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**Alzheimer
Scotland**
Action on Dementia

What helped people living with dementia during the Covid-19 pandemic: A co-produced research project

SUMMARY REPORT
OF FINDINGS



ndcan
National Dementia Carers
Action Network

Background

In March 2020, in response to the Covid-19 pandemic, the UK went into lockdown. This was the start of a period of around 18 months when we lived under public health restrictions that limited our contact with people outside our own households. It meant that almost overnight, the community groups and other methods of support for people with dementia were stopped and it was a difficult time for everyone. Families who take care of someone with dementia also had a hard time because they couldn't get a break or find help easily.

The Alzheimer Scotland Hidden Impact Report (2020) gathered evidence of the impact of the pandemic and lockdown on people with living with dementia and their families. There is no doubt that for many people with dementia and family carers, the pandemic and periods of lockdown intensified challenges and their sense of isolation (Alzheimer's Society 2020). However, people living with dementia and their families came up with different ways to adapt and remain connected to friends and family during this period, as well as using technology to maintain hobbies and interests.

Through a conversation with members of the National Dementia Carers Action Network (NDCAN), the Scottish Dementia Working Group (SDWG) and the Alzheimer Scotland Centre for Policy and Practice, we identified that there are lessons to be shared about what helped people living with dementia and their families during this difficult time. As there was no research focusing on this, we decided to do it ourselves!

Our co-produced study aimed to investigate the things that made a positive difference to the lives of people affected by dementia who were living in their own homes during the pandemic. Using a consensus-building research method called Nominal Group Technique (NGT), we identified the most helpful things and made recommendations about the lessons we learned.

Research Team

Our research team was made up of 13 people who all worked as co-researchers together. There were six academic members and seven members from NDCAN and SDWG. Together we designed and completed all stages of the research project. We undertook training together to be familiar with project methods and to appreciate our respective research strengths and preferred project contributions.

Study Aim

To identify with people living with dementia and their family carers the things that helped them most through the COVID-19 pandemic.

Methods

The Nominal Group Process involves a series of steps. Participants consider a question and individually create a list of ideas in response to that question. These ideas are then shared with the group and discussed. The discussion informs the development of a short list of shared ideas. Participants individually vote on the shared idea items according to which are most important to them. Votes are added

up and the item receiving the highest number of votes is the top priority (1st ranked) for the group. The second highest scoring item is the second most important item (2nd rank) and so on. The process is undertaken in a way to ensure that everyone's opinion is heard, and group consensus achieved.

The Nominal Group Technique is an established research method involving several steps that are usually undertaken within a single group meeting known as a Nominal Group Interview.

We adapted the approach to make the group meeting less intense. We did this by sending participants the question to consider at home before we met as a group. Support was provided to help individuals with dementia to prepare a written list of up to six ideas and send to the research team in advance of the group meeting. This allowed the researchers to draft the shared short list of ideas to be discussed and refined through group discussion prior to voting. The two groups, People with Dementia Group and the Couples Group were given the choice of meeting in person or at a distance online. The people with dementia opted for an in-person meeting and the couples online. A team of trained facilitators, including people with lived experience, conducted the Nominal Group Interviews. Discussions were audio recorded to provide qualitative data and quantitative data was gathered to capture votes and generate scores also known as ranking.

Ethical approval was secured from the University of the West of Scotland School of Health and Life Sciences Ethics Committee (Reference 2022-18031-15736).

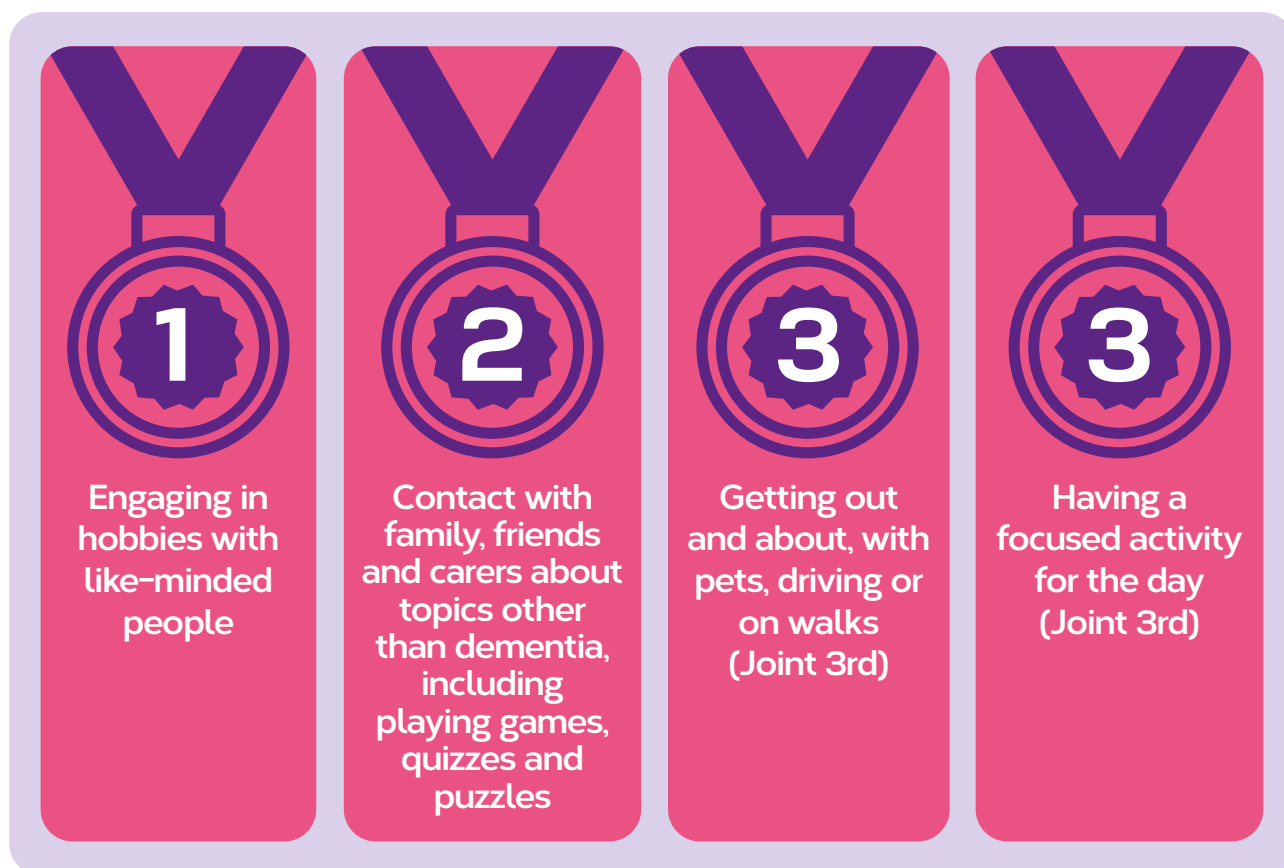
Results Group One: People with a Diagnosis

Participants were invited to prepare their own list of items in response to the question, before they met as a group. Alzheimer Scotland staff provided support as appropriate. Ideas were shared at the in-person meeting and discussed. Then the group developed a short list of eight items:

- 1 Engaging in hobbies with like-minded people
- 2 Contact with family, friends and carers about topics other than dementia
- 3 Playing games, quizzes and puzzles
- 4 Watching TV
- 5 Support and communication from SDWG
- 6 Getting out and about, with pets, driving or on walks
- 7 Technology supporting communication and activities
- 8 Having a focused activity for the day

Participants voted for the items they thought most important, using sticky dots on a flip chart. The results of their voting identified four important items rather than three. This was because two items received the same number of votes putting them in joint third place. As shown in Table 1, the 1st ranked item with the highest number of votes was 'Engaging in hobbies with like-minded people'. The 2nd ranked item was about contact with and activities undertaken with family, friends and carers. The two equal 3rd ranked items were about getting out and about, and having a focus for the day.

Table 1. Most Helpful Things Identified by People with Dementia

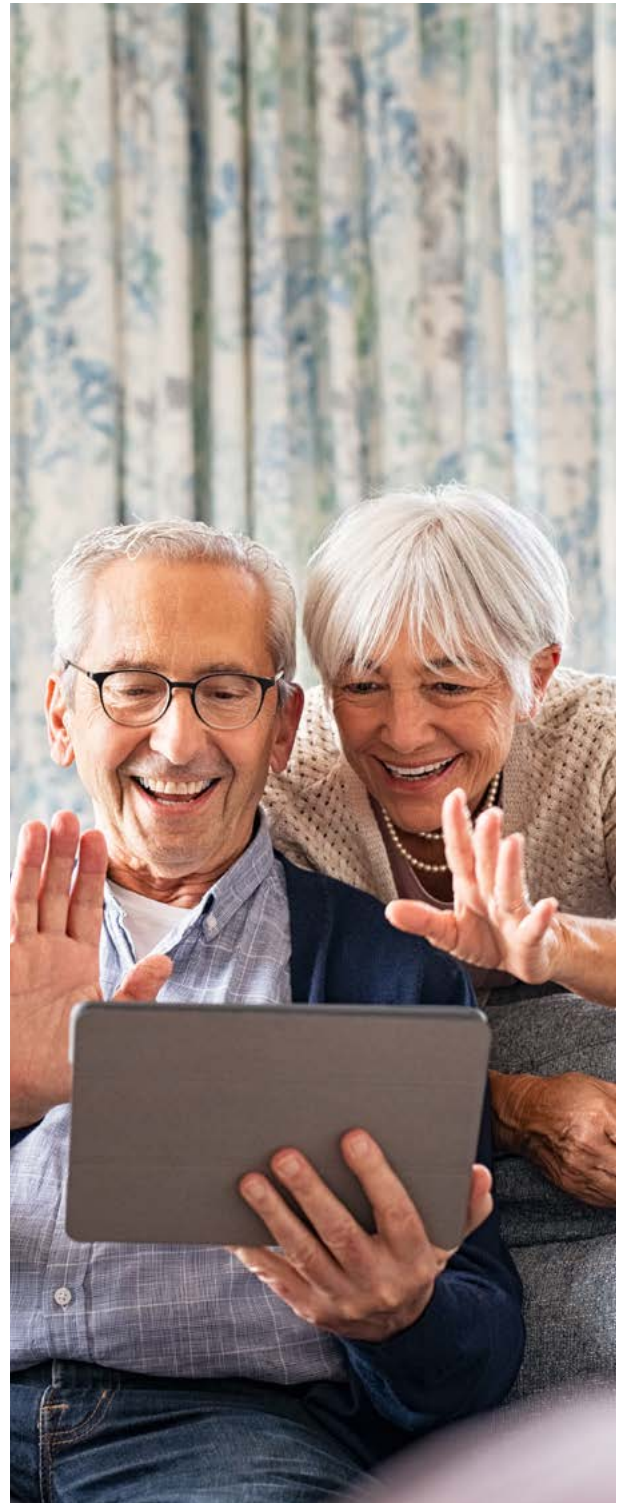


The top three items selected by the group highlighted the importance of engaging in hobbies with like-minded people, and maintaining contact with family, friends and carers about topics other than dementia. Participants gave some examples of the type of things they would do with family and friends online and on the phone. It was important to the participants that they stressed that although a lot of communication was supported by technology, other methods of connecting and communicating with others also helped them. The group expressed concern for people with dementia who were not able to use technology to connect with others during the pandemic.

Results Group Two: Couples

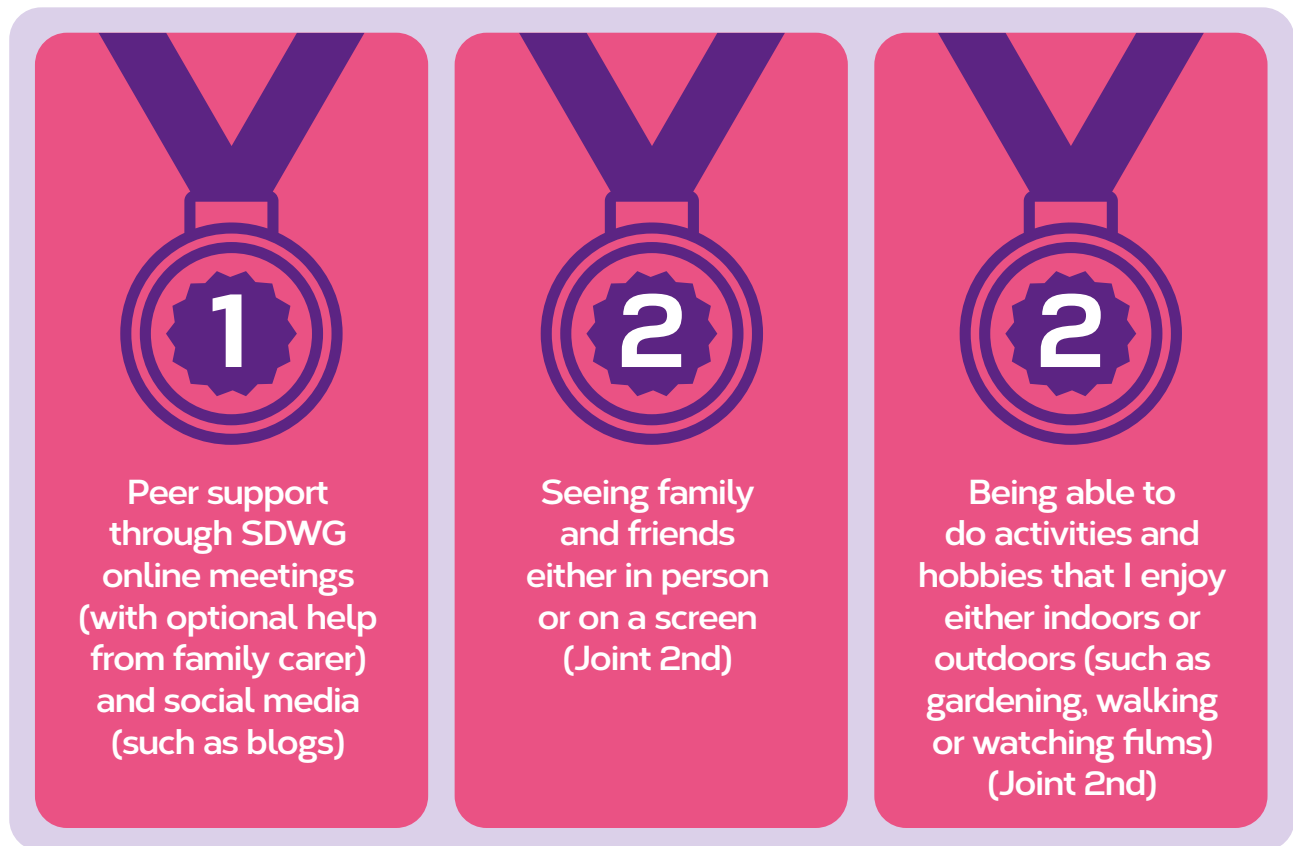
The group meeting was facilitated online via Teams. Shortlisting was undertaken prior to the online meeting. Couples considered the question together and emailed their list to the research team. From a combined list of twenty-three items the researchers created a shortlist with six items. This was sent to participants by email the day before the NGT session. The six shortlisted items were:

- 1 Someone I trust explaining the pandemic rules.
- 2 Knowing that someone would check up on us
- 3 Peer support through SDWG online meetings (with optional help from family carer) and social media (such as blogs)
- 4 Seeing family and friends either in person or on a screen
- 5 Being able to do activities and hobbies that I enjoy either indoors or outdoors (such as gardening, walking or watching films)
- 6 Taking part in group activities such as singing, exercise classes, activity packs and quizzes



Following discussion at the online meeting, couples voted for the short list items most important to them. The three items receiving the highest three scores are shown in Table 2.

Table 2. Most Helpful Things Identified by Couples



The top three items affirm the benefit of purposeful activities and continuity of relationships with other people. During the group meeting, couples acknowledged the advantages that they and other people who had access to the internet had compared to those less able to access events and information online.

Couples also discussed how easy it was or not to respond and vote as a couple. Two couples acknowledged that the person living with dementia and the supporter had different experiences and perspectives, while three couples felt their experiences during the pandemic had been more alike. There was a collective view that when deliberating how to vote and select the importance of the shortlist items, the view of the person with dementia had been the strongest influence.

Results at a Glance

The findings from the two groups reveal some interesting similarities in terms of the focus on activities that enable people to continue with hobbies and interests, and to connect with others who are important to them. The infographic shows some of the topics thought to be important.

It is interesting to note that there were some differences between the priorities of the two groups. People with dementia found having a focus for their day important. In contrast, the couples' group, family carers highlighted how much they valued being able to join in an online group originally intended for members with dementia.

What helped people living with dementia during the Covid-19 pandemic?



Social Connections



Hobbies and Activities



Peer Support



Lessons Learned and Recommendations

The research has helped us understand what helped people living with dementia during Covid. This helps us to learn what we could do to continue to support people living with dementia in the post-pandemic world. Based on the findings from the research we make the following recommendations:

- The online groups and activities that started during the pandemic could still be helpful for those with dementia post-covid, especially for those who can't easily connect with others in person due to where they live, physical limitations, or other reasons.
- Being socially connected is important for wellbeing, and it's crucial that services and activities create a supportive social environment. This means that people can engage in different ways based on what they need.

We have also learned some lessons about carrying out research that can influence how researchers approach this type of study in the future. These are:

- There is a need to carefully consider how to invite people to participate in research so that there is a diverse group of participants.
- Adaptations to the NGT process can help people with dementia to participate, however there is a need to be flexible which may not always be in line with the structure of the NGT process.
- When carrying out research with couples where one person has dementia, it might be challenging to agree on things. One partner's opinions could have a bigger impact, leading to tensions.

Conclusion

This report presents the findings of our co-produced research project exploring what helped people living with dementia during the Covid-19 pandemic lockdown. These findings can inform how we can adopt good practice around online activities and into the way we support people with dementia now and in the future. As a collaborative research team, we have shown that it is possible for people with dementia, family carers and academics to work together to co-produce research that can positively impact the lives of people living with dementia.

Further detail about this study is available in the full report. If you would like more information or a copy of the full report, please contact:

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