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**Blue badge call for evidence on the challenges to mobility presented by
Alzheimer's disease and dementia**

This response to the call for evidence from the Welsh Assembly Government has been
prepared by

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Methods

In gathering the evidence, the following approaches were taken:

1. A scoping review of the scientific literature
2. Focus groups with 14 people with dementia and their carers, 2 facilitators and 2 Alzheimer's Society staff members from two Alzheimer's Cafes (Wrexham and Caernarfon).
3. A call for responses – circulated by the Wales Neurological Alliance to their members and circulated by DSDC to the academic members of NEURODEM Cymru ¹(8 responses).

Findings

Q. What are the mobility barriers that individuals with Alzheimer's or dementia face?

Dementia is considered one of the most severe chronic diseases contributing to disability in later life, which is further exacerbated by the increase in co-morbid physical health problems (Alzheimer's Disease International, 2009). According to most diagnostic definitions, all people with dementia experience some degree of functional disability. A decline in mobility is one of the most significant factors for people with Alzheimer's disease or dementia. Additional help and support may be needed as locomotion becomes increasingly difficult, walking slows down and falls become increasingly likely. Stiffness, difficulty moving around, loss of muscle strength and weight loss all confer to make moving from one place to another challenging to people with dementia and their carers (Cotter, 2007; Gillette Guyonnet et al. 2007).

As well as a decline in locomotion, Alzheimer's disease pathology is highly associated with significant frailty, as measured by four components; grip strength, time taken to walk 8 feet, body composition (BMI) and fatigue (Buchman et al. 2008). Frailty is recognised as reduced age-related physiologic reserve and is thought to be a result of the accumulation of significant chronic conditions such as cardiovascular and pulmonary disease, and is therefore a significant mobility barrier to someone with Alzheimer's disease.

In addition, there are strong associations between many dementias and abnormal gait patterns including Alzheimer's Disease, Subcortical Ischaemic Vascular Dementia and Frontotemporal Dementia (however, gait abnormalities are also associated with mild cognitive impairment without dementia; Scherder et al. 2007). Morgan et al. (2007) go

¹ <http://www.neurodemcymru.org/>

as far as to list the gait characteristics associated with each of the dementia types e.g. for Alzheimer's disease (moderate-severe) difficulties include reduction in gait velocity, shorter stride/step length, increased postural instability, increased stride length instability, decreased arm swing, shuffling, start-and-turn hesitation. Undoubtedly gait abnormalities such as these would lead to significant mobility barriers to a person with Alzheimer's disease.

"When parking a car it is often extremely difficult to get a dementia patient out of the car because of the narrow space in a normal car park and often impossible if a wheel chair is involved. It is clearly not very safe to leave the patient at the side of the road or outside a busy Store while one searches for a parking space. The use of the Blue Badge to find the extra width of a Disabled Parking Space makes the whole task much more possible." (Carer)

In one of the focus groups, it was felt important to have the car visibly parked close by to the destination, as being far away not knowing in which bay it was left creates confusion and upset. Becoming more tired than usual is a symptom reported by the carers, and having to walk a long distance increased tiredness and subsequent confusion. Carers also report difficulties with balance in the person with dementia, increasing the risk of fall.

Summary: The significant decline in an individual's ability to mobilise and be mobile and the increased risk of frailty indicates support is needed for people with Alzheimer's disease or dementia through inclusion in the Blue Badge scheme.

Q. What barriers do individuals with Alzheimer's disease or dementia face [other than mobility] that may need to be considered as eligibility criteria for a Blue Badge?

There are a range of other changes in cognitive function due to dementia that can present as significant barriers. These include changes in attention, perceptual skills, memory, decision-making and speed of information processing. These are important for day to day functioning, and increase the need for assistance. Progressive functional decline in skills for daily living both in instrumental activities of daily living (cooking, managing money, using the 'phone) and basic activities of daily living (ADLs) (washing, dressing, feeding) (Slaughter & Bankes, 2007) increase vulnerability. Problems with activities of daily living highlight the limitations an individual has with living independently. It is likely that if a person is finding aspects of self-care difficult then their ability to keep safe by the road would also be impaired. For example, someone experiencing difficulties with basic activities of daily living may have more problems with routine tasks such as opening a car door and getting out of the car.

*One focus group participant notes: "...the whole thing about a badge is enabling people to be as independent as possible for as long as possible because that's what it's meant to be. It's meant to be **living** with dementia and we're meant to be promoting self care and self independence".*

As function declines they may also have difficulty in recognising the difference between the pavement and the road, putting them at significant risk the further their car is from their destination. Cognitive decline has been shown to be a contributory factor in older pedestrian casualties (Organisation for Economic Cooperation and Development, 2001). It is important to note that people with Lewy Body dementia, vascular dementia and fronto-temporal dementia initially present differently to those with Alzheimer's disease and decline does not follow a predictable and progressive rate as in Alzheimer's disease.

In Australia older people (i.e. those over the age of 65 years) make up less than 13% of the population yet account for about 32% of all pedestrian deaths (Australian Transport Safety Bureau, 2002a). Whilst the total number of older people who have been killed on our roads in Wales is not available, the number of pedestrians killed or seriously injured (includes children) in 2009 was 1221; annual totals have been dropping year on year (Road Safety Wales, 2010). To reduce this further the protection of those who are vulnerable, both children and older adults is vital. Furthermore, in the UK, where someone with dementia is killed in a road accident, the fact that they had a diagnosis of Alzheimer's disease or dementia is not recorded either as an 'underlying' or 'contributory cause' of death despite the fact that this may have directly contributed to the accident; as a result records regarding pedestrian deaths do not make any link between those with dementia and their vulnerability on our roads.

Gorrie et al (2006) have found an increased amount of neurofibrillary tangles in the brains of a sample of older people who died in pedestrian accidents; neurofibrillary tangles are most commonly known as a primary marker of Alzheimer's disease and are associated with neuronal dysfunction (abnormal cell activity). In a further study they examined the crash characteristics of the same sample and found that of 52 fatalities most occurred on a weekday morning, close to the person's home, involved a passenger vehicle and occurred when the person was attempting to cross a two-way road (80.2%). In 73% of the accidents, the pedestrian was considered at least partially responsible (Gorrie et al., 2006).

Disorientation and wandering were noted as problematic by carers in the individual responses and the focus groups. In this instance, mobility may not necessarily be significantly impaired, but the need for easy access from transport to facilities/services

is an important consideration. *“But the big thing I find with [Mrs. W] is that she gets completely lost”* (focus group participant).

“I had an experience a few years ago...about two or three years ago, we were on a cruise and I went to the room, came back, and I didn’t know where I was. I hadn’t a clue where I was” (focus group participant with dementia).

“... I can’t take him a long way from somewhere without him panicking going through crowds and a long way. He goes ‘how we getting back, how we getting back?’ I say ‘the same way as we come’; he says ‘But I won’t find my way’...I say ‘well that’s what I’m here for’. You know, he panics. You wouldn’t think he would, but he does.” (focus group participant).

The focus groups and individual responses note that shopping trips are a necessity, but could be a cause of stress for carers and the person with dementia. Carers note that people with dementia are unable to be left on their own for any length of time. One carer notes: *“I find it much easier to shop by myself, without having to worry about my husband, but if he is with me, then a Blue Badge would be very beneficial for both of us. He would know where to find the car, there would be no major worry about the time limit for parking, and I could tell him exactly where the car was”*.

In nearly all cases, the person with dementia needs to be accompanied by someone when they go out, usually their main carer. One carer notes the difficulties in not being able to park close when attending a recent hospital appointment, and their worry that if they dropped their partner off at the door, *“there is no knowing where he would have gone”*.

The other barriers relate to regular parking provision, of which regular provision is often limited: *“normal parking slots are narrow, the car door has to be opened fully to get out, which is a slow, laborious process”* (Carer).

A focus group participant notes: *“I think compliance issues as well, you know, if the person with dementia who doesn’t want to...you know, you’ve walked into town from the car park, and then you know, and they don’t want to walk back, and the car is, you know, a mile away...”*

“You know it’s quite difficult when you’ve got to take...and he looks normal, you know a man or woman [with dementia] looks normal..., it’s quite hard for other people to see that there’s anything wrong with them. If they’re in a wheel chair you think ‘oh, better move out the way’ don’t they. You know, it’s not all about wheelchair bound.” (focus group participant).

Summary: Cognitive decline may be very different to the usual mobility reasons for which a Blue Badge is allocated, but given that it can lead to people behaving

'unexpectedly' e.g. walking into traffic, it is a significant contributory factor to road traffic accidents, putting both pedestrians and drivers at risk of death or serious injury. Reduced walking speeds and cognitive decline combined are significant factors to consider when allocating Blue Badge holders to older people with Alzheimer's or dementia. By allowing people to park in designated disabled bays exposure to traffic and confusion caused by disorientation would be reduced.

Q. Is there any supporting data or research?

This response presents a range of research in relation to each of the questions posed in the consultation.

Q. In what circumstances does supervising an individual with Alzheimer's or dementia become so difficult or stressful that the allocation of a Blue Badge would be beneficial?

Carers and those who live with people with dementia are twice as likely as others to have significant psychological illness (AD International, 2009). Cognitive decline can impact upon key brain functions vital for pedestrian road awareness and safety, such as complex attentional processes, visuospatial ability and problem solving. As such supervising someone with Alzheimer's or dementia whilst near or crossing roads could be highly stressful particularly given a lack of awareness commonly found in people with these conditions; Gorrie et al. (2006) liken the difficulties in supervising a person with dementia as being similar to that of a child prior to them learning road safety and that awareness and education to protect this vulnerable group should be as significant as it is for young children; a point that came across at the focus group: "*it's like taking the children again*". The allocation of a Blue Badge would enable a supervisor to park nearer to a building or place of interest and thus reduce the amount of time and therefore exposure of the person with dementia to potentially dangerous road situations. The increased difficulties in locomotion and associated stiffness put additional demands on carers particularly when out and about.

"My own mother, who died in 2009, was faced with increasing mobility problems, as the dementia ate into the parts of her brain controlling movement, so that, when I took her out of her residential care home for a meal, I needed to choose a venue where I knew parking would be guaranteed close by - for her sake. Geographical proximity between vehicle and venue - this is the crux of the issue." (Carer).

Being able to remain part of society and minimising exclusion are important. One carer notes: *“it is essential to get out of the house to relieve the constant worry of trying to remember, and helps prevent depression”*.

Another notes that one of the symptoms of dementia, agitation, to be a problem and create the *“need to be able to get back to the car easily and possibly go back home”*.

“If the disabled [spaces] are near to the entrance then you don’t get stressed out looking for your car when you come out. I mean if you had to walk down to the big car park in the hospital, you could be down there for hours.” (focus group participant).

“But you see, it’s very stressful, you’ve got a disability as it is, without getting stressed about it” [finding the car] (focus group participant).

One of the focus group participants notes: *“in an incident we had just before Christmas, we were in Llandudno, as it happens, we parked the car and [it was] quite a bit of a walk from the centre of town. On the way back to the car we had an incident where she tripped over a paving stone. She bumped her head. Well, I thought it best to call an ambulance and fortunately there wasn’t much damage done. But things like this happen, especially with us well over 80 now...”*

Q. What data do you have to indicate the number of people who have severe Alzheimer’s or dementia?

It should be noted that currently, few cases of dementia are diagnosed in the early stages. In the UK there are 821,884 people diagnosed with dementia (just under 40,000 in Wales). The Dementia UK report (Alzheimer’s Society, 2007) suggests 55.4% have mild dementia, 32.1% have moderate dementia and 12.5% have severe dementia. The numbers with dementia are set to double over the next forty years (Alzheimer’s Research Trust, 2010).

Q. How could a person with Alzheimer’s or dementia be assessed to ensure that Blue Badges are allocated on the basis of need?

It is important to point out that the diagnosis of dementia can often be complex, particularly in the early stages. With respect to Alzheimer’s disease, it is thought that frailty (as measured by the above four components) is a non-cognitive precursor of Alzheimer’s disease pathology that presents itself prior to dementia. A measure of

frailty could possibly be used as an indicator of severity and an indicator of need for a Blue Badge holder.

In the early stages of Alzheimer's disease, function is lost in the instrumental ADL skills such as driving, shopping, managing money etc whereas in the middle to late stages progressive functional decline is noted in basic ADL skills such as communication, walking etc. Longitudinal research indicates that functional decline in people with early to middle-stage Alzheimer's disease living in the community deteriorates at the rate of 1 item per two months on the Disability Assessment for Dementia Scale (Feldman et al., 2001). Such skills are associated with loss of mobility and cognitive ability and could therefore inform decisions regarding allocation of the Blue Badge. A carer interview would also provide significant information regarding functional decline as measured by ADL skills (ADL's are not measured through formal neuropsychological testing but through the assessment of day-to-day tasks).

Clearly there may come a time in the progression of the Alzheimer's disease or dementia when function, cognitive ability and mobility become significantly impaired so as to meet current criteria for the allocation of a Blue Badge. One possible way of marking/assessing this transition would be when function associated with activities of daily living is disrupted to the point where basic ADL's (feeding, dressing etc) become impaired; this point typically takes place some time after impairment occurs in instrumental ADL's (cleaning, cooking etc). It is important to point out that the diagnosis of dementia can often be complex, particularly in the early stages, however, if the Blue Badge scheme applied only to those individuals with moderate level dementia this would mean they had reached a stage where diagnosis was unambiguous and need clearly apparent.

However the severity of the disease progression may not be the only criterion that would be appropriate in dementia. The focus group participants were of the opinion that the badge should be awarded based on the level of difficulties, and not the different stages of the illness. A combination of mild dementia and physical frailty for example, might increase the need. Or a person with mild dementia who is fit, but impulsive and lacking in judgement, might be seen as posing a challenge for their care-giver that could be assisted with a Blue Badge. The carers also noted that the levels of dependency could vary on a day to day basis. It was also suggested that it could help to have the badge in the earlier stages of the illness, so that a routine can be established. The carers strongly emphasised the importance of routine, and the avoidance of change.

"..they see then what a Blue Badge parking space looks like and they just keep going into it, keep going into it and then it's engrained, you know, when they get...I think so anyway. "

Summary: The correct assessment and allocation of a blue badge will be important to ensure those that need them the most are able to easily access them. Regardless of the method of assessment chosen, it is vital that they are reliable, valid, easy to use, efficient and cost-effective. The research evidence and carer perspectives converge to highlight a number of mobility and other barriers that people with dementia and their carers face. These present a good case for the blue badge scheme to be extended to those with Alzheimer's disease and dementia. However, whilst these are likely to be experienced by a significant number of people, this may not be a universal experience. One respondent to the consultation notes:

"My father was diagnosed with dementia 6 years ago, and is finally needing full time nursing care. I am also a GP so am used to filling out Blue Badge applications-or not supporting the claimant-depending on the degree of mobility problems. In answering your points:

1) we do not feel there have been any significant problems with Dad's mobility over the years

2) We have not found there to be barriers that should make us eligible for a Blue Badge

3) Parking for appointments, trips to the shops etc. has never been a problem where we live and Dad has always been mobile with a stick. We can imagine it is harder for city dwellers-particularly Londoners.

Overall, we are conscious that these Blue Badges need to be restricted to help those with genuine problems with mobility-and an inability to walk more than 25 yards- to be able to park easily in a disabled bay. My brother had a massive stroke 3 years ago, and his Blue Badge has proved invaluable-but it is disheartening when he sees able walkers using disabled parking spaces."

Should the Welsh Assembly Government decide that provision of the Blue Badge Scheme is to be extended to those with Alzheimer's disease and dementia, we would recommend that clinicians and those who regularly assess and work with people with dementia are involved in deciding on the final assessment criteria and process for badge allocation.

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