



Summary of the Report on the Effects of the Pandemic on People Affected By Dementia in Merton

1. Introduction

In July and August 2020, staff and volunteers at the Merton Dementia Hub, Wimbledon Guild and Carers Support Merton were asked to write case studies about how Covid-19 and the pandemic response have affected older people, mostly with reference to people affected by dementia. In this period Alzheimer's Society also published a study surveying nearly 1700 carers and 134 people living with dementia about how the Covid-19 pandemic and response has affected them.¹ Following on from this, Dementia Support Workers and Dementia Advisors at the Hub spent September and October 2020 collecting responses to a survey, designed to evaluate the prevalence and demographic breakdown of the issues discovered in the case study work. In total 38 responses were received, with data on both carers and people with dementia. Alongside the other work mentioned above, this provides a small snapshot of the effects of the pandemic on people in Merton, with reference to the issues discovered by the much larger Alzheimer's Society study, and guided by the open-ended case study work in which professionals were able to give their understanding of the issues without being influenced by the expectations of the researcher or previous findings of the field.²

Contents:

1. Introduction
2. Summary
3. Mental Health
4. Symptoms of Dementia
5. Public Services
6. Recommendations

Although this is still too few people for any solid conclusions, in context of larger studies we none the less get an indication of how Merton is doing and any issues that might be specific to the Borough. The demographic breakdown also provides an indication of how any solutions posed for people affected by dementia in Merton might need to consider how different communities are already responding to the pandemic, and how different communities are variously affected by individual issues.

¹ The Alzheimer's Society study was published as *Worst Hit: Dementia During Coronavirus* in 2020, and can be found at <https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>.

² This study was conducted by Jordan Dyck, the coordinator of the Merton Dementia Action Alliance, which is a Dementia Friendly Community managed by Alzheimer's Society and commissioned by the London Borough of Merton.

2. Summary

Below is a summary of the results to the questions asked in the survey, which will be followed by some commentary on the most striking things that were revealed, as well as some conclusions and recommendations for those considering policy responses with respect to people affected by dementia.

	Abbreviated Question to Carers	Total	Out of	Percent
1	Have you moved in together since start of lockdown?	3	16	19%
2	Shielded during lockdown?	10	16	63%
3	Felt sadder during lockdown?	9	9	100%
3	Felt happier during lockdown?	1	9	11%
3	Felt lonelier during lockdown?	9	9	100%
3	Felt more bored during lockdown?	5	9	56%
3	Felt more anxious during lockdown?	9	9	100%
4	Less social time during lockdown?	15	16	94%
5	Less social time since lockdown?	10	16	63%
6	Fewer in-depth conversations since lockdown?	7	16	44%
7	Unsatisfied with hospital communication?	3	16	19%
8	Found ordering groceries online difficult?	7	8	88%
9	PLWD ³ receiving more care than before lockdown?	7	16	44%
10	Unsatisfied with care provision organisations?	3	16	19%
11	Provided with enough care support information?	13	16	81%
13	Able to continue accessing support groups?	12	16	75%

	Abbreviated Question to People Living With Dementia	Total	Out of	Percent
2	Have you shielded during lockdown?	6	6	100%
3	Felt sadder during lockdown?	14	15	93%
3	Felt happier during lockdown?	2	15	13%
3	Felt lonelier during lockdown?	14	15	93%
3	Felt more bored during lockdown?	14	15	93%
3	Felt more anxious during lockdown?	14	15	93%
4	Symptoms increased deterioration during lockdown?	19	22	86%
5	Less social time during lockdown?	16	22	73%
6	Less social time since lockdown?	16	22	73%
7	Fewer in-depth conversations since lockdown?	17	22	77%
8	Socialise over phone twice weekly?	7	21	33%
9	Socialise online twice weekly?	4	22	18%
11	Found ordering groceries online difficult?	8	11	73%
12	Receiving more care than before lockdown?	12	22	55%
13	Unsatisfied with care provision organisations?	3	12	25%
14	Provided with enough care support information?	17	21	81%
15	Struggled to remember pandemic and restrictions?	18	22	82%
16	Able to continue accessing support groups?	5	20	25%

Notable issues arising from this study can be broken into three areas: **mental health**, the **symptoms of dementia** and ramifications for **public services**. For more details on any of these areas please see the full study.

³ Person Living With Dementia.

3. Mental Health

Among issues related to mental health, the word that came up most often in the case study work was 'loneliness.' 100% of carers and all but one of the people with dementia surveyed, when

QUICK STATISTICS

- 100% of carers and 93% of people with dementia felt more sad, lonely and anxious during lockdown.
- 20% of White carers reported a decrease in social time during lockdown, compared to 82% of BAME carers.
- 86% of carers surveyed believed that the symptoms of the person with dementia are deteriorating more quickly during lockdown.
- 75% of carers are continuing to access support services remotely during lockdown, but only 25% of people with dementia, and both of these figures vary considerably by ethnicity.

asked to choose between an array of positive and negative responses, reported feeling more lonely, sad and anxious since the start of the pandemic. We know from the larger study conducted by Alzheimer's Society that this is much more the case for those who live alone than for those who do not, which is perhaps obvious but should nonetheless affect any professional support being offered.⁴ This problem stretched into the summer of 2020, as lockdown measures were easing and shielding ceased to be compulsory, when only 17% of people living alone with dementia nationwide reported meeting friends or family outdoors.⁵

Although the experience of increased loneliness during lockdown is nearly universal for people affected by dementia, one of the more interesting results of the study was the stark differences in the sources and amounts of social time that lead to that increased loneliness – while nearly everyone is more lonely in lockdown, the forms and amounts of social time people experienced varied, with notable differences arising between ethnicities, genders, and between carers and people with dementia. With respect to the situation during September-October 2020, only one of the five White carers reported a decrease in social time compared to before lockdown, but nine of 11 BAME⁶ carers did. Similarly, while 44% of all carers reported having fewer in-depth conversations during the pandemic, this included none of the White carers. Specific data

on modes of communication was not collected for carers, but this data supports the hypothesis below, that IT access and/or skills tend to be more of a barrier to socialising for BAME people in Merton.

For people with dementia, 77% of them reported having fewer in-depth conversations, about equally in White, Black and Asian homes. Yet when it comes to online socialising, BAME people with dementia fare much worse. All of the people with dementia who said they socialise more than once a week online were White (four). One possible explanation for the discrepancy between online socialising without a discrepancy in meaningful conversation is that Asian households in Merton tend

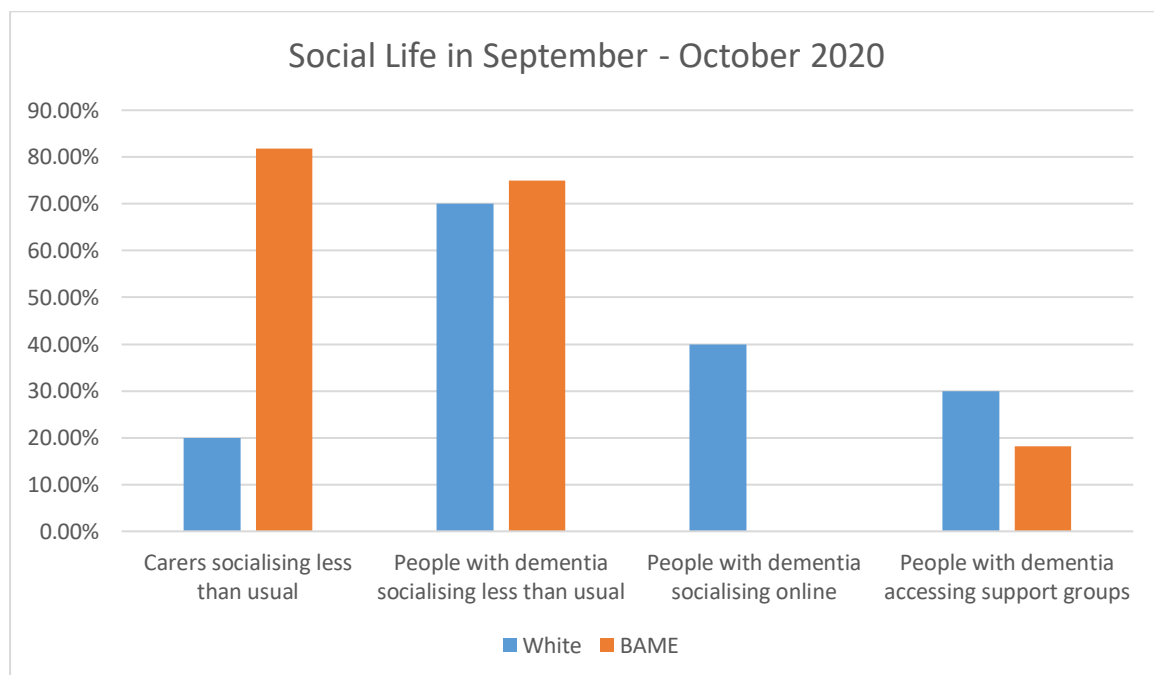
⁴ That study reported that 23% of people with dementia living with others reported feeling lonelier during lockdown, rising to 56% among people with dementia living alone. *Worst Hit: Dementia During Coronavirus* Alzheimer's Society, 2020, p. 27.

⁵ 'The Impact of Covid-19 on People Affected by Dementia' (an earlier summary of the *Worst Hit* study data), Alzheimer's Society, July 2020, p. 26.

⁶ In this study, the acronym 'BAME' stands for Black, Asian, Minority Ethnic.

to have more occupants, so there is more possibility for meaningful conversation within the home.⁷ Nonetheless, all people with dementia need to be able to access support services, the majority of which have moved online, and those from BAME homes are less likely to be accessing them during lockdown (18% as compared to 30% of White people with dementia).

Putting this all together, both carers and people with dementia are facing increased loneliness, and IT skills/access are a contributing factor to this, particularly among Merton’s BAME population. Further, while larger households might be mitigating the extent to which the pandemic is resulting in decreased social time for BAME people with dementia (resulting in similar rates of socialising to White people with dementia despite the difference in access to technology), they nonetheless are less likely to be accessing their usual support services. Inasmuch as the small sample size warrants any conclusions, the data consistently shows both that access to technology and/or IT skills are a major barrier to accessing support needed during the pandemic, and that this barrier needs to be considered in relation to Merton’s ethnic and socio-economic divides.



4. Symptoms of Dementia

Another challenge is the relationship between the pandemic and the actual symptoms of dementia, with the pandemic (and probably isolation in specific) causing many people with dementia to experience their symptoms worsening at a faster rate than might have otherwise been anticipated. Among people living with dementia in the wider Alzheimer’s

“My husband has deteriorated a great deal. Before lockdown he would make his own way [to places] by foot and bus, which gave me a break each day. Since lockdown he has forgotten his routines, lost confidence, become depressed, does not communicate and has no interest in leaving the house.”
 - A carer in Merton

⁷ The 2006 study ‘Ethnic Minority Communities in Merton Research Report’ by Merton Council reported that ‘All Asian residents have higher than average levels of overcrowding’ (p. 38), and this has not changed in more recent census data. Overcrowding should not be regarded as a positive, but the prevalence of larger households would explain the lower prevalence of loneliness among Asian people with dementia.

Society study, 47% report increased memory loss, 48% report increased difficulty concentrating and 45% report increased agitation/restlessness.⁸ For those living on their own, 54% report increasing memory loss. In Merton, one charity worker noted that her client's hallucinations and anxiety seem to have become much worse while socially isolating. In that case these issues were compounded by an awareness that something terrible existed outside of the house, without comprehension of what that thing is. In line with this, 86% of the carers in Merton who were asked about the person with dementia's symptoms responded that they believe them to be deteriorating more rapidly during the pandemic. Consequently, *any services being designed to support people with dementia to combat the effects of isolation should be regarded with the urgency of a medical intervention, as a matter of public health rather than recreation.* Lastly, the symptoms of dementia are relevant to pandemic response in that 82% of people with dementia in Merton said that they struggled to remember new restrictions in place, like wearing a mask or social distancing. This should impact how restrictions are put in place, and awareness must be spread that people with dementia might still be capable of doing things independently (like shopping), but *might need assistance or gentle reminders in doing so.*

5. Public Services

There are some bright sides when it comes to access to support services during the pandemic. One recipient of Alzheimer's Society's remote support services commented that 'They help to make me feel connected, part of the world. I often wake up feeling depressed, and [the Alzheimer's Society Dementia Support Worker] cheers me up. I don't feel down anymore after I've talked to her. I really look forward to her calls.' While the barriers discussed above are real and vary between ethnicities, overall 75% of carers said that they had been able to find a way to continue with previous support groups – so, at the very least, moving support online and to the telephone can be successful when IT skills and access are in place. However, this 75% falls to just 25% for people with dementia. This suggests that people with dementia need not just to be offered remote support services, but also to be offered training in IT skills, since they are likely to have the same access to technology as carers, but perhaps are not being offered support in learning to use IT, or the assistance they need to use it.

Questions were asked about the support being given to access information about care provision, and about amounts of social care provision during the pandemic. The responses here were encouraging, with 81% of people with dementia saying that they are provided with enough care support information (with the remaining 19% a mix of those dissatisfied and those with no opinion).

"The bi-weekly Carers Group delivered by the Alzheimer's Society has been a godsend, just being able to connect with other carers and the Alzheimer's Society team member regularly has made a huge difference to my own emotional and mental health."

- A carer in Merton

Only 25% were dissatisfied with organisations that help them to access care.⁹ While these numbers do leave room for improvement, they compare favourably with nationwide data.¹⁰ Likewise, there were a few cases of dissatisfaction with communication during hospitalisation that arose in the case study work, but these

⁸ *Worst Hit: Dementia During Coronavirus* Alzheimer's Society, 2020, p. 28.

⁹ This question was kept open, so could be referring to information support, social services or social care provision.

¹⁰ Nearly half of those who receive a care and support package have had this reduced or stopped since lockdown began. *Worst Hit: Dementia During Coronavirus* Alzheimer's Society, 2020, p. 35.

referred to situations that arose very early in the pandemic, and these issues did not appear widely in the later survey work, which reported only three of 16 carers having had difficulties with communication during hospitalisation (which were also cases from earlier on in the pandemic). Less positively, seven of eight carers who were doing grocery shopping online found it difficult, as did one of two people with dementia doing grocery shopping online. This is another reason why working to increase IT skills should form a part of pandemic response.

6. Conclusions and Recommendations

In conclusion, while many of the findings are quite positive (available services, access to care and information, and a decrease in complaints about hospital communication), some recommendations can still be made on the basis of this study.

- The main concern reported is loneliness, which has knock-on effects for accelerating deterioration and increasing the amount of support and healthcare needed, also making it more difficult to access support. Services that combat loneliness during the pandemic should be of high priority. Loneliness of both the person with dementia and carer must be considered.
- More regular medical check-ups could be needed as deterioration accelerates, or more awareness on the part of all support workers to advise seeking advice from the GP whenever noticeable deterioration or new symptoms occur.
- Remote support, such as online groups and phone support, are proving effective when they are able to be accessed.
- The main barriers to accessing these services that reduce loneliness are access to IT skills and the technology itself, both of which vary between carers and people with dementia, and those of different ethnicities and means.
- Two approaches for increasing the amount of people with dementia who have the skills to access support services remotely could be: (1) training could be offered to help them to learn IT skills and/or re-learn the skills they might have lost; and (2) carers could be specifically encouraged not to presume that those they support are not capable of using IT, and instead to offer to support and encourage them to use it.
- Technology could be made available to people with dementia and/or carers who would access support if they had the means.
- Specific support is needed in accessing groceries, either in the form of providing groceries or assisting people in ordering them online. Providing training in IT skills could have the knock-on effect of helping with this issue as well.
- Carer support is even more necessary now than usual, when they are perhaps isolated with the people for whom they care. Carer support must be sufficient, and linked to the priority outcomes of the Carer Strategy.
- Measures put in place by local authorities or other institutions should include consideration of people with dementia who might have difficulty remembering new restrictions, and so might either need reminding or some sort of exception. One approach might be for the form of the restrictions themselves to be made more dementia-friendly, if there is a way to put them in place that does not depend upon memory. Often the most dementia-friendly solutions require intentional creativity, rather than the removal of independence.
- Although it seems to be the case that Merton is doing well in providing care and information when compared with nationwide figures, care must be taken that information is provided widely and effectively, through means that do not depend upon technology or on skills not universally possessed.