

Responding to COVID-19 in the Liverpool City Region

COVID-19 and Social Care: The Impact of the Pandemic on People with Dementia and Carers

Dr Clarissa Giebel

Map of Liverpool City Region Combined Authority (LCRCA) boundary (in red) and constituent local authorities



Data sources: Westminster parliamentary constituencies (December 2018 - ONS), local authority districts (December 2018 - ONS), and combined authorities (December 2018 - ONS)

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Key takeaways

1. The COVID-19 pandemic and public health measures implemented in response have significantly impacted upon the delivery and access of social support services (e.g. day care centres, peer support groups, befriending services) for people living with dementia, carers, and older adults in the UK.
2. Being unable to access social support services has a detrimental effect on people's mental health and their capacity to live well and independently in the community for as long as possible. It is vital that these services are better enabled to deliver high quality support both throughout the present crisis, but also afterwards.
3. Our UK-wide COVID-19 dementia and ageing social care research found that nearly all social support services closed down during the first national lockdown, with very few providing any form of remote assistance. Among other effects, this caused heightened levels of uncertainty, faster deterioration in those people living with dementia, and forced many unpaid carers to take on additional responsibilities.
4. Carers should not be forgotten. They are vital in providing support to people living with dementia, with unpaid carers providing over £10.1 billion worth of dementia care each year in England. They too require psychological and other tangible supports.
5. Recommended changes to the delivery and access of social support services include clearer direction from government on how old age social support services should be, or could be, delivered; the tailoring of services so that they are more flexible in their delivery; and supporting people living with dementia and older adults to access support services provided remotely better.

1. Introduction

Living with dementia affects all aspects of life – from being able to make a meal, to changes in behaviour and not remembering your friends and family. In the UK alone, dementia affects over 850,000 people, and over 50 million people are afflicted with the disease worldwide (Alzheimer's Disease International 2020). To enable people living with dementia to live well, independently, and in the community for as long as possible, it is critically important to have access to social support services. Social support services are offered by a mixture of different providers, ranging from NHS Trusts to third sector organisations, small private businesses to local authorities. They include peer support groups, social activities in the community, day care centres, respite care, paid home care, and befriending services.

As all of these social support services involve social and face-to-face contact, it was unclear to what extent public health measures introduced in response to the COVID-19 pandemic would affect service delivery and access. We know that engaging in social activities are crucial for someone's mental well-being, so how has the pandemic potentially hindered access to these services?

In this policy briefing, I discuss some of the emerging findings from our UK-wide social care research and outline suggested actions to address the harmful impact of COVID-19 public health measures on the lives of people living with dementia and their carers. This includes a brief review of why it is important to make changes to social support services in light of the ongoing pandemic, who should implement these changes, and the likely consequences of inaction.

2. Researching social support services during the pandemic

As part of a larger [COVID-19 dementia and ageing social care project](#), we conducted a mixed-methods study focused on understanding how COVID-19 related social support service changes have affected the lives of people living with dementia, carers, and older adults. This ongoing study is being led from the University of Liverpool, and we are working closely together with clinicians, third sector organisations, support providers, and people affected by dementia as part of the project team.

Our study proceeded in two parts. First, in our 50 baseline (April 2020) and 20 follow-up interviews (June/July 2020) we asked unpaid carers, family members and friends, as well as people living with dementia about their experiences of accessing social support services during the pandemic, and how things had changed since the beginning of the first national lockdown in the UK. Second, in our longitudinal online and telephone survey, we asked people living with dementia, carers, and older adults about their use of social support services and their mental well-being at three different time points between April and August.

3. What has our research shown?

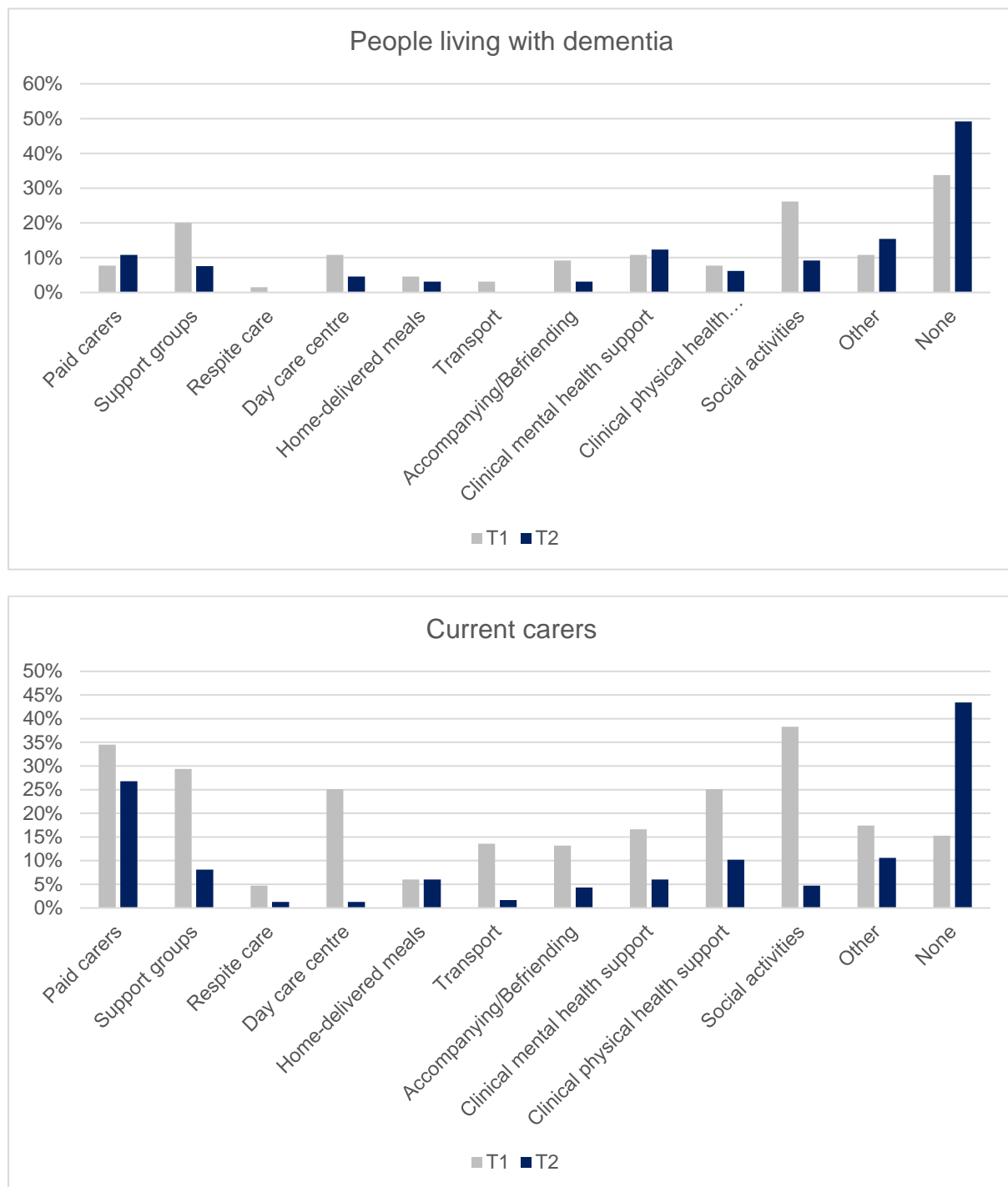
Our UK-wide research has shown the detrimental impact that COVID-19 public health measures have had on social support service usage and the lives of people living with dementia, carers, and older adults. Speaking to unpaid carers and people living with dementia, we found that suddenly in March 2020 nearly all social support services were reported to have closed down, with very few providing any form of remote assistance (Giebel et al. 2020a).

This left people with high levels of uncertainty – e.g. whether their relative with dementia would be able to return to services once re-opened; and questions over when services would re-open, and in what form. Already in April, carers reported faster deterioration in those people living with dementia, which they attributed to the lack of social, cognitive, and physical stimulation. Being restricted to the home, and not having the routine of attending social support services, also contributed to their deterioration.

Paid home care was the type of service affected the least in terms of usage. This is because paid home care was still possible, as opposed to day care centres and support groups, which simply shut down and only provided very limited remote support, if at all. Unpaid carers faced very difficult decisions whether or not to continue paid home care during the pandemic (Giebel et al. 2020b). Many carers decided to cancel paid help entering the home for fear of virus transmission. As a result, they took on the additional caring duties, and were quickly overburdened. Others decided to continue paid home care, as they were unable to cope without this service.

Findings from our longitudinal survey complemented these qualitative results. Our baseline survey showed that reductions in weekly social support service usage between pre-pandemic times and early into the lockdown were associated with poorer mental health in people with dementia, carers, and older adults (Giebel et al. 2020c). In total, 569 participants fully completed the baseline survey, providing a quantitative picture of how badly social support service closures have been affecting some of the most vulnerable in society. Specifically, Figure 1 shows how usage of services, such as support groups and day care centres, reduced from pre-pandemic times (T1) during the first weeks of lockdown (T2).

Figure 1. Social support service usage UK-wide before and since the first COVID-19 lockdown by group



(Source: Giebel et al. 2020c)

Legend: T1 = Before first COVID-19 lockdown; T2 = Since first COVID-19 lockdown.
 Bar charts represent the proportion of participants within each group who reported having accessed individual social support services pre and post-COVID.

4. Why is accessing social support services so important?

Accessing social support services is crucial to people living well and independently for as long as possible. Lack of social engagement, and thus a lack of both cognitive and physical stimulation due, for example, to restricted access to walking groups, dancing, or swimming classes, is linked to poorer mental health. This can cause faster care home entry because people with dementia might become dependent more quickly due to rapid advances in their condition.

Considering that most people wish to stay at home for as long as possible, in their familiar environment, but also due to the high costs associated with care home residency, the aim is to delay care home entry and enable well and independent community living for as long as possible. Particularly now during the pandemic, when care homes can easily develop into virus hot spots, people are more wary of sending their relative to a care home.

5. Recommended changes to delivering and accessing social support services

Given the detrimental impact of COVID-19 related social support service closures on the lives of people with dementia, carers, and older adults, we propose a targeted focus on the following:

- (a) Enabling social support services to deliver care during the pandemic, either face-to-face with clear guidelines or remotely, depending on the severity of infection rates;
- (b) Supporting people living with dementia and older adults to access remote support services better.

Whilst there is some government guidance on general adult social care (Department of Health and Social Care & Public Health England 2020); the provision of home care (Department of Health and Social Care 2020a); as well as

unpaid care (Department of Health and Social Care 2020b); there is no clear direction on how old age social support services should be, or could be, delivered during the pandemic. This is critically important, as although some services have developed their own approaches effectively, others have struggled. Therefore, clearer general guidance can enable every service provider to deliver their care as best as possible given the continuing restrictions.

Unpaid carers in our study have not reported facing issues in accessing services remotely, as they were familiar with digital technology. However, they expressed concern over the inability of their relative with dementia using the internet and having no access to a smartphone, tablet, or laptop computer. With most people with dementia aged 65+, digital illiteracy issues arise that require addressing by policymakers, for example, by providing free and easily accessible training.



Digital literacy is sometimes a challenge for certain age groups (Credit [Georg Arthur Pflueger](#) on [Unsplash](#))

Next steps, what should be implemented and by whom?

As a next step, social support services should adapt the way in which they provide support during the pandemic. Services need to be flexible in their delivery, taking into account an individual's wishes for how to engage, and by utilising as many different channels of communication and support as possible. For example, services can be provided via Zoom and Skype channels, or WhatsApp

groups, telephone, email, hand-written letters, YouTube videos, social media, and, if possible and safe, via face-to-face contact.

However, as many service providers are third sector organisations or small businesses, which are severely affected financially by the pandemic, government aid is necessary to enable these services to continue to provide support throughout the present crisis, but also afterwards. Otherwise, services might be unable to continue both in the immediate and longer term.

Implications of leaving social support services as they are

To reiterate from above, if no action is taken to improve delivery and access to social support services, people living with dementia will continue to deteriorate faster due to lack of social, cognitive, and physical stimulation and engagement. This can lead to not only faster care home entries, but also possibly faster mortality, considering that dementia is a neurodegenerative disease.

Critically, we cannot forget the many unpaid carers and their support needs too. Unpaid carers provide over £10.1 billion worth of care to people living with dementia in England alone, each year (Wittenberg et al. 2019). If carers do not receive assistance in dealing with the increased caring duties for their relative or friend with dementia, they are overburdened and can suffer from poor mental health. That is why policy needs to target both the person living with dementia, and their unpaid carers, because both are affected by the pandemic and the lack of effective social support service access.

In addition, let us not forget care staff, whether home care, domiciliary or care home staff, facing the potential of catching the virus whilst on the job. Carers working in the social care sector have had some of the highest levels of COVID-19 mortality in the early stages of the pandemic, likely due to a lack of adequate Personal Protective Equipment (PPE), and with

their job involving personal and close care (Office for National Statistics 2020). Whilst PPE supplies are allegedly better now than they were at the beginning, and better guidance is in place for home care staff, social support service providers are still lacking adequate guidelines, which could cost lives.

6. Concluding thoughts for the Liverpool City Region

As we enter the second national lockdown in England, it is unlikely that social support services will be delivered face-to-face, except for paid home care. With Liverpool the first UK city to begin [trailing mass coronavirus testing](#) of its entire population, a faster move towards comprehensive face-to-face service delivery may transpire in the City Region. If everyone is tested regularly – and I mean everyone, as staff can easily bring the virus into a care setting (Livingston et al. 2020) – then the City Region can slowly, hopefully, move to some form of normality again with adequate social support service provision. Liverpool might illuminate how this could be achieved for the rest of the country.

Considering that the Liverpool City Region is also amongst the most economically disadvantaged areas in the country, we need to be mindful that fewer people with dementia and older adults in general who are in need of support will likely have access to a laptop or smartphone and the internet. If all services are delivered remotely, and mostly online, then this creates a huge inequality that cuts off even more people from vital care and support.

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7. References

Alzheimer's Disease International [ADI]. 2020. *From Plan to Impact III: Maintaining dementia as a priority in unprecedented times*. London, UK: ADI.

Giebel, Clarissa, Jacqueline Cannon, Kerry Hanna, et al. 2020a. "Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: a qualitative study." *Aging & Mental Health*.
<https://www.tandfonline.com/doi/full/10.1080/13607863.2020.1822292>.

Giebel, Clarissa, Kerry Hanna, Jacqueline Cannon, et al. 2020b. "Decision-making for receiving paid home care for dementia in the time of COVID-19: a qualitative study." *BMC Geriatrics*.
<https://bmcgeriatr.biomedcentral.com/trac k/pdf/10.1186/s12877-020-01719-0>.

Giebel, Clarissa, Kathryn Lord, Claudia Cooper, et al. 2020c. "A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers." *International Journal of Geriatric Psychiatry*.
<https://onlinelibrary.wiley.com/doi/10.1002/gps.5434>.

Department of Health and Social Care & Public Health England. 2020. "Coronavirus (COVID-19): adult social care guidance." *GOV.UK*, April 15, 2020.
www.gov.uk/government/collections/coronavirus-covid-19-social-care-guidance.

Department of Health and Social Care. 2020a. "Coronavirus (COVID-19): providing home care." *GOV.UK*, May 22, 2020.
www.gov.uk/government/publications/coronavirus-covid-19-providing-home-care.

Department of Health and Social Care. 2020b. "Coronavirus (COVID-19): providing unpaid care." *GOV.UK*, April 8, 2020.

www.gov.uk/government/publications/coronavirus-covid-19-providing-unpaid-care.

Office for National Statistics [ONS]. 2020. "Coronavirus (COVID-19) related deaths by occupation, England and Wales: deaths registered between 9 March and 25 May 2020." Accessed November 4, 2020.

www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/coronaviruscovid19relateddeathsbyoccupationenglandandwales/latest.

Wittenberg, Raphael, Martin Knapp, Bo Hu, et al. 2019. "The costs of dementia in England." *International Journal of Geriatric Psychiatry* 34 (7): 1095-1103.

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Heseltine Institute for Public Policy, Practice and Place
University of Liverpool, 1-7 Abercromby Square, Liverpool, L69 7ZH

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About the author

Dr Clarissa Giebel

Clarissa is a research fellow at the NIHR ARC NWC at the University of Liverpool. She leads a number of research studies exploring how people with dementia can be supported to live independently and well at home, whilst exploring health inequalities in accessing the right care.

The information, practices and views in this Policy Brief are those of the author(s) and do not necessarily reflect the opinion of the Heseltine Institute.

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