementia:



Providers and purchasers still routinely decide contract specifications by private agreement and this leads to services being commissioned on the basis of what the local providers can provide rather than what patients and their families actually need to achieve good clinical outcomes. Where costs are under pressure the outcome has effectively been a race to the bottom line as well as a race to the bottom, rather than a plan for patient experience improvement and better clinical outcomes. [Think Tank]

Section 5

Work

Article 27 - Work and employment

Article 28 - Adequate standard of living and social protection

The Committee asks the UK government how it ensures the Work Capability Assessment is individualised and based on the social not medical model of disability (Article 28). This is highly relevant to people with dementia.

Wendy Mitchell was working with the NHS when she received her diagnosis of dementia:



Managers and Occupational Health openly admitted that they had no knowledge of how to support someone to continue to stay in work with dementia. My manager asked 'How long have you got'? I had to come up with my own plan and the only help I received was in completing the ill health retirement application forms.

A member of the SUNshiners group in Kent (also in the NHS) had also had her rights ignored:



When I got a diagnosis they couldn't wait to get rid of me, no support there – and it was a caring profession!

This person, a district nurse, was told she was wasting people's time being there if she could not do her job. She acknowledged her service was quite short-staffed at the time, which added to these pressures.

Nigel Hullah describes his experience:



Following the diagnosis and prior too, the usual things happened. I lost my job, became isolated and I was subject to lots of sympathy - but no encouragement to view my future with positivity.

A member of the Buddies group adds:



It's been a long time since I have had a job, maybe over 12 years ago. I had my own business and, when I was diagnosed with dementia, and I told my insurer, they cancelled my insurance and my company folded. I know I have applied for lots of jobs but have never been successful. Once I tell people I am living with dementia I don't get the job... But that was a while ago, I've given up trying now, I give my time freely, working free of charge for people I like.

A district nurse from Kent also experienced issues with retirement. The letter for Occupational Health got lost at first, and communication was bad between herself, Occupational Health and Human Resources. She didn't know what was happening and felt the employer did not care at all. Things only got better when she got her Union involved, and they helped her to get early retirement. She still had to go to a hearing though, in which she had to say why she wanted to leave work. This felt quite negative to her and she did not feel supported.

Another person raises the issue of fear of discrimination in the workplace:



[People are] scared to let employers know because of their reaction.

Losing work has many impacts, including on income, pensions, roles, relationships and self-esteem:



The biggest concern for me is I can no longer work and provide for my family... but we live frugally, build things, recycle as much as possible. Financially we live an adequate life, [though] my benefits have been cut. [Buddies group]



My role within the house has changed, my wife earns the money and I ensure the house is always ready for her to come home. I cook the meals and support her as she supports me. [Buddies group]



My financial advisor looked into whether I would get an enhanced pension because of the diagnosis. I wouldn't as I was still working and driving. [Think Tank]

In contrast, another member of the SUNshiners group showed how things can be when the right to work is recognised:



People in the head office were extremely helpful and supportive. When I had issues with something or found things difficult they were trying to help out, cover some tasks for me when needed.

Another acknowledged that things are getting “somewhat better though” and highlighted the campaign to support nurses who have dementia to remain working.

Recommendations

Think Tank members hope that this evidence is useful to the UN Committee and that it will inform and influence their response to the UK government.

They would like to see much greater attention given to the promotion, protection and implementation of the rights of persons with dementia, which have long been ignored.

In particular, they would like all levels of government to:

- 1. Invest in greater public and professional understanding of dementia, including young onset dementia. This should be based on the social not the medical model of disability, and should include attention to imagery and language.**
- 2. Require transport and parking providers and local authorities to review staff attitudes and arrangements, so that all people with dementia can exercise their right to get out and about.**
- 3. Review the impact of benefits reassessments and cuts on the ability of people with dementia to live independently, and, in the words of the Dementia Strategy, to 'live well with dementia'.**
- 4. Undertake a radical review of the nature and quality of the way in which diagnosis is delivered.**
- 5. Improve and standardise the provision of follow-up healthcare and post-diagnostic support/information (including information about driving).**
- 6. Promote consistent signposting to peer support and other community resources.**
- 7. Ensure that employers understand that people with dementia have the right to continue to work for as long as possible in an open, inclusive and accessible environment.**

The last word goes to Nigel Hullah of Think Tank:



Society values people with intact cognition above those whose cognition is compromised. This has led to people with dementia being treated in ways that have undermined their personhood and infringed their human rights. The presence of dementia has been used to justify the denial of human rights to older people who are cognitively impaired.

I intend to hold people to account where I see social injustice applied to me and others living with Dementia. It is my intention to use political connections and the Human Rights Act to bring injustice into the light and work with like minded people across all agencies and convince those who may be reluctant.

I will keep on doing as much as I possibly can, for as long as I can... If we all work together we can effect change.



Nigel Hullah publicises his message on social media

*This report was produced in July 2017.
It can be downloaded free from www.dementiavoices.org.uk*