The impact of COVID-19 and lockdown restrictions on people affected by dementia

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Table of Contents

Summary

Almost one million people in the UK are living with dementia, and the majority of these are over the age of 65 years and living with other health conditions. Whilst living with dementia at any time brings challenges for the person with dementia and those around them, the temporary cessation of social care and support services can have a considerable and detrimental effect on their daily lives and physical and mental wellbeing. We carried out a survey and follow up qualitative interviews to understand the impact of the COVID-19 pandemic and restrictions and people's experiences of accessing support provided by Alzheimer's and Dementia Support services during this period. A total of 46 people took part in the survey (6 people with dementia and 40 carers). Six carers took part in follow-up interviews. The key findings address three broad questions as follows:

1. How have people with lived experience of dementia been affected by the pandemic?

Daily living:

There was an impact of the restrictions on daily living.

- 98% of people felt that the pandemic and coronavirus restrictions had an impact on their daily routines.
- This seemed to mostly be in relation to their contact and connection with other people and the increased pressure upon carers. Practical tasks around the home seemed to be less of an issue with the exception of food shopping.

Access to health and social care:

There were also concerns and worries about accessing a range of services.

- 43% of people were worried about accessing their GP and other NHS services.
- Carers in particular (45%) were worried about access to GP/NHS services.
- People reported difficulties with navigating the services and feeling unhappy about remote contact with health professionals. Some talked about feeling abandoned.
- 20% of people were worried about accessing social care and support and 48% reported that their care arrangements had changed.
- Several people told us that they had reduced their contact with paid carers because of fears of catching the virus.

Physical and mental wellbeing:

Unsurprisingly, there has been an impact on mental wellbeing.

- 57% of people told us that they had been worried about their mental wellbeing.

- 63% reported that there had been a negative effect of the pandemic and restrictions on their wellbeing.

- The ONS life satisfaction measure show that respondents' wellbeing score of 5.70 was worse than general population score of 7.13.

- 93% of people said they experienced a level of isolation from others.

- Feelings of isolation, changes in daily routine and in particular contact with others and fears about the uncertainty of the future can be linked to worries about mental health and poor life satisfaction scores.

2. What did people do to help them cope with the lockdown?

- People have adapted and developed different ways of coping. People are 'getting on with it' and 'adapting their daily lives'.

- Staying connected is crucial with 91% saying that they stayed in touch with family and friends mostly by telephone (89%) and/or video calling (72%).

- Keeping busy by being physically and mentally active in home-based activities which do not require going outside were also important for this group with more than half saying that they did this.

- 83% of people told us they had been accessing ADSS support with 54% using ADSS activity packs to keep them mentally active at home.

- The majority of people were very positive about the support received from ADSS and 94% felt that it had made their lives better given the circumstances, although there was a preference for face to face support.

3. What are people's feelings about the future and how have these been shaped by the pandemic?

- There was a general concern for the future, particularly the winter period, and a sense of unease/uncertainty about what that would bring with it although there was a level of acceptance of and adaptation to the situation.

Conclusions

Our research has demonstrated that the COVID-19 pandemic and the implementation of 'lockdown' has had a wide-ranging impact on people affected by dementia resulting in many people experiencing worries and difficulties with accessing health and social care, concerns over mental wellbeing, poor life satisfaction and feelings of isolation and abandonment. The reconfiguration of

ADSS services and continuation of home-based support in this context has proved to be vital and beneficial for existing service users although some need support to carry out practical tasks such as shopping. The combined use of both non-traditional methods and traditional methods including virtual social groups to help people stay connected, activity packs to keep them stimulated and telephone support providing information and reassurance has been beneficial those who have been able to access it. However it is important to recognise that online and virtual access to health and social care is not ideal for everyone and that more support is needed to help people affected by dementia to navigate these services or some adaptations to online support need to be made to help people join in and feel included as future lockdowns come into place. The findings from this research indicate that nothing can replace the beneficial effects of face to face service provision and therefore it is important for ADSS to further modify services to ensure that face to face social interaction is offered in a safe way and that virtual services continue during a potential second wave of the virus and social restrictions.

Background

Around 850,000 people in the UK are living with dementia, and the majority of these are over the age 65 and living with other health conditions.[1] The COVID-19 pandemic has caused disruption to all aspects of life as measures aimed at slowing the spread of the virus have interrupted normal ways of living. Whilst living with dementia at any time brings challenges for the person with dementia and those around them, measures aimed at slowing down the spread of the virus can have a considerable effect on their daily lives and physical and mental wellbeing. People living with dementia and their carers are often heavily reliant on accessing face to face support including attending groups and participating in activities in the community to help them stay socially active and get the support that health care services cannot provide. However, during the pandemic there has been a temporary cessation of face to face support services leaving gaps in support and care.[2,3] In this context, there is an urgent need to understand and address the impact of the COVID 19 lockdown restrictions on those affected by dementia.

Alzheimer's and Dementia Support Services (ADSS) are Kent's biggest independent charity dedicated to providing support to people affected by dementia. Working within the Dartford, Gravesham and Swanley area since 1991, ADSS have been providing face to face and telephone care and social support to people affected by dementia. During the height of the first wave of the pandemic ADSS temporarily reconfigured services to support people affected by dementia remotely by providing virtual and telephone support. This report describes the findings from research undertaken by ADSS between May and September 2020 looking at the impact of the lockdown on those with lived experience of dementia and their experiences of accessing support.

Aims of the research

The research aimed to answer three broad questions:

1. How have people with lived experience of dementia been affected by the pandemic?

2. What did people do to help them cope with the lockdown?

3. What are people's feelings about the future and how have these been shaped by the pandemic?

How did we gather people's views?

To explore these questions in detail we conducted:

- A survey of those affected by dementia (either a person with dementia or a carer or relative) promoted on the ADSS website and social media channels and through contact with people affected by dementia during welfare calls, emails and when providing information about virtual support groups. In total, 46 people (6 people with dementia and

40 carers or relatives of those with dementia) gave us their views by completing a 10-minute online/telephone survey on life during lockdown and their experiences of using reconfigured services provided by ADSS.

- A qualitative study comprising telephone interviews with a purposive sample of people who had completed the survey (to include both people with dementia and carers or relatives) and agreed to participate in a telephone interview to explore further their experiences of life during lockdown and their feelings about the future. In total 12 people agreed to be followed up although only six eventually took part in the 30-minute telephone interviews.

This report is a synthesis of both these strands of work.

Who took part in our research?

Of the 46 people who responded to our survey, six (13%) were people with dementia and 40 (87%) were carers. Most of our sample (80%, n37) were over the age of 60 years, female (70%, n32) and all described themselves as being of White background. The majority (96%, n43) lived with someone e.g. a relative or carer and two people lived alone (one of whom had caring responsibilities for a relative with dementia and one was a person with dementia). At the time of the survey, just over three quarters (78%, n35) were either staying at home and only going out for essential shopping and exercise or going out but following social distancing rules. Around 15%, (n7) were self-isolating, 5% (n2) were key workers and continuing their jobs normally.

Interpreting the findings

The turnaround of implementing this research has led to some limitations. Respondents to the survey were self-selecting and most (99%) had the means to complete it online. This means that the views of individuals who are digitally excluded and who are not connected to the ADSS support network and therefore may have been socially vulnerable may not have been captured. Therefore, the results may not be representative of the wider population of people affected by dementia. The survey and follow up interviews also capture a moment in time several months after the lockdown started and during the phase in which some restrictions were being lifted therefore people's concerns and priorities may have been different compared with the early weeks of the lockdown. The sample size particularly relating to those with dementia was small and therefore we need to exercise caution when interpreting differences between those who had dementia and carers

What did people tell us?

How have people with lived experience of dementia been affected by the pandemic?

In our survey, we wanted to understand what effect COVID-19 and the pandemic had on the lives of those affected by dementia and whether they had any concerns or worries about different aspects of life. Using survey data including open-ended responses and interview data we grouped our findings into four key areas.

- Access to information about COVID-19
- Daily living
- Access to health and social care
- Physical and mental wellbeing

Access to information about COVID-19 and the pandemic

We wanted to know where people accessed information about COVID-19 and the restrictions and how easy it was to obtain accurate and understandable information. Whilst most people (87%, n40) obtained information about the pandemic and coronavirus by watching the news on the TV, **14% (n6) struggled to obtain accurate and understandable information about the virus and lockdown restrictions**.

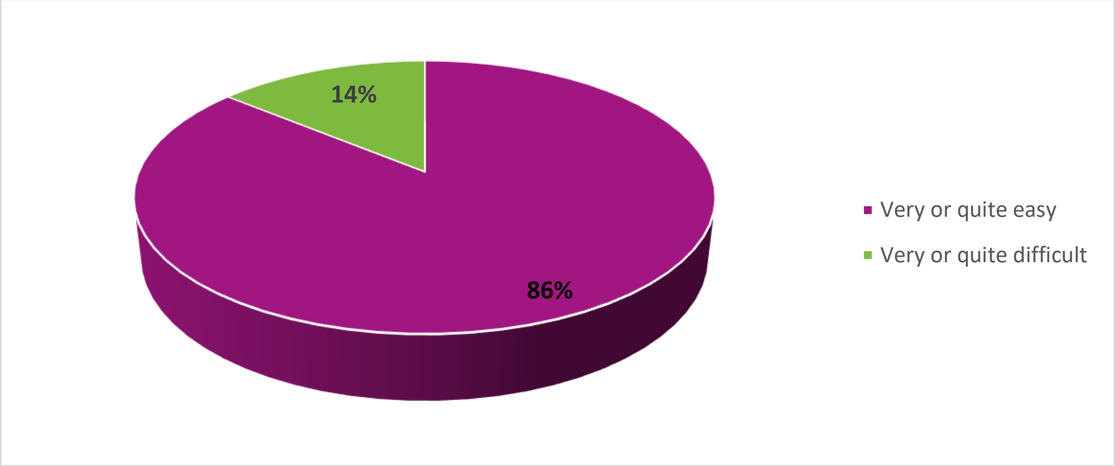

Figure 1 Ease of access to information

Daily living

We asked people how much COVID-19 had changed their daily routines. Overall, the majority **98% (n45) of people felt that the pandemic and coronavirus restrictions had an impact on their daily routines** (Figure 2). All six people with dementia and 39 carers felt this way.

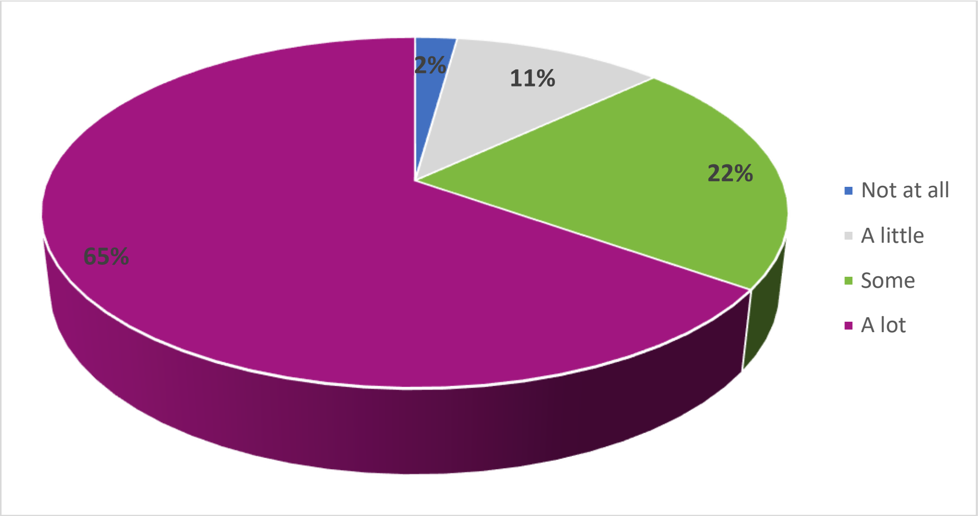

Figure 2 Impact of COVID-19 on daily routines

During interviews, several carers described how they missed taking part in structured face to face social groups, functions, and activities that they had attended prior to lockdown (including dementia support groups). They felt that these restrictions had a profound effect on their caring responsibilities and noticeable effects on the partners they cared for including a loss of independence and a deterioration of symptoms.

"I have had to take on more of the caring role because things like Day Centres everything stopped as soon as the COVID came into force, which involved me doing much more for my husband than I would normally have done and didn't give me a break. This has got more difficult for me, also my husband had a relapse during the COVID which meant he is now bed bound and he wasn't at the beginning" **(Wife and Carer)**

"He [husband] is led by me as he has lost his independence that is quite hard to do anything about. If things were the same, we would have popped into [name of place] met a few friends, but things are by appointment now." **(Wife and Carer)**

There were reported positives in terms of how the experience of lockdown had affected daily life. With normal routines suspended some carers/relatives who were balancing care responsibilities with work commitments felt that restrictions had given them time to focus on themselves and spend more time caring for family members who had dementia.

"To be honest, it's quite strange for me to say this but it has changed my life, I do not have to go into [city name] anymore, when I do start back [at work] I will not be going in every day. It will be very flexible, once a week. So, it has changed my life dramatically, yes, in a good way. I have more time to myself. I haven't stopped going to mum's, I go there all the time, I do her washing her housework and feed her when the carers do not have time." **(Daughter and Carer)**

For a minority of people lockdown restrictions did not make a big difference to their daily lives. One wife and carer described how her life was already limited in relation to care of her partner with dementia and that this did not worsen or change this during lockdown.

"When we first went into lockdown of course [name of husband], who has Alzheimer's, it didn`t make our life very different. I was able to leave the house to shop, so I just did that once a week and we have a gate across a courtyard so I could leave [husband's name]. He was never really put in a position or situation because I knew he couldn't come shopping with me anyway. Our life wasn't really very different." (**Wife and Carer)**

We also asked people to tell us if they had any worries about carrying out a range of practical tasks during the lockdown. Respondents were able to tick all the responses that were applicable to them, so they gave more than one response. **Half of respondents (50%, n23)** mostly carers (n21) and two people with dementia (n2) reported that they **did not have any worries** about carrying out any of the practical tasks listed.

Just under a third **(31%, n14) were worried about shopping for food**. A smaller proportion of people were worried about things done around the home for example repairs (22%, n10) and paying household bills (2%, n1). Concerns about shopping for food was a particular worry for respondents who had dementia (50%, n3) compared with carers (27%, n11).

During interviews, people told us about the help and support they received to carry out practical tasks for example being on the priority list for shopping deliveries, and or the help and support of neighbours and volunteers.

"The important thing for me was mainly we were able to get all our food delivered and everything else. We were a priority. There was no worries as to getting medicine to ourselves from volunteers." **(Husband and Carer)**

"We've not done too badly and have managed OK we have good neighbours too who help out as they can." (**Husband and Carer)**

Access to health and social care

We asked respondents if they were worried about accessing health and social care during the pandemic and explored this further during individual telephone interviews. Respondents were able to provide more than one answer when presented with the options, so the responses are not mutually exclusive. Six people (13%) reported that they did not have any worries or concerns about access to health. Just under half **(43%, n20) of respondents were worried about accessing GP and**

other NHS services, although getting medication proved to be less of a concern with only 9% of people indicating that they had been worried about this. (Figure 3). **Access to GP care and other NHS was a particular concern for carers (45%, n18) compared with those living with dementia (33%, n2).**

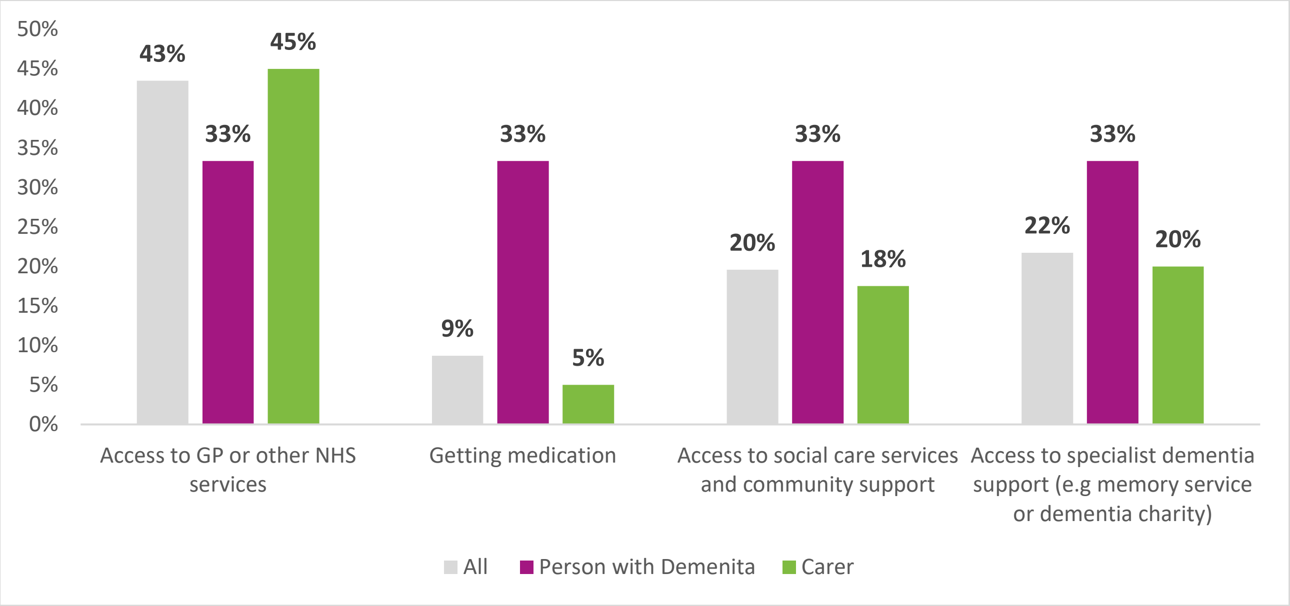

Figure 3 Worries about access to health and social care

During interviews carers described the impact of not being able to access physical or online face to face virtual appointments.

> *"I have found hospital appointments have been a bit weird in COVID, [Husband's name] has Parkinson's and the follow up was a telephone call, I did express could you not do this by 'Zoom' , it did work out OK, but in a 'Zoom' call she [the doctor] would have been able to see how [Husband's name] is."* **(Wife and carer)**

Difficulties accessing GP services during the pandemic also increased anxiety and left some carers feeling abandoned to cope alone. One woman who sadly lost her husband during the lockdown reconciled the reasons for her husband's breathing difficulties on the weather in the absence of medical advice.

> *"The thing I was unhappy about was when [Husband's name] was obviously, his breathing wasn't right and I didn't know if that was part of the Alzheimer's or if it was something else effecting him, trying to get hold of a doctor, it was like asking to see the queen you know. It was ridiculous it really annoyed me. It was so hard to access support, from a GP or anybody in the medical profession Nobody was there to talk to about the clinical stuff. When you've got Alzheimer's apart from an organisation like yours you are pretty much on your own, when it comes to the NHS they have pretty much written you off. My husband kept assuring me he was in no pain and so we just kept going, for the very short time he*

> *was unwell. I suppose but that was when it was really really hot and anyone over 60 was walking around as if they was on their last legs. It was difficult, I then just put his shortage of breath down to heat."* **(Wife and Carer)**

One in five (20%, n9) also reported that they had been worried about accessing social care and community support (Figure 3). At the time of conducting this survey 29 people were accessing care at home. **Just under half (48%, n14) reported that their usual care arrangements had changed** during this period.

Open-ended comments from the survey indicated that for some care arrangements changed significantly from a relative being moved out of hospital after a fall into a care home, the cessation of care and respite visits and the reliability of care visits. Some respondents voluntarily reduced care visits as they were worried about how visits might expose them to the risks of catching the virus and the possible ramifications for those they cared for.

> *"I reduced the time that the carer comes in so that he [the carer] can visit other people who are worse than my husband and also to reduce the amount of time he is exposed to other people."* **(Wife and Carer)**
>
> *"I am not having anyone coming to my home because of the effect of coronavirus and how it might affect my husband if he were to catch it. Also, who would look after my husband if I were to catch it."* **(Wife and Carer)**

During interviews with survey respondents which took place during July and August 2020 there was indication that some care services had resumed and in one case increased due to the deterioration in health of a person with dementia.

> *"We do have regular carers (different company) twice a day to help her with washing and getting dressed in the morning and then again in the evening to help her get ready for bed. There was a small break in them coming when it looked like she might have COVID and would not come until proved clear of it. A paramedic came and said it was OK and that she [Wife's name] had a urine infection and gave some antibiotics we did feel a bit out on a limb while that was going on but the carers came back and we've just got on with it."* **(Husband and Carer)**
>
> *My husband had a relapse during the COVID which meant he is now bed bound and he wasn't at the beginning, so I have had to increase the care I receive to three times a day, where it was only once a day before then.* **(Wife and Carer)**

Additionally, **22% (n10) reported that they had been worried about access to specialist dementia support** for example a memory clinic or support from a dementia charity. Open-ended comments indicated that people were unhappy about the cessation of face to face dementia support groups and services which was exacerbated with not being able to meet with family and friends.

Physical health and wellbeing

We also asked people to tell us if they had any worries about their physical health and mental wellbeing. This included concerns about catching COVID-19 (Figure 4). Respondents were able to tick all the responses that were applicable to them, so they gave more than one response. Seven people indicated that they did not have any worries about the items listed. However, **more than half of respondents (57%, n26)** reported that they **had been worried about their mental wellbeing** compared with only 37% (n17) who had been worried about their physical health. A slightly higher proportion of people with dementia had been worried about this (67%, n4) compared with carers (55%, n22).

Around two thirds (65%, n30) reported that they had been worried about catching coronavirus with a similar proportion (67%, n31) expressing concern about others they knew catching it. (Figure 4)

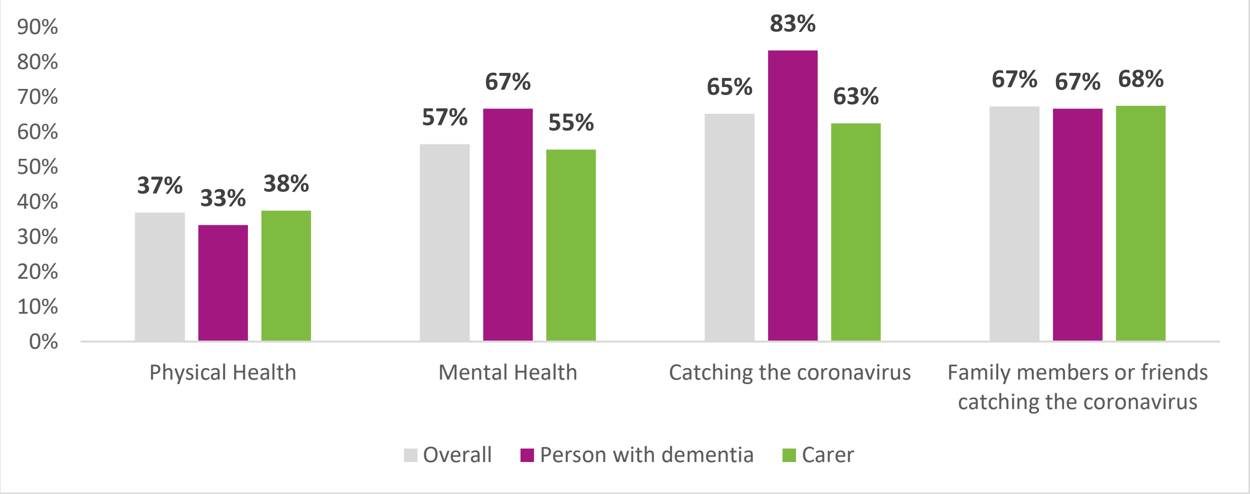

Figure 4 Worries about physical health and mental wellbeing

We asked people about their views on their own individual wellbeing using the first question from the Office for National Statistics subjective wellbeing questionnaire. [4] This provides us with a valid and reliable indicator of overall feelings of wellbeing. People were asked to tell us how satisfied they are with life nowadays on a scale from 0 to 10, where 0 is not at all and 10 is completely. Their scores were then grouped into low, medium, high and very high ratings of life satisfaction.

Overall, **just under two thirds of respondents (63%, n29) reported that the pandemic had a negative effect on their wellbeing** during the first wave of the pandemic and lockdown restrictions. This included 26% (n12) reporting low levels of satisfaction with life and 37% (n17) reporting medium levels of satisfaction with life (Figure 5). **A higher proportion of people with dementia (53%, n4) felt less satisfied with life compared with carers (47%, n25).**

The average score for all those who responded (n46) was 5.70. Although we would expect the scores to be lower in this population of respondents, it is quite a bit lower than the average score of 7.13 reported by the ONS for the general population in June 2020.[4]

It is important to note that we asked respondents this question at one point in time, so it is not possible to say whether their scores are better or worse than pre-pandemic.

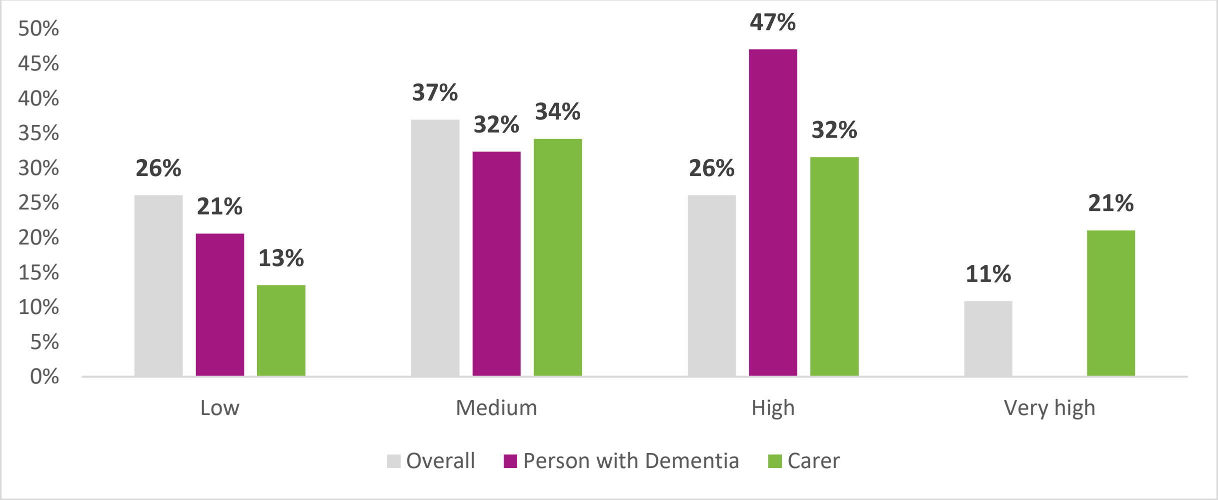

Figure 5 Life satisfaction

During telephone interviews people described the detrimental effect of the pandemic and lockdown on mental wellbeing both for themselves and those they cared for. There were noticeable differences in the health and wellbeing of those cared for relatives with dementia as a result of not being able to get out and interact with others via social and support groups.

> *"It has had a detrimental effect on my husband because he has not been able to get out and see other people because the day centre was shut, the carers support group, we would have been going out in the car to perhaps have something to eat or a coffee, just to break the monotony of being indoors really. If the lockdown had not have happened more people would have been coming into see him, giving him a bit of stimulation. It's not being able to see anyone else that's been the problem for him."* **(Wife and Carer)**

Although for some coping with day to day living seemed manageable, the impact on mood was more profound particularly in the context of fears about the pandemic worsening.

> *"The difficulty for me was coping with what is happening really. It hasn't been a difficult exercise from a day to day thing except for sometimes, the situation does get worse, you know. I've felt sad, very sad."* **(Husband and Carer)**

We also asked people how much they felt isolated from others during the first wave of the pandemic and lockdown restrictions. **Most people (93%, n43) reported that they had experienced some degree of isolation. All people with dementia and 92% (n37) of carers felt this way** (Figure 6). Although these feelings seemed to have been mitigated by access to virtual support and the easing of lockdown restrictions during the summer.

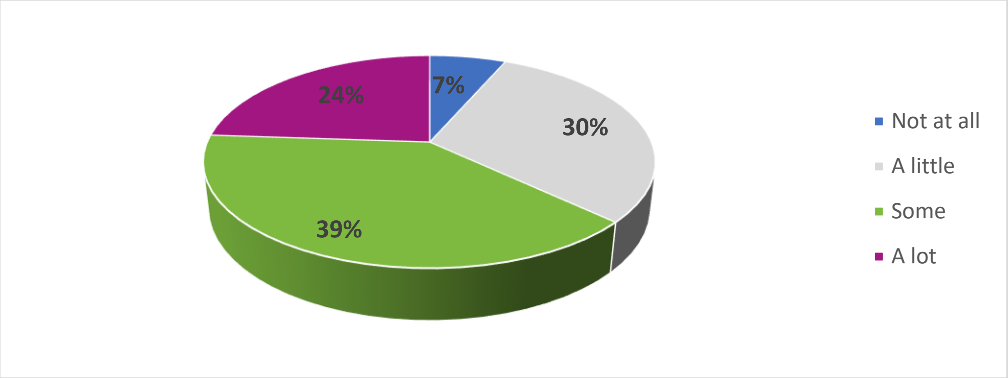

Figure 6 Feelings of isolation

Isolation was also a key theme arising during telephone interviews. Feelings of being cut off from usual activities and separated from close family added focus on the impact of the lockdown on mental wellbeing. People felt their lives had stopped particularly during the early days of lockdown often leading to a sense of abandonment.

> *"I just think my life has sort of come to a stop at the moment, we was very sociable people, going out for meals and things like that. Even if it was just for fish and chips on a Friday evening, they all loved him*[husband] *up there they thought he was wonderful. I don`t know really, well when the kids [grandchildren] were at school often my niece would ask can you have the children, but they were obviously now at home with them because they was working from home. So that meant we didn't see them so often or we didn't see them at all really."* **(Wife and Carer)**
>
> *"Initially I felt when the lockdown came about first of all and everything stopped I felt very alone and sort of deserted by everyone really. It just stopped so suddenly, but gradually we have had support from ADSS, they have been phoning up regularly asking how we are and if there was anything that they could do, and things like that. It does make me feel I haven't been forgotten."* **(Wife and Carer)**

What did people do to help them cope with the lockdown?

In addition to seeking to understand people's concerns during the COVID-19 pandemic and the impact on them, we asked people to describe anything that they had been doing to help their wellbeing and mental health.

Staying connected

People described how keeping in regular contact with friends and family, often by telephone or video calls, was key in coping with the effects of the lockdown on their wellbeing. **Most people (91%, n42) reported that they stayed in touch with family and friends** (Figure 7). **The most popular method to stay in touch with others was by speaking on the telephone (89%, 41))** followed by using Skype or Zoom (72%, n33) and face to face (37%, n17). **Just over three quarters**

(76%, n35) said that they found this easy to keep in touch with family members or neighbours. A slightly smaller proportion (72%, n33) said it was easy to keep in touch with friends.

Keeping busy

Keeping busy through participation in a range of other activities also helped people to cope. This included keeping busy at home by doing physical activity and/or doing arts and crafts, puzzles, listening to music or reading and watching TV (Figure 7).

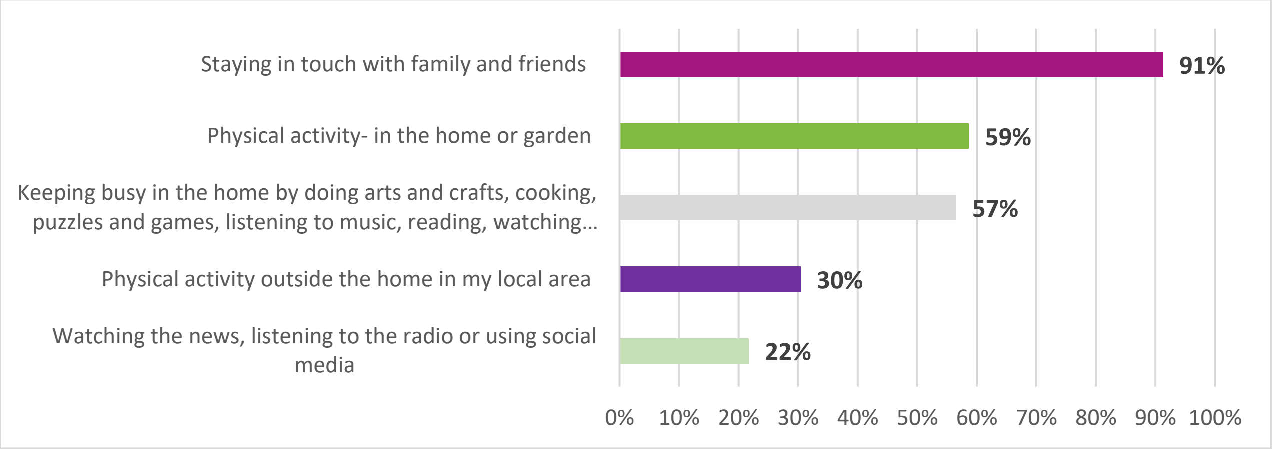

Figure 7 Coping methods during the pandemic

Accessing ADSS support services

Around 83%, (n38) told us they had also been accessing support provided by ADSS during the COVID-19 pandemic and lockdown restrictions. The use of activity packs sent out by ADSS to service users was the most popular service accessed by just over half of people (54%, n25). Other popular methods of accessing support included participation in virtual groups for example 'Singing Back the Memories' by 48% (n22) of people and support via welfare phone calls (30%, n14).

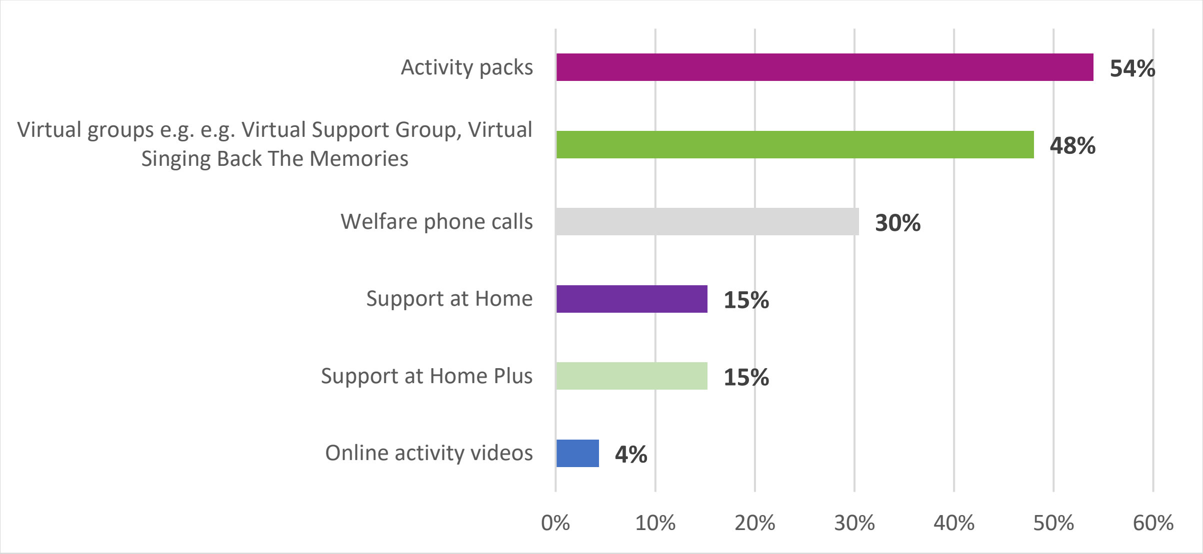

Figure 8 ADSS services accessed

Experiences of ADSS support services

More than three quarters of people (94%, n30) reported that access to ADSS services had made their life better.

Open ended comments from the survey and telephone interviews indicated that people were grateful for ADSS support provided virtually or through activity packs sent to them which helped them stay socially connected with people in the same situation, supported mental stimulation and reassured them that they had not been forgotten.

"People are approachable and come back to you. I'm full of praise as I would have felt very alone if ADSS hadn't thought outside the box thinking how we can still engage with people." **(Wife and Carer)**

"Appreciated the welfare calls as its reassuring to know that people are there caring about your welfare." **(Wife and Carer)**

"Singing group and virtual groups and activity packs have made a big difference in keeping my husband stimulated." **(Wife and Carer)**

"The virtual memory café had been very enjoyable and helped to give the week some structure. The activity packs have helped to while away a few hours and keep our brains active. It is also nice to get the occasional phone call, so we feel we have not been forgotten." **(Wife and carer)**

I am grateful for [support worker's name] calls. Don't feel quite so isolated." **(Wife and Carer)**

*"They brighten our days and we feel part of a group, we feel less isolated." (***Person with dementia)**

"I have enjoyed the zoom links with the local carers support group which has helped me to feel connected with others in the same situation." **(Wife and Carer)**

Although some people found the engagement with virtual services more challenging and preferred groups to be smaller or have some focus for discussion making it easier to manage for people with dementia. There was also a preference for face to face support.

"I feel that zoom meetings with a smaller group of participants with a common focus e.g. something specific to talk about would have been easier. It became too large for my husband to engage in. It was difficult for [husband's name] to engage in." **(Wife and Carer)**

"It has helped a bit in that it is good to hear that people care. But it is not a substitute for face to face meetings and cafes." **(Wife and Carer)**

"My husband cannot and will not take part in zoom meetings and I think that applies to most of the people suffering from dementia. I appreciate the effort, but I don't find them easy." **(Wife and Carer)**

What are people's feelings about the future?

Follow-up interviews revealed general concern about the uncertainty of the future with many hobbies and plans for trips away to be put on hold for the near future. There was a strong sense that life could not go back to the way it was and there were concerns about what things would be like with the resumption of some services and moving into the winter period.

"I'm worried about what is going to happen later on when we get towards the winter period, how it's going to be coped with, during that period when we start getting into that flu side of things as well. But that's life and it's just something we are not just going to sail through. I am looking forward to the end of the COVID, so people can start relaxing. A good holiday, there is no way we would go on holiday while the situation is like this, it just not worth taking any chances so for next year for next year it's somewhere nice to go for a change". **(Wife and Carer)**

"The future isn't as mapped out as it used to be, nobody's future is certain as we do not quite know anymore. Uncertainty is in the mix which wasn't there before." (**Wife and Carer)**

There was also a level of acceptance with the situation. Comments revealed that people "just got on with it". Some talked about learning to adapt their ways of living although living with the uncertainty about the future left them with nothing to look forward to. This in turn may exacerbate feelings of low mental wellbeing and life satisfaction moving forwards. These findings resonate with those of the work of Giebel et al who also found that both carers and people living with dementia had accepted the fact that this was the new normal and were adapting their lives in light of the pandemic.[3]

"We are learning to live with it and adapting our way of living I think it's going to be with use for a long time, so I think it is going to change a lot of things. A bit apprehensive really in some ways with each new thing that's happening, the opening up of schools and things like that, and the coming of winter, where they say it might get worse again. I don't have any worries than I would normally have living with someone who has dementia. There is nothing I am looking forward to at the moment." **(Wife and Carer)**

Conclusions and key messages

Our research has demonstrated that the COVID-19 pandemic and the implementation of 'lockdown' has had a wide-ranging impact on people affected by dementia resulting in many people experiencing concerns and worries and difficulties with accessing health and social care, concerns over mental wellbeing and feelings of abandonment and isolation. The availability of social support can mediate the influence of these factors however, when planning services, the priority has to be on immediate support to ensure that people with dementia and their carers are not left without any support. The reconfiguration of ADSS services and continuation of home-based support in this context has proved to be vital and beneficial for existing service users. In particular, the combined use of both non-traditional methods and traditional methods including virtual social groups to help people stay connected, activity packs to keep them stimulated and telephone support providing information and reassurance has been beneficial to those who have been able to access it. The continuation of these services is vitally important given that we are entering a 'second wave' of cases and restrictions are being imposed in different areas. Priority should be given to support those who have worries and difficulties with practical tasks such as shopping and navigating access to virtual NHS health and social care services.

Whilst the use of non-traditional methods might reach some people it may not be feasible to shift all support to technological based solutions moving forward should a second wave occur. Not only is the lack of access to and knowledge of using technology an important impediment to engaging more broadly with those affected by dementia, there may also be impediments in supporting those with more advanced dementia who may struggle to use technology even with the assistance of their carers or relatives. ADSS services have been vital for people during this time, but online and virtual support is not ideal for everyone. There may also be a long-term detrimental effect on carers of new restrictions being imposed. The findings from this research indicate that nothing can replace the beneficial effects of face to face service provision and therefore it is important for ADSS to further modify services to ensure that face to face social interaction is offered in a safe way. As restrictions began to ease during the summer months, ADSS commenced organising outside events so that people could benefit from some face to face contact with their peers in a COVID safe way. Feedback about face to face services has reinforced findings about the beneficial effects on people affected by dementia However, in preparation for potential further restrictions and the weather changes they will resume virtual support services.

"My husband and I would like to thank you for this morning. It makes such a difference to him being with people rather than looking at a screen. Thank you for all you do to make the life better for those with dementia & for the support you give carers."

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