



# ARCBITE



Brokering Innovation Through Evidence

## “A piece of paper is not the same as having someone to talk to”: accessing post-diagnostic dementia care before and since COVID-19 and associated inequalities

### Background:

Accessing and engaging in post-diagnostic support for dementia care is not only hugely beneficial for people living with dementia (PLWD) but also vital for carers. Post-diagnostic support should be the bedrock of quality care as this is reflected in national guidelines, standards and recommendations. However, differences in how services are paid for and provided, how they are accessed, where PLWD live, their economic background etc can all have a direct impact on health inequalities.

Health inequalities appeared to be magnified when the Covid-19 pandemic of 2020 saw an immediate collapse of post-diagnostic support for PLWD and their carers with day centres, peers support groups and many services having to stop providing support to follow government guidelines to halt the spread of the virus. Researchers from the University of Liverpool and key dementia studied the inequalities in social service support before and since the pandemic to try to identify the impact the pandemic had on PLWD and their carers.

### The Research:

This study, with ethical approval, interviewed a total of fifty PLWD and unpaid carers over the telephone. The aim was to listen to the experience of accessing social support services before and after the Covid-19 pandemic and then analyse the results. The participants in the study were recruited via social support service, third sector organisations (mainly from the North West of England) but also across the UK via dementia support organisations.

The interviews took place in April 2020 by researchers trained and experienced in recorded telephone interviews. Eight team members then analysed the transcripts and recordings and grouped the themes into five areas of concern.

**Theme 1 – Service issues.** It was recognised that a few services did try to adapt services (e.g. provide on-line support) but this was deemed unsuitable for some and exclusive to those with internet access and devices. In addition, some people felt that there was no clear information to help find suitable support.

**Theme 2 – Access issues.** Before Covid-19, most people described access to dementia support services as difficult and challenging with lack of clear information. This was exacerbated by transport issues, postcode and social inequalities and associated costs (e.g. fees).

**Theme 3. Relying on own initiative.** Most unpaid carers had to rely on their own initiative to find suitable dementia support before Covid-19 and yet again this was especially relevant during the pandemic. The impact on carers is probably unmeasurable with many having to move house, reduce or give up employment or traveling long distances to care for someone living with dementia.

**Theme 4. New inequalities.** Dementia, for whatever reason, was not a recognised condition of vulnerability on the government’s priority list. Therefore, accessing food and medical supplies was

reported as a struggle and due to the limited capabilities of health care providers (e.g. GPs) basic health services and access to them proved extremely difficult and created anxiety among the participants of the study.



**Theme 5. Missing out on the benefits of support services.** Participants of the study highlighted the benefits of support services (e.g. keeping fit and active, socialising etc) on both the PLWD and the carer. However, during Covid-19 it was common to see a decline due to the withdrawal of service and this resulted in issues such as increased memory loss, confusion, motivation and ability to function.

### **Conclusion:**

This is the first study to look at inequalities before and after the Covid-19 pandemic on PLWD and their unpaid carers. This study has highlighted that existing inequalities have been worsened since the pandemic. In practice this means addressing the urgent need for targeted support and equitable access for all. Commissioner and provider services need to be adapted to become flexible and nimble in providing support to make access and support easier and more proactive. Ending the variation in dementia care now means we will be more prepared in the future, less likely to cause harm and create a society without inequalities.

### **What is NIHR CLAHRC / ARC North West Coast?**

The Applied Research Collaboration North West Coast (ARC NWC) superseded CLAHRC NWC in September 2019. It is a partnership between universities, NHS, public, etc.

Its mission is to undertake applied research to improve public health, wellbeing, quality of care & reduce health inequalities across the North West Coast region.

<https://arc-nwc.nihr.ac.uk/>