



An independent research report looking at; the current provisions for people living with dementia (plwd) and their carers; how transport and health budgets can work together for the benefit of said plwd and their carers

With a focus on the Merseyside region

Tory Robbins University of Liverpool placement student for thred CiC

Contents

Introduction	. 2
Dementia policy in the UK	. 3
Current provisions for plwd in Merseyside	. 4
Current transport and health provisions for plwd and their carers in Liverpool	. 5
Transport	. 5
Health	. 6
Overall	. 7
The link between transport and health for plwd and their carers	.7
Health and economic benefits of merging public sector budgets for the benefit of plwd and their carers	. 8
How can transport and health be merged to benefit plwd and their carers	10
Overall recommendations	11
References	12

Introduction

Dementia is the umbrella term for several conditions that affect the brain, including Alzheimer's disease, vascular dementia, and frontotemporal dementia (Dementia UK, n.d.-a). Alzheimer's disease is the most prevalent form of dementia, making up almost 60% of diagnoses (Dementia UK, n.d.-a). Knowledge of young onset dementia – people diagnosed with dementia before the age of 65 –has increased but figures are less accurate for this type of dementia due to limited awareness and an average diagnosis time that is double the diagnosis time for people aged over 65 (Dementia UK, n.d.-b). It is estimated that up to 9% of dementia diagnoses are young onset (Dementia UK, n.d.-b).

The Coronavirus pandemic has had an impact on diagnosis rate – 'since April 2020, there has been a consistent pattern of lower diagnosed prevalence rates for dementia in over 65 year olds compared to before the pandemic' (OHID, 2022). This is due to lockdown protocols and reduced GP and hospital access, and may not be a true reflection of the numbers of people living with dementia (plwd) in the UK. Statistics from before the pandemic are likely to paint a better picture. In 2019, it was estimated that there were 'almost 885,000 older people with dementia in the UK' (Wittenberg et al., 2019:3) with a projected increase of 80% (totalling 1.6 million people) by 2040 of mild, moderate, and severe dementia diagnoses (Wittenberg et al., 2019:4). 'The total costs of dementia in the UK [not including young onset dementia] in 2019 amount to £34.7 billion', of which 14% was NHS/health care, 45% was social care – both homecare and residential care – and 40% was unpaid care provided by family members (Wittenberg et al., 2019:6). Ultimately this displays that there are large health and social costs associated with dementia for both the government and individuals, but funding in other areas, such as transport may reduce health and social costs – exactly the message that Thred CiC promotes.

Thred CiC is a grass roots organisation, comprising of four directors – two people with dementia and two former carers of plwd – who recognise the recurring link between transport, health, research, and the economy to be developed as a whole approach to improve the lives of plwd and their carers (thred CiC, n.d.). This is because it will divert the focus from plwd being reliant on others to maintaining their independence for longer to provide autonomy and choices in life, preventing social isolation and the connected impacts isolation has on mental and physical health (thred CiC, n.d.).

Impacts of dementia include forgetfulness, losing track of time, behaviour changes, and hallucinations, but it affects every person differently (WHO, 2021a). As it progresses symptoms get worse and therefore means that slowing progression as much as possible is of vital importance. Ways to prevent progression include continuing social inclusion after diagnosis which is why it is vital that transport and health budgets are seamlessly integrated to ensure that this is possible. By maintaining transport links for plwd, it allows them to remain a part of their local community, as well as the economy, ensuring mental and physical health do not worsen through isolation and loss of autonomy post-diagnosis.

The conclusions of this report are;

- Plwd and their carers need to be involved in policy-making discussions,
- Hidden disability awareness training should be compulsory for all transport employees
- Public transport needs to strive to become more age-friendly,
- Earlier support towards cessation of driving to ease anxieties concerning other modes of transport before they become necessary,
- An overall reduction in social isolation is essential to maintain healthy living for plwd.

Dementia policy in the UK

In 2006, there began a global push for cities to become age-friendly. The WHO age-friendly cities framework proposes eight interconnected domains that identify and address barriers to the wellbeing and participation of older people (AFW, n.d.). These domains are;

- Community and health care,
- Transportation,
- Housing,
- Social participation,
- Outdoor spaces and buildings,
- Respect and social inclusion,
- Civic participation and employment,
- Communication and information.

This framework, used globally, highlights the many barriers that older people, including those diagnosed with dementia, face in society. Transport, for example, if lacking can lead to isolation and loneliness; a lack of 'affordable public transport... isolates older people... and makes participation in community life difficult, increasing the risk of isolation and loneliness. When transport is available... it enhances mobility and facilitates social participation and a sense of belonging in one's community (AFW, n.d.). This framework provides cities around the world with the means to make their community accessible for all members of society – with Liverpool City Region joining the UK Network of Age Friendly Communities in 2020 and joining the WHO Network of Age Friendly Communities more recently (LCRCA, n.d.).

The WHO has also produced dementia friendly initiatives that are geared towards individuals with little to no experience in programme planning, implementation, and/or evaluation – meaning previous experience is not required to become dementia friendly (WHO, 2021b). These initiatives were produced following the adoption of the global action plan on the public health response to dementia from 2017 to 2025 (WHO, 2021b:5; WHO, 2017), signalling 'an important step forward in achieving physical, mental and social wellbeing for people with dementia, their carers and families' (WHO, 2017:V). Ultimately, it is being increasingly noticed that work needs to be done to make society accessible for plwd, as well as their carers and families.

Within the UK there have been policies produced pertaining directly to plwd. The National Dementia Strategy 2009 had three ambitions – 'to raise awareness, facilitate assessment, and improve services' (Greaves and Jolley, 2010:193). Further government policy was launched in 2012 when David Cameron launched the 2012 Dementia Challenge, aiming to 'deliver major improvements in dementia care and research by 2015' (Parkin and Baker, 2021:10) by delivering change in three key areas; 'creating dementia friendly communities that understand how to help... driving improvements in health and care... better research' (Parkin and Baker, 2021:10). In 2015, the progress was outlined but the challenge renewed with the Challenge on Dementia 2020 (DOH, 2015:3). The aim of this update was that by 2020 England would be 'the best country in the world for dementia care and support... and the best place in the world to undertake research into dementia and other neurodegenerative diseases' (DOH, 2015:3). To achieve this, various aspects were highlighted including increasing public awareness, support for plwd and their carers after diagnosis, training for staff that have direct contact with plwd and their carers, and for the Alzheimer's Society to deliver an additional 3 million Dementia Friends in England (DOH, 2015).

Plans for dementia policy include the pledge in the Conservative Party 2019 Manifesto that 'finding a cure for dementia would be one of the Government's biggest collective priorities', the process of

which is often referred to as the *Dementia Moonshot* (Parkin and Baker, 2021:13). Through this *Moonshot* investment, the Alzheimer's Society set out five key priorities for dementia research (Alzheimer's Society, 2021);

- Training the dementia researchers of the future
- Research to ensure the early detection and diagnosis of dementia
- Transforming care through technology for people with dementia
- Making research a reality through Centres of Excellence in Dementia Research
- Understanding the underlying causes to find a cure

In 2019, various reports were published by different organisations. In January, the NHS Long Term Plan committed the NHS 'to continuing to improve the care provided to people with dementia and their carers' (NHS, 2019, as cited by Parkin and Baker, 2021:16), while in May the Alzheimer's Society published *Fix Dementia Care*, setting out the case for a new Dementia Fund (Parkin and Baker, 2021:16). In June, the All-Party Parliamentary Group (APPG) highlighted societal barriers preventing people with dementia from living independently; employment, social protection, social care, transport, housing, and community life (APPG, 2019).

Ultimately, there have been a range of policies, both national and international, committed to improving the lives of plwd, yet most policies do not consider how integration of sector-specific policies could improve the overall benefit for plwd and their carers. Therefore, focus needs to be directed to how policies and budgets from different sectors can work together to benefit plwd and their carers.

Current provisions for plwd in Merseyside

One of the main characteristics of Liverpool that benefits plwd positively is the age-friendly status of the city. In 2012, 'Liverpool's mayor Joe Anderson signed a pledge signalling the city's commitment to being an age-friendly city' (WHO: Age-Friendly World, n.d.), with initial plans including 'a multi-million pound plan to transform social care for people living with dementia' (WHO: Age-Friendly World, n.d.) – part of this work being a £7.8 million dementia hub in Speke and an £8.2 million dementia centre in Anfield. These plans also aimed to benefit carers through the *Push to Talk* initiative, that brings 'isolated carers together via the telephone' (WHO: Age-Friendly World, n.d.). More recently the council 'promised to ensure that the services it provides are dementia-friendly by raising awareness about the condition amongst its workforce' (Good News Liverpool, 2019) including training around the needs of plwd and commitment towards becoming increasingly age friendly. Alongside the hubs in Speke and Anfield is a day centre in Norris Green that provides assessment and respite facilities along with a range of therapies designed to keep users active (Good News Liverpool, 2019).

Furthermore, in Dementia Action Week last year, Metro mayor Steve Rotheram announced that he was seeking for Liverpool City Region Combined Authority to become the first to gain Dementia Friendly Community status, awarded by the Alzheimer's Society (ITV News Granada, 2021). The Liverpool Dementia Action Alliance (DAA) also completed a research project for Liverpool City Council and Liverpool Clinical Commissioning Group (CCG) to update their dementia strategy from 2014 (DAA, n.d.), and further work such as their Action Plan can be found at *www.dementiaactionliverpool.com* – which includes work with transport businesses, BAME communities, and charities and organisations that represent plwd and their carers (DAA, n.d.).

At a more local, community level there are many organisations, both national and local, that provide services and support for pwld and their carers across the five boroughs in Merseyside (Knowsley, Liverpool, Sefton, St. Helens, and the Wirral). All boroughs offer assistive technology and carers

centres, alongside needs assessments for plwd (delivered in accordance with the Care Act 2014) and carers assessments to understand what support is needed for both plwd and their carers. There are national charitable organisations that cover all boroughs, such as the Alzheimer's Society, Age UK, Dementia UK, Tide, Healthwatch, and Carers UK, as well as community activities that are independent to each borough, led by volunteers. Using *The Live Well Directory* (n.d.), along with the borough council websites, the wide range of services available in each borough can be found, and resources based on research and experiences of plwd and their carers can be found on the *Living with Dementia Toolkit* (n.d.).

The NHS and social care services are available for all, being operated in Liverpool by Mersey Care. Mersey Care allocate care navigators, offer counselling and post diagnostic groups, and Liverpool Social Services can direct and advise on all aspects of care at home (Mersey Care, n.d.). Types of support can be in the home, the community, non-residential day care, or residential day care (Wirral.gov.uk, n.d.). Dementia UK provide Admiral Nurses – specially trained dementia nurses – for beneficiaries of the British Legion, to give tailored advice and support in many forms, along with home visits and signposting to local services (Dementia UK, 2022).

There are also various housing and financial schemes to help plwd. Plwd and their carers may be entitled to relief on their council tax and housing benefit and plwd may be entitled to Attendance Allowance to help with personal support due to a disability, while carers may also be entitled to Carer's Allowance (Mersey Care, n.d.; GOV.UK, n.d.). While there are many of these services that focus on the financial aspect, they are not the focus of this report – unlike transport and health services – and therefore I will not go into too much detail surrounding these aspects of support.

Current transport and health provisions for plwd and their carers in Liverpool

Transport

One of the most well-known provisions related to transport for disabled people are Blue Badges. Blue Badges are available for people with disabilities, or their carer, although a diagnosis of dementia may not mean the automatic issuing of a Blue Badge (Mersey Care, n.d.). A diagnosis of dementia does not necessarily lead to the loss of a driving license however the DVLA must be notified. Plwd are entitled to an assessment if they wish to keep driving, as people can continue to drive safely once being diagnosed, however there may come a time when a person with dementia can no longer drive safely and therefore their license is removed (APPG, 2021). By losing this form of independence it can put plwd at increased risk of depression, or can worsen their anxiety about leaving the house meaning they access their usual activities less regularly – which in turn has a negative impact on their health. The removal of a license also means that the demand for adequate accessible public transport becomes greater, meaning it is vital that public transport within Merseyside is able to provide for people who have lost their usual access to independence.

Passengers over 60 who live in Merseyside are allowed to travel for free on buses, trains and Mersey ferries (Liverpool City Council, n.d.). Disabled people can also qualify for a Merseytravel National Travel Pass if their disability is permanent or long-lasting, and therefore plwd are able to apply for this. This pass can be used on buses, trains and Mersey Ferries in Merseyside anytime, any day, and on buses in England during certain times (Merseytravel, n.d.). However, there is no pass available for a designated carer meaning travel to support groups, if using multiple forms of public transport, may be too expensive for the carer to travel and therefore means that the plwd is not able to attend a support session or community activity if they are unable to travel on their own.

If the plwd is unable to use public transport unaided or their carer is not available to take them to a day service that has been recommended in a support plan produced after a needs assessment, then council-provided transport can be arranged for the journey – likely a minibus, but sometimes may be a taxi (Liverpool City Council, n.d.). There is also the Merseylink option for people who find using public transport difficult however this cannot be used for hospital appointments or day care facilities, or for travelling to services that are part of a person's support plan (Liverpool City Council, n.d.). Ultimately, it places the burden of getting to their support services on the plwd, and on their use of public transport or relying on a carer or family member to either travel with them or provide transport for them, and as highlighted above can be significantly impacted if there are unaffordable costs for the carer's travel.

The desire/ease to use public transport can also be impacted by transport employees and other passengers. The difficulties and anxieties that already exist around using public transport can be 'compounded by a lack of understanding and patience from fellow passengers and staff' (APPG, 2021:32). The Alzheimer's Society's Dementia Friends programme has a positive impact in this respect by tackling stigma, allowing members of the public to be more understanding of the difficulties faced by plwd when out and about, yet more still needs to be done. The Equality Act 2010 should protect people with disabilities against discrimination, yet disability awareness is not required for all licensing and transport authorities and therefore means that companies are not making adequate adjustments for people with disabilities – particularly hidden disabilities such as dementia.

Health

The Health and Social Care Act 2012, amongst other things, created legislative changes that meant patients were able to 'choose their needs, including from charity or independent sector providers, as long as they meet NHS costs' (DOHSC, 2012:1), giving them independence and control over the care they wanted to receive. Further to this was the Care Act of 2014 that enshrined the assessment of an adult's needs for care and support by a local authority in law, regardless of the level of needs or the financial resource of the adult. The assessment must include the impact of the adult's needs, the outcomes the adult wishes to achieve, and the extent that the provision of care could contribute to those outcomes. This legislation allows all people with care needs to be entitled to a fair assessment, and the provision of services by their local council in line with the outcomes the adult wants to receive allowing them to again have independence and control surrounding their care. For some, this may include the provision of transport to and from services and is an example of where transport and health can come together to better provide for plwd and their carers. Yet there are issues with the Care Act 2014, including the fact that 'provisions to implement a cap [on lifetime care]' have not been introduced to date (HSC Committee, 2021:9), and shows how even though entitlements have been made in law, it does not necessarily mean that they are followed through in action.

Day support services (Liverpool City Council, n.d.), run by Liverpool City Council, are for all eligible Liverpool residents, including plwd. Once a needs assessment has been carried out an application can be made to any of the types of support – person-centred planning, outreach services, or building-based services – each allowing different aspects of living well to be planned. These can include finding community-based activities through the outreach services, or gaining confidence and skills to become more independent at building-based services. These services are vital to continue providing good quality of life, as it reduces loneliness and maintains mental and physical health, and therefore access to these services is necessary and must be considered non-negotiable – meaning public transport should provide this access. If public transport is not able to provide this then plwd and their carers should still be given the ability to access services so this may include the local borough organising

transport to services from local pickups, allowing plwd in the area to attend their recommended or desired support.

Short breaks are also available for looked after adults and their carers, which could be something that someone in the later stages of dementia may benefit from. Both the plwd and their carer would be able to have a break, sometimes over night or as part of a small group to enjoy a leisure activity, the necessity and appropriateness of which is assessed through a carer's assessment (Liverpool City Council, n.d.). By encouraging this, it allows plwd to know that they are still able to engage with people outside of their routine and thus inspires the self-confidence that allows them to continue living independently. As previously, transport should not be a restricting factor for opportunities such as this.

On a more local level, personal budgets – 'an amount of money allocated by a local authority to meet a person's care and support needs' (Alzheimer's Society, n.d.-b) – are available for plwd, if a needs assessment deems they are eligible for support. They are able to be spent in a number of ways – one possibility being a direct payment, meaning they are given more control and flexibility over their care and support, and therefore promoting the continuation of their independence. Yet improvement is needed in this area as the process of applying for personal budgets is not dementia-friendly and therefore may lead to discouragement from applying (Alzheimer's Society, n.d.-a).

Overall

As can be seen above, there are many ways that plwd and their carers are provided for by transport and health initiatives – both national and local. However there are still gaps that these initiatives do not cover, which I will discuss in the next section.

The link between transport and health for plwd and their carers

With the cost of dementia standing at nearly £30 billion a year, and 45.8% of this being spent on social care (LSE, 2019, as cited by HSC Committee, 2021), it is vital that budgets are linked effectively to ensure benefits are created for plwd and their carers, as well as their community and the economy as a whole.

The planned spending for the Department of Health and Social Care in England is £190.3 billion for 2021/2022 (The King's Fund, 2022). In absolute terms this has increased, yet demand has also increased (HSC Committee, 2021) and therefore accessibility to support for plwd and their carers is just as difficult, if not more so – supported by the fact that there is a gap of £6.1 billion between the increase in adult social care cost pressures and the increase in total funding (HSC Committee, 2021). As if current health budgets weren't already insufficient for plwd and their carers, the so-called 'dementia tax' only adds to this – 'people with dementia who have assets including their house over £23,250 in England are often paying hundreds of thousands of pounds for their care... for many other long-term health conditions, such as cancer and heart disease, medical treatments are available for free on the NHS' (Alzheimer's Society, n.d., as cited by HSC Committee, 2021:9). This makes it appear that central government does not deem it necessary to subsidise the illness of dementia, in comparison to other long term health conditions. If there are ways in which efficiency of spending could be improved by merging budgets and therefore spending less but achieving more overall then this should be prioritised, hopefully increasing the likelihood of central or local governments adopting them.

Liverpool CCG and Liverpool City Council worked together on a commissioning strategy for dementia from 2014-2018 where there were seven key areas prioritised for action;

- 1. 'Increased awareness of dementia and work towards Liverpool becoming recognised as a dementia friendly city;
- 2. Timely identification and diagnosis within targeted high risk groups;
- 3. Delivering improvements to dementia care through participation and engagement;
- 4. Establish joined up working & care between GP and Specialist Dementia services;
- 5. To provide access to high quality post diagnostic support;
- 6. To provide good hospital care for people with dementia;
- 7. To stimulate housing provision that is supportive of people with long term conditions including dementia.' (Liverpool CCG and Liverpool City Council, 2014)

These refer solely to health budgets and ways of improving the experience of care for plwd through health budgets, yet some of these areas could be improved with the help of transport budgets, such as providing access to high quality post diagnostic support and delivering improvements to dementia care, showing that there is the potential for merging health and transport budgets. A lot of the focus of health budgets also seems to be on dementia care, but there is little acknowledgement that this need for more regulated and structured care could be mitigated through increasing the involvement and continued independence of plwd after diagnosis when they are still in the early- to mid- stages of dementia. In the Liverpool Commissioning Strategy (2014) it is mentioned briefly that there is a need to 'reduce social isolation and loneliness in order to improve the quality of life of people living with dementia and their carers' (Liverpool CCG and Liverpool City Council, 2014:24) yet there is no discussion on how this is to be achieved. One of the major ways that this could be achieved is through improving the accessibility of transport, and shows how connected the link between transport and the health of plwd is.

The Autumn Budget and Spending Review in October 2021 'includes £5.7 billion for London-style transport settlements in English city regions over five years including... Liverpool City Region' (Peachey, 2021) so there is a focus to improve transport in Liverpool. However it is unclear whether this improvement focuses on accessibility specifically. If there is a focus on making transport more accessible this usually tends to focus on the elderly or physically disabled passengers, meaning hidden disabilities are not always given due attention. In Ormerod et al.'s (2015) *Future of Ageing* evidence review, they state that 'underpinning the principles is user engagement' (Ormerod et al., 2015:10) and therefore to make changes that work effectively for plwd and their carers on transport, they need to be involved in – and leading – the discussions. Within the age-friendly status of the city, it is noted that consultation with older people's groups has been undertaken for new plans being written (LCRCA, n.d.), which suggests that for dementia specific policy, Liverpool City Region will consult with plwd and their carers.

Health and economic benefits of merging public sector budgets for the benefit of plwd and their carers

For plwd and their carers the benefits of merging public sector budgets, namely that services provided become more efficient and accessible for plwd, will result in both health and economic benefits. The detrimental effects of social isolation on health have been widely studied – 'social isolation has been identified as a risk factor for poor health, reduced well-being, mortality, depression and cognitive decline' (Courtin and Knapp, 2015). Further to this, the effects of dementia, including mood swings, anxiety, and depression (Krivec, 2021) increase with social isolation, and therefore means extra measures need to be taken to avoid unnecessary worsening of the factors that plwd are already susceptible to. A diagnosis does not mean that the way plwd live their lives needs to change – at least not straight after diagnosis – it just means that a little extra support is needed to allow them to carry

on as usual, and they should be viewed as being able to carry on independently regardless of a diagnosis of dementia.

Mobility is important for fulfilling three needs; practical/utilitarian, psychosocial/affective, and aesthetic (Musselwhite and Haddad, 2010; 2018). Focusing on the psychosocial and aesthetic aspects are just as important as the practical aspect for keeping plwd connected with their community, and therefore benefitting their health. Mobility and access to transport are vital for preventing isolation for plwd, encouraging them to maintain their independence and reduce the need to be reliant on others once diagnosed. Combined with the fact that giving up driving is related 'to a decrease in wellbeing and an increase in depression and related health problems' (Ormerod et al., 2015:22), reliance on other modes of transport is not only important in the practical sense but also vital for the psychosocial and aesthetic aspects. This will ensure that good health remains and living well is promoted for plwd and their carers. The benefits of social inclusion result in a healthier, happier life, where a diagnosis of dementia is not detrimental, as it is perfectly possible to live well with dementia if there is the support available.

The types of transport used by those who have given up driving/are no longer able to drive tend to depend on the rurality of their location. Those close to city areas and towns can make use of buses and trains while those in more rural locations have less flexibility around transport and may have to rely on other forms of transport such as taxis – that come at a larger expense – or volunteer carpools, which for plwd may be more difficult if they do not feel comfortable sharing with someone they do not know. This means that plwd and their carers in rural areas are at an even greater disadvantage than those in more urban locations, and highlights the need not only for an improvement in accessibility of transport but also an improvement for better provision of this transport in rural areas – something that would benefit not just plwd but all transport users and reduce isolation for multiple groups in rural areas.

As for the economic aspect, it is extremely beneficial to ensure that disabled people are still able to access their local economy and spend money – 'Britain's disabled people are estimated to spend £80 billion per year' (Department for Work and Pensions, as cited by thred CiC, 2021:35). When compared with the value of the 'purple pound' – 'a term used to describe the spending power of disabled people and their families' (thred CiC, 2021:35) – which stands at an 'estimated £212 billion to the British economy' (thred CiC, 2021:35), this is a significant amount of lost income to the British economy. Further to this, transport is one of 'the top three growing sectors for older consumers' (Dimitriadis, 2019:21), alongside recreation and culture, and household goods and services, and therefore it should be a main focus of policymakers to ensure transport is accessible to all groups of people, not just the young and able-bodied. There is evidence of multiple barriers to travel that prevent or discourage disabled and elderly people from using transport, meaning they are unable to participate in the economy;

- thred CiC (2021:36)
 - \circ Lack of easily understandable, accurate and relevant travel information both before and during the journey
 - o Ability to access public transport interchanges and interchanges between all modes
 - Ability to access public transport vehicles
 - Concerns regarding safety and comfort on the public transport network
- Musselwhite (2021) although based on a Greater Manchester case study it is still relevant due to recognition for national change, not just issues local to Merseyside
 - o Bus driver's lack of awareness of older people's issues
 - Poor quality bus stops poor signage and information

- Lack of help on/at railway services, along with confusing tickets and ability to get a seat
- Not being involved in policy decisions affecting transport

How can transport and health be merged to benefit plwd and their carers

Transport, health and the economy are all intrinsically linked; by improving provision of accessible transport for plwd, social isolation is reduced along with the negative impacts on mental and physical health it brings. Improving transport also means that plwd are still able to access their workplace, if they have chosen to continue working after their diagnosis, so their mental and emotional well-being is supported through remaining independent, while also benefitting the economy by reducing business costs associated with loss of productivity. By improving the health of plwd this reduces the need for spending in health budgets and shows how expenditure in transport budgets, with the aim of improving health, (and vice versa) could save money for central government and be a more efficient way of spending money. Improved transport also helps with retaining independence through the ability to access spending opportunities within their local community, benefiting the local and national economy. Retaining independence for plwd also implies that lesser help will be needed from a carer, leading to lesser mental and financial strain on the carer, overall reducing demand on health and financial services by carers.

Most of the problems surrounding transport are easily solved through changes to operation;

- Lack of awareness from transport staff and passengers
 - Hidden disability awareness courses for all transport employee members would improve the experience of using public transport for plwd and others with hidden disabilities. Not only will this mean that transport employees are better equipped to spot passengers with hidden disabilities, but it will also mean that they can better aid those who wear the hidden disability lanyard.
 - Greater information by disabled seats and on transport surrounding hidden disabilities so that other passengers are more aware of hidden disabilities, meaning there is lesser chance of judgement from other passengers questioning their disability. This will reduce anxiety around travelling for plwd and therefore decrease the likelihood of plwd avoiding using public transport, consequently reducing the likelihood of social isolation and the negative impacts on health it brings.
 - At interchange locations, the designation of transport officers specifically to help people who may find using transport difficult or who worry with changing transport, ensuring they are on the correct transport and reducing anxiety surrounding their journey.
- Age-friendly status of transport
 - More frequent signage in larger fonts, repeated audio announcements paired with visual announcements.
 - Greater provision of information regarding the expected arrival time of the transport to reduce confusion and anxiety around whether the passenger has missed the transport or if it is just running late. This can be achieved through overhead real-time updated information signs not just the provision of standard timetables.
- Difficulty of accessing transport in some locations
 - Improved service provision to rural areas, not just relying on the availability of community transport schemes or the financial ability to pay for taxis, would be greatly

beneficial in reducing social isolation for plwd. By reducing social isolation, this will also reduce the negative impacts on health that social isolation brings and therefore reduce the demand on health services and GPs.

Overall recommendations

- Plwd and their carers need to be involved in the discussions surrounding improvements that are being designed to benefit them. This will ensure that changes being made will provide the benefits required for plwd and their carers.
- Hidden disability awareness to be compulsory for all transport employees, regardless of mode of transport (ie: bus/train/aviation/taxi), so that people with hidden disabilities feel comfortable and safe using public transport.
- Improvement of public transport to become more age-friendly, easing some of the anxieties faced by plwd when using public transport.
- Support in general could be given to life beyond the car from a younger age 'to help build solutions and confidence in transport use beyond the car' (Musselwhite, 2010) therefore meaning the change from driving to cessation of driving is less abrupt when plwd are no longer able to drive.
- An overall reduction in social isolation should be aimed for, therefore improving the quality of life and health of plwd and their carers as they are able to still play a part in their local community.

References

All-Party Parliamentary Group on Dementia (APPG) (2021) Hidden no more: Dementia and Disability. London, United Kingdom: House of Commons. Retrieved from https://www.alzheimers.org.uk/sites/default/files/2019- 06/APPG_on_Dementia_2019_report_Hidden_no_more_dementia_and_disability_media.pdf>

Age-Friendly World (AFW) (n.d.) *The WHO Age-friendly Cities Framework - Age-Friendly World*. [online] Available at: https://extranet.who.int/agefriendlyworld/age-friendly-cities-framework/ [Accessed 5 April 2022]

Alzheimer's Society (n.d.-a) *Dementia-friendly personal budgets*. [online] Available at: https://www.alzheimers.org.uk/about-us/our-dementia-programmes/dementia-friendly-personal-budgets?msclkid=c7432633bcb911eca272ea661ffdd12c> [Accessed 5 May 2022]

Alzheimer's Society (n.d.-b) *Personal budgets*. [online] Available at: <https://www.alzheimers.org.uk/get-support/legal-financial/personalbudgets?msclkid=58c4072abcba11ec87252ac5e23bcfee> [Accessed 5 May 2022]

[Accessed 6 April 2022]

Alzheimer's Society (2021) *Maximising the UK Dementia Research Moonshot for people affected by dementia*. [online] Available at: https://www.alzheimers.org.uk/news/2020-02-12/5-priorities-government-dementia-moonshot> [Accessed 6 April 2022]

Care Act 2014, c. 23. Available at: < https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted?msclkid=1a2bab71b9dd11ec80b0 4206350543a2> [Accessed 11 April 2022]

Courtin, E. and Knapp, M. (2015) Social isolation, loneliness and health in old age: a scoping review. *Health and Social Care in the Community*, 25(3), pp.799-812.

Dementia Action Alliance (DAA) (n.d.) *Liverpool Dementia Action Alliance*. [online] Available at: <https://www.dementiaaction.org.uk/local_alliances/3012_liverpool_dementia_action_alliance> [Accessed 6 May 2022]

Dementia Action Liverpool (n.d.) *Public Services*. [online] Available at: < https://www.dementiaactionliverpool.com/publicservices.html#:~:text=Mersey%20Care%20NHS%20Foundation%20Trust%20The%20Mersey%20Care ,Details%20of%20Dementia%20Services%20can%20be%20found%20here.> [Accessed 11 April 2022]

Dementia UK (2022) *Nine ways an Admiral Nurse can support you this year*. [online] Available at: <https://www.dementiauk.org/nine-ways-admiral-nurse-support/> [Accessed 6 April 2022]

Dementia UK (n.d.-a) *Types of dementia.* [online] Available at: <https://www.dementiauk.org/about-dementia/types-of-dementia/> [Accessed 4 April 2022]

Dementia UK (n.d.-b) *Young onset dementia facts and figures*. [online] Available at: <https://www.dementiauk.org/about-dementia/young-onset-dementia/about-young-onset-dementia/facts-and-figures/> [Accessed 4 April 2022]

Department of Health (DOH) (2015) *Prime Minister's challenge on dementia 2020.* London, United Kingdom: Department of Health. Retrieved from

<https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/fil e/414344/pm-dementia2020.pdf> [Accessed 6 April 2022]

Department of Health and Social Care (DOHSC) (2012) *The Health and Social Care Act 2012 [fact sheet]*. London, United Kingdom: Department of Health and Social Care. Retrieved from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/138257/A1.-Factsheet-Overview-240412.pdf> [Accessed 6 May 2022]

Dimitriadis, S. (2019) *Maximising the longevity dividend*. London, United Kingdom: International Longevity Centre. Retrieved from: https://ilcuk.org.uk/wp-content/uploads/2019/12/Maximising-the-longevity-dividend.pdf> [Accessed 5 May 2022]

Good News Liverpool (2019) *Liverpool City Council signs up to become age friendly*. [online] Available at: https://www.goodnewsliverpool.co.uk/2019/01/18/liverpool-city-council-signs-up-to-become-age-friendly/> [Accessed 6 May 2022]

GOV.UK (n.d.) *Attendance Allowance*. [online] Available at: <https://www.gov.uk/attendance-allowance> [Accessed 6 April 2022].

Greaves, I. and Jolley, D. (2010) National Dementia Strategy: well intentioned – but how well founded and how well directed? *British Journal of General Practice,* 60(572), pp. 193-198

Health and Social Care Act 2012, c. 7. Available at <

https://www.legislation.gov.uk/ukpga/2012/7/contents?msclkid=3696bee1b9dd11ec8b625893e0bb 423f> [Accessed 11 April 2022]

Health and Social Care (HSC) Committee (2021) *Supporting people with dementia and their carers* (HC 2021-2022, 96) Retrieved from:

<https://committees.parliament.uk/publications/7662/documents/79983/default/> [Accessed 3 May 2022]

ITV News Granada (2021) Metro Mayor Steve Rotheram sets out commitment to make Liverpool City Region the most dementia-friendly place possible. [online] Available at: <https://www.itv.com/news/granada/2021-05-16/metro-mayor-steve-rotheram-sets-outcommitment-to-make-liverpool-city-region-the-most-dementia-friendly-place-possible> [Accessed 6 May 2022]

Krivec, R. (2021) *14 Effects Of Dementia On A Person [Mental & Physical]*. [online] ReaDementia. Available at: <https://readementia.com/effects-of-dementia/> [Accessed 4 May 2022]

Liverpool City Council (n.d.) *Travel passes for 60+ and disabled people*. [online] Available at: <https://liverpool.gov.uk/adult-social-care/getting-out-and-about/travel-passes-for-60plus/> [Accessed 7 April 2022]

Liverpool Clinical Commissioning Group (CCG) and Liverpool City Council (2014) *Liverpool Commissioning Strategy for Dementia (FINAL): 2014-2018*. Liverpool, United Kingdom: Liverpool CCG and CC. Retrieved from: ">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018.pdf?msclkid=ca8aa24abcc411ecb58b7b23bb2daf85>">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018.pdf?msclkid=ca8aa24abcc411ecb58b7b23bb2daf85>">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018.pdf?msclkid=ca8aa24abcc411ecb58b7b23bb2daf85>">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018.pdf?msclkid=ca8aa24abcc411ecb58b7b23bb2daf85>">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018.pdf?msclkid=ca8aa24abcc411ecb58b7b23bb2daf85>">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018.pdf?msclkid=ca8aa24abcc411ecb58b7b23bb2daf85>">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018.pdf?msclkid=ca8aa24abcc411ecb58b7b23bb2daf85>">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018.pdf?msclkid=ca8aa24abcc411ecb58b7b23bb2daf85>">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018">https://www.liverpoolccg.nhs.uk/media/1077/liverpool-dementia-strategy-2014-2018"

Liverpool City Region Combined Authority (LCRCA) (n.d.) *Age Friendly Liverpool City Region*. [online] Available at: <https://www.liverpoolcityregion-ca.gov.uk/age-friendly/> [Accessed 5 April 2022]

Living with Dementia Toolkit (n.d.) *Living with Dementia Toolkit*. [online] Available at: <https://livingwithdementiatoolkit.org.uk/> [Accessed 6 May 2022]

Mersey Care NHS Foundation Trust (Mersey Care) (n.d.) *Dementia Services*. [online] Available at: https://www.merseycare.nhs.uk/our-services/liverpool/dementia-services/ [Accessed 6 April 2022]

Merseytravel (n.d.) Disability Concessions Travel. [online] Available at:

<https://www.merseytravel.gov.uk/tickets-and-pricing/people-with-disabilities/> [Accessed 7 April 2022]

Musselwhite, C. (2010) The importance of driving for older people and how the pain of driving cessation can be reduced. *Journal of Dementia and Mental Health*, 15(3), pp.22-26.

Musselwhite, C. and Haddad, H. (2010) Mobility, accessibility and quality of later life. *Quality in Ageing and Older Adults*, 11(1), pp. 25-37.

Musselwhite, C.B.A. and Haddad, H. (2018) Older people's travel and mobility needs. A reflection of a hierarchical model 10 years on. *Quality in Ageing and Older Adults*, 19(2), pp. 87-105.

Musselwhite, C.B.A. (2021) Prioritising transport barriers and enablers to mobility in later life: A case study from Greater Manchester in the United Kingdom. *Journal of Transport and Health*, 22(2021), 10185.

Office for Health Improvements & Disparities (OHID) (2022) *Statistical commentary: Dementia profile, March 2021 update*. [online] Available at:

<https://www.gov.uk/government/statistics/dementia-profile-updates/statistical-commentarydementia-profile-march-2021-update#contents> [Accessed 4 April 2022]

Ormerod, M., Newton, R., Phillips, J., Musselwhite, C., McGee, S. and Russell, R. (2015) *How can transport provision and associated built environment infrastructure be enhanced and developed to support the mobility needs of individuals as they age?* London, United Kingdom: Foresight, Government Office for Science. Retrieved from: <

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file /443508/gs-15-7-future-ageing-transport-er23.pdf> [Accessed 4 May 2022]

Parkin, E. and Baker, C. (2021) Dementia: policy, services and statistics. House of Commons Library Briefing Paper no. 07007. London, United Kingdom: House of Commons Library. Retrieved from <https://researchbriefings.files.parliament.uk/documents/SN07007/SN07007.pdf> [Accessed 6 April 2022]

Peachey, A. (2021) Autumn Budget and Spending Review 2021: Chancellor spends on transport and infrastructure – transportandenergy. [online] Transportandenergy.com. Available at: https://transportandenergy.com/2021/10/27/autumn-budget-and-spending-review-2021-chancellor-spends-on-transport-and-infrastructure/ [Accessed 3 May 2022]

The King's Fund (2022) *The NHS budget and how it has changed*. [online] Available at: https://www.kingsfund.org.uk/projects/nhs-in-a-nutshell/nhs-budget?msclkid=7ee4756abcba11ecb75ef0a471e05df4 [Accessed 8 May 2022]

The Live Well Directory (n.d.) *Welcome to the Live Well Directory*. [online] Available at: <https://www.thelivewelldirectory.com> [Accessed 7 April 2022]

thred CiC (n.d.) *Home |Thred CiC* [online] Available at: <https://www.thred.org.uk> [Accessed 5 April 2022]

thred CiC (2021) *How can urban and rural transport systems help people diagnosed with dementia live independently for longer*? Dementia Enquirers. Retrieved from: < https://dementiaenquirers.org.uk/individual-projects/ thred-in-liverpool/> [Accessed 4 May 2022]

Wirral.gov.uk (n.d.) *Charging and paying for adult care and support services*. [online] Available at: https://www.wirral.gov.uk/health-and-social-care/adult-social-care/charging-and-paying-services [Accessed 8 April 2022]

Wittenberg, R., Hu, B., Barraza-Araiza, L. and Rehill, A. (2019) *Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040.* London, United Kingdom: Care Policy and Evaluation Centre, London School of Economics and Political Science. Retrieved from https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf> [Accessed 4 April 2022]

World Health Organisation (WHO) (2017) *Global action plan on the public health response to dementia 2017-2025.* Geneva, Switzerland: World Health Organisation. Retrieved from [Accessed 5 April 2022]

World Health Organisation (2021a) *Dementia*. [online] Available at: <https://www.who.int/news-room/fact-sheets/detail/dementia> [Accessed 5 April 2022].

World Health Organisation (2021b) *Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives (DFIs).* Geneva, Switzerland: World Health Organisation. Retrieved from [Accessed 5 April 2022]

World Health Organisation: Age-Friendly World (n.d.) *Liverpool - Age-Friendly World*. [online] Available at: <https://extranet.who.int/agefriendlyworld/network/liverpool-uk/> [Accessed 6 May 2022]