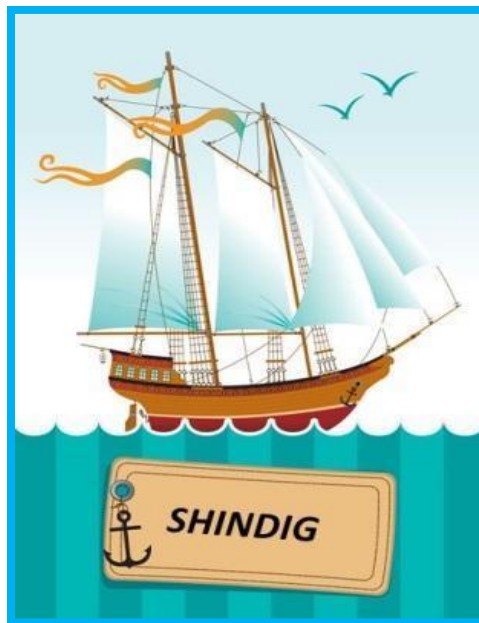


Sheffield Dementia Involvement Group



23 July 2020

The Impact of Covid-19 and lockdown

Background

The topic for this SHINDIG was 'The impact of Covid-19 and Lockdown'. This idea was taken to a 'Tea and Talk' meeting on 25 June and questions relating to this topic were discussed and adapted by people with Dementia, carers and facilitators. Five questions were agreed upon to use for July's SHINDIG.

This SHINDIG was attended by 24 people living with Dementia, family carers/supporters and was supported by 10 staff facilitators. As a consequence of Covid-19, both Tea and Talk and SHINDIG were delayed and unable to run in the usual format. Both events had to run virtually using Zoom. A significant aspect of SHINDIG valued by attendees, is the shared lunch which takes place prior to group discussions. Attempts were made to replicate some degree of social opportunity by placing people into 'chat rooms' on arrival. As attendees were mostly sharing PC's at home, they were unable to make their usual choice regarding which type of group they joined, People with Dementia group, Carer group or a mixed group.

Lead facilitators' recruited technical assistance from Sophie Tucker from the Alzheimer's Society to aid the running of this first 'virtual' SHINDIG. A separate Zoom meeting took place with facilitators on 03 July in order to prepare them and discuss any concerns they may have. The decision was made to limit the amount of attendees who were volunteers to those with an essential role. We did have expressions of interest from people wanting to attend in a 'visitor' capacity and will review if this is deemed appropriate in future.

Questions and prompts were used to guide discussions and responses were recorded by scribes allocated to each of four groups. Scribes kindly typed up their notes which have then been used to produce this report which reflects the key responses to the questions asked about the impact of Covid-19 and lockdown.

Summary

- Staying connected with others was seen as important by everyone. Existing services have adapted their practise to maintain contact with people, which has clearly been appreciated.
- Extended family have been essential in managing practical matters like shopping and collecting medication.
- Concern was expressed by some people who weren't sure who to contact in an emergency and how they would manage if the Person living with Dementia needed to be admitted to hospital.
- Most saw the benefit of virtual events like Zoom cafes and other online groups.
- One person living with Dementia had been active in setting groups up and helping others learn how to access them.
- People enjoyed seeing familiar faces on screen and having something to look forward to each week.
- For people living with more advanced Dementia one to one contact via Zoom or telephone calls seemed preferable and easier to manage.
- People did miss meeting face to face and not being able to touch or hug.
- Keeping busy and having access to the outdoors were also seen as good ways of coping. People had used their imagination to keep busy from trying 'video ballet' to 'building a miniature log cabin'.
- Carers discussed the impact Covid-19/Lockdown has had on mental health and physical health for themselves and the person with Dementia.
- Not having access to usual routines and resources has had a negative impact.

Main Report

1. How do you feel you have coped during lockdown, what resources have you found most important?

People living with Dementia

People living with Dementia generally felt they had coped well with 'Lockdown' and were able to list numerous resources which had helped them. Being able to maintain contact with other people be they family members, friends or services making contact with them was seen as hugely important. People valued the one to one contact made by staff from the Alzheimer's Society and Darnall Dementia Group.

- *A volunteer phones me once a week and chats with me for thirty minutes and asks what I'm doing, how's it going, she says. It's comforting to know someone cares, they take time to pick up the phone and speak to me, it's really lifted me.*

A number of people are regularly accessing cafes being run via Zoom and clearly enjoy both the social aspects of these sessions and activities provided.

- *Loved the company and the singing, felt like a family.*

One person has been pro-active in setting up online Dementia Cafes and has assisted a number of others to start using computers and become acquainted with the use of Zoom. A great example of the Person living with Dementia taking the lead and sharing their knowledge to help others.

- *I have been very busy, some days having up to 7 meetings a day, I have run 60 cafes so far.*

For some people whose Dementia was more advanced Zoom groups did not suit them, they found it 'too much' and preferred one to one company. Keeping busy and accepting things as they are were recognised as important. People had often re-visited old hobbies or explored new ones. Learning new skills out of necessity, like how to shop online and use Zoom were seen as positive outcomes of lockdown. There was recognition of the importance of keeping both body and mind stimulated. One person had added 'video ballet' to his repertoire of interests. Having projects which could be re-visited was seen as beneficial by a number of individuals as the following comments illustrate:

- *I have a big oval table and I've been able to put a dolls house on it, I have painted it and even made little pieces of furniture out of spare wood. I want to give it back to my friend who gave it to me as he isn't very well. I had my wife watching me all the time so it had to be perfect. This has really helped me.*
- *Making and painting a little log cabin and making tiny tables and chairs out of the left over bits of wood.*

Getting outdoors was an important way of coping for many people and being unable to go out caused confusion and frustration.

- *I didn't understand why I couldn't go out.*
- *Wanting to go out for a walk but not being able to.*

One couple had dealt with this challenge by using their car to visit different areas for stimulation while remaining in the car to maintain a safe distance from others.

- *Have car will travel, Huddersfield, Retford, Stoney Middleton, Tideswell and Bradwell.*

Carers

Echoing People living with Dementia, Carers also felt that maintaining contact with others was hugely important. Carers valued, being able to speak to friends who were in a similar situation. A number of people had made contact with others 'In the same boat' which was deemed helpful.

- *Us four are friends through the Alzheimer's Society, they live nearby so we've been taking our chairs, drinks and some snap to sit outside and see them.*

Carers were also appreciative of their extended families who helped with practical tasks like shopping. Being able get outdoors was also seen as a valuable coping strategy. One person demonstrated how he shares control of journeys in the car with his wife.

- *My wife does the navigating, go left I go left, go right I go right. We end up all over, used to do that with the kids.*

Carers did value the efforts being made by places like The Parson Cross Forum who in addition to regular online cafes have delivered 'activity' goody bags to individual households.

All were grateful of the good weather as this has enabled regular access to the garden for both activity and relaxation.

Carers were more forthcoming about the negative impact lockdown had had on the person living with Dementia and themselves. People acknowledged that lack of stimulation for the person with Dementia has led to deterioration in both mental and physical health.

- *It's been terrible for my wife because she's a meeting up person, she really misses the hugs and physical contact.*

- *Isolating, all that pressure on one person, it's contributed to a lot of peoples poor mental health. Walking and mobility has declined during lockdown, doing less, more tired and feel older.*

One carer highlighted how his own health needs take second place in order for him to look after his wife:

- *I have pain in my leg and hip, if my wife wasn't here I wouldn't get up for the day, but I have to for her.*

Carers have been shocked by how long the situation is lasting and felt unprepared for such a prolonged change to their usual routine. It was evident that people feared going outside again not only because of the virus but due to the exposure of multiple stimuli after being inside for so long.

- *Normal life was disappearing and this was alarming. I started 'disaster planning'. Good things are doing things together but stimulus from outdoors was difficult to deal with. My husband has coped better than me.*
- *I'm scared to go to Meadowhall for a passport photo but I need to go so I can re-new the 29 page Blue Badge form.*

2. What services have you used or been supported by during lockdown?

Person living with Dementia

People living with Dementia spoke about the services they valued currently and those they really missed. One individual pointed out there is no support for people living with Dementia under the age of 65.

Regular telephone calls were appreciated.

- *Burton Street welfare calls most helpful, something to look forward to during the week and keep us connected.*

- *I miss the cinema, Life Story group and Driving group with Sheffield University has stopped, it leaves a hole in your life.*

Carers

Carers also recognised the importance of welfare calls but had also gained a lot from accessing various groups and activities via Zoom. Darnall Dementia Group and Age UK were mentioned, Darnall in particular as they offered one to one Zoom sessions for PWD.

- *Darnall Dementia Groups one to one face time works best for my wife, it's her thing. It's 70/80% her and only 20/30% me. For group Zooms it's 70/80% me and only 20/30% her. She can't get a word in when there are fifteen screens.*

A number of carers had made efforts to learn how to use new technology and different methods to communicate in order to remain connected. Getting help from younger members of the family was an important part in achieving this.

- *I had a lesson from my granddaughter sitting on the landing telling me what to do.*

Overall, carers seemed keen to learn and have access to what was on offer. One carer spent two weeks on and off learning how to access Zoom.

"Now we can join in as well, I've bought a tablet".

One carer recognised that speaking to students via Zoom was helping her husband maintain his communication skills. Another observed how her husband had enjoyed seeing all the familiar faces onscreen during group Zooms. Some people felt that Zoom had offered more regular contact with friends.

- *Dore Zoom Dementia Cafe is every Tuesday, they have singers, exercises, it's a right laugh. We've got to know people better there and that's been one of the best things about this lockdown for me.*

In addition to online resources carers listed their Church, food parcels and 'goody bags' as valuable sources of support.

3. Have you accessed your GP or hospital during lockdown, if so what has been your experience?

Person living with Dementia

Some people living with Dementia had not required such services others had experienced cancellations or delays with appointments or blood tests. One person had been administered a B12 injection on the door step. In some instances consultations had taken place over the phone. One person shared differing experiences of this.

- *Broken tooth and triage over the phone only for advice from Dentist. Advice was to buy an emery board and repair kit.*
- *Tablet review over the phone, good chat with Pharmacist, very positive appointment.*

Carers

Carers shared mixed experiences, again some had experienced delays or cancellations of appointments. Others who had attended hospital had received a swift service. Contacts with GP's had been positive but there was mention as in a previous SHINDIG of receptionists.

- *Putting you off*

A key issue that this question did raise which caused high levels of anxiety for carers is how their loved one would cope if admitted to hospital. One person shared the level of input he previously had to provide when his wife had been admitted to hospital.

- *I don't know how I would have coped if my wife had to go in hospital and I wasn't allowed to visit her. Last year when she was in hospital I stayed with her each day 9am to 9pm. One night they called me to come back as they couldn't cope with her. I came back and stayed until she went to sleep and didn't leave until early morning. What would they have done?*

4. Have you known how and where to get support, Information and services whatever the issue or time of day?

Person living with Dementia

One person living with Dementia referred to using their wrist alarm if a crisis occurred.

- *In a crisis I have City Wide Alarms which I pay for, I have a button on my arm.*

Others referred to their spouses managing medication for them and having shopping delivered to the home. This service was not easy to access at the start of lockdown.

Carers

Some carers were well informed and up to date with relevant websites and other sources to find information. A Community Mental Health Team had provided information as had using the BBC website. A number of carers were not sure who they should contact in an emergency. Understandably this resulted in frustration being expressed as highlighted in the following comments.

- *Why is it all online? That's no use, I need a telephone number. Isn't there just one number for Sheffield? If there's an emergency I need to pick up the phone and ring one number.*
- *I've got a load of numbers and would know what to do in a crisis but wouldn't know what to do in the middle of the night.*
- *What happens to my wife if I go into hospital?*

In addition carers expressed frustration at the difficulties they had experienced trying to do their shopping online and also in having medication delivered. One lady shared a positive example in her area of students putting leaflets through the door offering their help.

5. Do you have any concerns about the future, what are your hopes/fears?

Person living with Dementia

Responses to this question highlight two equally important but very different realities:

- *Not about Covid, but I won't have any choices as my Dementia progresses, we become none people. Clinicians talk to my wife not to me.*
- *I take each day as it comes, I have found today fascinating I have learnt so much and I have helped students learn. I love what we are all sharing, ladies keep up the good work.*

Carers

A number of carers referred to 'Life being on hold' and trying to take each day as it comes. Numerous holidays and planned time with family had been cancelled leading to low mood and significant disappointment. People were starting to see loved ones again and that was helping them.

- *More content now family come here. Not seeing people is hard, it's nice to forget the worries and awfulness.*

Some carers raised concerns about losing the services they value.

- *My biggest concern is for the Alzheimer's Society. Last year they had a record income for a charity yet their services have decreased. Dementia Cafes have dropped in number since Alzheimer's left them. I don't find the cafes friendly now. The staff don't circulate. There are no leaflets out on a table to find out stuff. You can't just say 'Can I have a word' anymore.*

For both People living with Dementia and carers, being asked if they had concerns about the future, lead to far greater issues that the current pandemic and its impact.

- *I do worry how I can pay fees. I get through each day, some are good some aren't but it beats being dead. I get a lot of phone calls, they help me. I don't look to the future.*

Recommendations

- People living with Dementia and Carers need to maintain regular contact with others and have opportunities to have fun and socialise.
- People with Dementia can benefit from keeping busy, using their existing skills and having projects to complete.
- Having regular access to outdoor spaces is essential for many people in order to remain well.
- Some people need information to be provided in leaflet form.
- There is a need for provision of PCs to enable access to online resources.
- Education is required on how to use technology and explore virtual ways of communicating. Is there scope to collaborate with People living with Dementia and also explore intergenerational ways of working? (younger people with older people)?
- More effort needs to be made to monitor the mental health of the person living with Dementia and Carers.
- Services need to work with Carers to make sure there is an agreed plan in place for times of crisis.
- Carers need to be made aware of where they can seek support.

Conclusion

This SHINDIG provided people with Dementia and their family carers the opportunity to share their experiences of Covid-19 Lockdown. The findings will be shared with all relevant SHINDIG stake holders including Sheffield City Council commissioners.

For more information please contact SHINDIG co-ordinators:

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