

Transport Committee
7 Millbank
House of Commons
London
SW1P 3JA

transev@parliament.uk

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Alzheimer's Society submission to Transport Committee inquiry into effectiveness of legislation relating to transport for disabled people.

Summary

- Alzheimer's Society would like to highlight the particular challenges to people with cognitive impairment accessing public transport.
- Small amounts of assistance can mean that people with dementia are able to access public transport for longer, enabling them to remain independent and active in their communities.
- Several transport companies have recently been investigating ways to make their services 'dementia friendly'. Alzheimer's Society would welcome further commitments from companies to do this.
- The level of visible staff support available and improved signage during the Olympics and the Paralympics was welcomed.

About Alzheimer's Society

Alzheimer's Society is the UK's leading support services and research charity for people with dementia and those who care for them. It works across England, Wales and Northern Ireland. The Society provides information and support for people with all forms of dementia and those who care for them through its publications, dementia helplines and local services. It runs quality care services, funds research, advises professionals and campaigns for improved health and social care and greater public awareness and understanding of dementia.

About dementia

The term dementia describes a set of symptoms that include loss of memory, mood changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease. Dementia is progressive, which means that people with dementia and their carers are coping with changing abilities over time. These changes in ability include a reduction in the person's capacity to make decisions about major life events and circumstances as well as day to day decisions. Eventually they will need help with all their daily activities.

How dementia affects ability to use transport

Difficulty with transport is not just affected by physical disabilities, but also by cognitive impairment, which can leave an individual with dementia totally dependant on someone else if they are to be mobile. Symptoms of dementia such as aggression and anxiety, a tendency to walk about and confusion can make any journey a very challenging undertaking. Problems with perception and comprehension also mean that it may also be difficult for a person with dementia to make an unfamiliar journey unaccompanied, or cope with changes to the journey, such as delays and cancellations. As such the disease can present particular problems when using public transport. In addition, dementia is not a visible disability, and it may not be immediately apparent to those around the person that they have dementia, leading to further mistakes and confusion.

It is also likely that as their cognitive impairment worsens the person with dementia may lose their driving licence, which will leave them more reliant on public transport, or transport provided by others. In addition, the eligibility criteria for a parking 'Blue Badge' is still based on how far a person can walk, which does not cover many of the issues faced by people with dementia. In Wales, the eligibility for 'Blue Badges' now covers people with a severe cognitive impairment. We would welcome a similar change in England.

In the numbered paragraphs below, Alzheimer's Society provides comments on the specific areas where evidence was sought by the committee.

1) The effectiveness of legislation relating to transport for disabled people: is it working? Is it sufficiently comprehensive? How effectively is it enforced?

Dementia is a disability and as such is protected under the Equalities Act. Despite numerous initiatives to make public transport more accessible for disabled people, many people with dementia still find it inaccessible and rely on friends or family to provide lifts or accompany them. Alzheimer's Society still hears numerous reports of people restricting their movements because transport is not available, such as when bus routes have been cancelled in rural areas. We also hear of facilities designed to help disabled people not always being available, such as people booking assistance on national rail services, yet assistance not being provided at the station. We also hear of difficulty using facilities on the transport, such as difficulty using the toilets on some national rail services.

In particular, we hear of numerous occasions where with minor assistance people may have been able to continue using transport, but this assistance is not provided which then restricts what the person with dementia is able to do. For example, assistance with automated ticket machines, or in understanding routes and timetables would enable more people with dementia to continue to use transport. In addition, insufficient staff understanding can lead to exclusion of people with dementia from transport due to misunderstanding of

their symptoms, for example staff mistaking the symptoms of dementia for alcohol intoxication and excluding the person as a result. As dementia is not a visible disability, this may contribute to confusion.

2) The accessibility of information: including the provision of information about routes, connections, timetables, delays and service alterations, and fares

It is important that information on transport is available in a variety of ways. Dementia can affect the comprehension and retention of information and it is often this which can cause problems in people accessing transport.

Particularly, it is important that information for planning a journey is not just available on the internet. The Office of National Statistics report that age has a sizeable effect on whether someone has ever used the Internet. Whereas almost all adults aged 16 to 24 years (99%) had used the Internet only 30% of adults aged 75 years and over had ever used the Internet (Office of National Statistics 2012). This constitutes 3.24 million people over the age of 75 in the UK, making up 43% of the 7.63 million people in the UK who had never used the Internet. As dementia affects predominately an older age group, in combination with the difficulty dementia presents to comprehending and retaining information, it is therefore likely that information available on the internet will not be accessible to them.

It is also important that information on delays or service alterations which occur while the journey is ongoing are communicated clearly, and that there are staff available to assist people with dementia who may not have understood the communication. There should also be support for carers who are supporting people with dementia in their journey.

3) The provision of assistance by public transport staff and staff awareness of the needs of people with different disabilities

As mentioned previously, the provision of assistance by staff trained in dementia awareness can make the difference between someone with dementia being able to continue to use transport, or this not being possible. As part of the Dementia Friendly communities strand of the Prime Minister's Challenge on Dementia (Department of Health 2012a), numerous transport organisations have been working with the Alzheimer's Society to develop a dementia friendly approach.

First group plc are providing 17,000 of their bus drivers with dementia awareness training in order to improve understanding of dementia and some of the challenges people with dementia face in using public transport. They are developing a new training module component on dementia for their Driver Certificate of Professional Competence. They are also developing their safe journey cards for passengers with dementia. This means that First Group staff will be aware of people with dementia using their buses and can ensure that they can use the bus service safely and get to their destination. (Taken from The Prime Minister's Challenge on Dementia Delivering major improvements in dementia care and research by 2015 A report of progress)

Transport for London has launched the Travel Support Card aimed to make travel easier for people with hidden disabilities. It is particularly useful for those with communication learning or cognitive disabilities who may find it difficult speaking to staff or asking for assistance. (Taken from The Prime Minister's Challenge on Dementia Delivering major improvements in dementia care and research by 2015 A report of progress)

Alzheimer's Society would welcome greater commitment from transport companies to make their services dementia friendly.

4) What can be learnt from transport provision during the Paralympics and how can we build on its successes?

Alzheimer's Society is keen to highlight the transport difficulties faced by people who have non-physical disabilities. By its nature, the Paralympics focused predominately on physical and visual impairment. However, many of the measures put in place, such as more visible signage, was of particular benefit to people with dementia, whilst also being of benefit to the public in general.

The level of visible staff support available during the Olympics and the Paralympics was welcomed. As highlighted above, support such as this from staff who understand dementia can make the difference between someone with dementia being able to access transport and them not being able to.

References

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