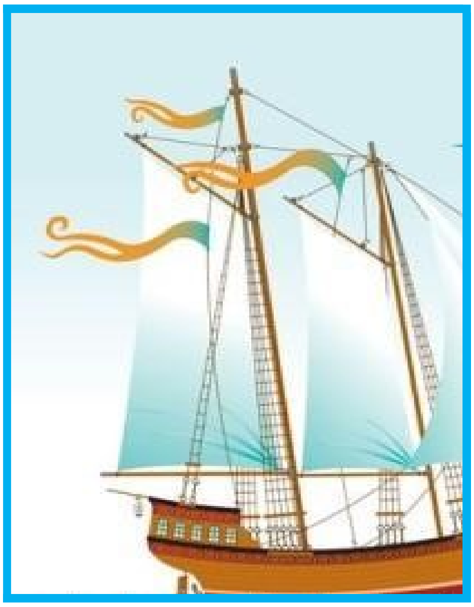
Sheffield Dementia Involvement Group



Friday 26th November 2021

Communication

Do we need an App?

Background

November SHINDIG was attended by 7 people living with Dementia, 3 people with a diagnosis and 4 carers. The event was supported by 4 experienced volunteers and we were joined by 2 students and 2 guests who had previously shown an interest in volunteering.

This was our first face to face SHINDIG event since March 2020. It is important to acknowledge that a reduction in attendees is a result of various factors.

- Some carers feel the group is no longer appropriate for their spouse. Two carers stated that they felt the group would now be over stimulating and their husbands would find it difficult to be around other people.
- Some people were unable to attend due to physical health issues.
- Others chose not to attend due to the requirement to conduct a lateral flow test. Some people had very strong beliefs about this and questioned why it was not necessary for the other groups they attend. Others felt it would cause distress.

A face to face Tea and Talk (planning event) took place on October 27th to introduce proposed topics, adapt questions and discuss the development of SHINDIG going forward.

Two groups had approached the SHINDIG Coordinator with potential topics earlier this year.

Jennie Mcritchie

Is an academic with backgrounds in music, electrical engineering and cognitive science. Her current focus is on developing new tools and technologies that help people living with Dementia interact with music in all its forms.

Family Phone

Fran Ferris-Ockwell and Grant Ripley are a new business funded by Bethnal Green Ventures. They are keen to develop an App that will help families living with Dementia to keep in touch.

Lokicoki Design and illustration

Emma Kitchen is a visual notetaker. We hired her for this event to document the voice of the person living with Dementia using drawing. The aim being to then use the images created to promote SHINDIG to a wider audience.

Unfortunately, Jennie and her colleague Justin had to withdraw their involvement on the day of SHINDIG due them having been in proximity to a student who later tested positive for Covid. We hope to re-visit their project as a SHINDIG topic at a later date.

This last-minute change resulted in 5 questions relating communication being selected to enable facilitated discussions.

Note

A recent study shared that some people living with Dementia find it difficult to read text in italics. Consequently, statements within SHINDIG reports will now be indicated in bold rather than italics.

Summary

Part One Communication

- How we communicate has changed since the Pandemic.
- Virtual communication is becoming more common.
- Mask wearing and adhering to Covid-19 restrictions has had a big impact on communication.
- People living with Dementia still feel they are treated differently in conversations.
- Gestures and touch can be extremely important in communication.
- Observing and celebrating our surroundings can connect us when words are no longer available.
- The environment plays a big part in communication.
- We need to promote SHINDIG by connecting with other groups and services.
- SHINDIG offers a space where people can share, learn and feel safe.

Part Two Family Phone

- The App should be customisable as people have different needs which can change over time.
- It needs to be easy to use.
- Use of bold text, familiar images (faces) and audio messages would all be useful.
- Keep it simple avoid offering too many choices.
- The following functions would be useful; falls detection, location tracking and being able to push a call through.

Main Report

Communication

Emma Kitchen the visual notetaker was seated next the group documenting their responses by drawing. Attendees had been made aware of this addition to the event in advance.

What does communication look like?

People referred to using physical gestures and the importance of demonstrating that you are listening to someone. Not pressuring people but encouraging them to join in if they want to.

“It’s about keeping it light-hearted”.

There was a strong theme on how ‘communication’ has changed since the pandemic. People spoke about the use of virtual communication and how this is now a regular part of their daily lives. Both carers and people living with Dementia spoke about the positives of this which for some people was a totally new way to communicate.

“I didn’t know what zoom was. I do three meetings a week now and quizzes every afternoon”.

One person living with Dementia spoke about learning new skills that he feels this is not only improving his physical health but also his cognitive function.

“I have been doing keep fit via YouTube and I am now learning classical ballet”.

He provided the group with a demonstration.

Another person spoke about keeping in touch and how he now has more contact with family abroad than before the pandemic.

“Zoom has been a blessing, I’m in touch with abroad, touch a button and talk to family in New Zealand”.

The group discussed how people with more advanced Dementia had been unable to use virtual communication and had become frustrated by it.

“For me trying to talk on zoom didn’t go well. Dad could not get used to her voice and her not being there”.

The group acknowledged the use of virtual communication had been a necessity in care homes/hospitals. Someone commented that having the visual representation of a loved one on screen could offer reassurance.

“He stroked her chin on the screen, he quickly lost concentration but we held the screen so she could still him and his surroundings”.

“I could see my husband on the screen. He managed to speak just a little bit and then after that I spoke to him on the telephone. I was reassured to be able to see him”.

The group moved on to discuss face to face communication and the importance of eye contact, body language and tone of voice. This led to people sharing the impact of the restrictions over the last two years.

“Even when I could see him face to face I wasn’t allowed to hold his hand”.

Several people spoke about specific events, particularly funerals. Some had attended virtually or sadly not at all. One of our members lost her husband in recent months. She was happy to share that his funeral took place when restrictions had been lifted.

“There were nearly a 100 people at my husband’s funeral”.

This led to a brief discussion on hope.

“My reasons for hope, dementia doesn’t have to be the end of the line. It isn’t hopeless. Recent research concentrating on functional decline in dementia has shown it has been slowed down or reversed. I feel more cognitively aware than I was one year ago. I was diagnosed with frontal-temporal dementia 12 years ago”.

This person offered an example of how preparation and practise in advance can help a person living with Dementia communicate what they need to share.

“I went to a dementia awareness session at Rotherham Healthwatch. Before I was interviewed, they gave me a one-to-one preview session, this built my confidence up”.

What prevents communication?

People reflected on their own experiences.

“Some people don’t know what to say to people with dementia, they tiptoe around”.

“Can’t cope with the fact you’ve got problems, not everybody has patience”.

Someone referred to people finishing your sentence, another person living with Dementia joked that

“Sometimes this is necessary”.

One person acknowledged feeling embarrassed.

“I still struggle, I feel daft now, difficulty finding words”.

The group spoke about sensory factors like hearing and visual impairments effecting communication. Several people recognised the role of the environment and how noise can be extremely disruptive for a person living with Dementia.

“When there are multiple things going on it can be overstimulating. I have a one-track mind”.

“Noise is too much, if we go to a café and there’s music on, he has to disappear”.

A new member spoke about the importance of feeling safe and not threatened. He acknowledged the warm welcome he had felt from his initial SHINDIG experience.

“You spoke to me like you already knew me. This group is a safe place, you can say what you want”.

Most people had experiences where they had been ignored and their spouse hade been spoken to or had been asked questions about them.

“He would go out, but people would just speak to his wife, and he would say “I am here you know”.

“His sisters talked between themselves, and he just sat there. I kept trying to bring him in to the conversation”.

One carer acknowledged doing this herself at times when she visits her husband.

“I’m guilty when I visit, I often talk to his one to one, then he will say “Oh shut up!” We were probably being too noisy”.

The groups agreed that communication is now more difficult since the requirement to wear facemasks. These impact upon the ability to see facial expressions which can be crucial in communication.

One person spoke about a time when his wife no longer recognised him.

“My wife would go to the day centre and when she came back, she would be saying “Get out of this this house, I don’t know you.” The following day she would ask me if that man had gone”.

How can a person communicate when they can no longer speak?

One carer spoke about the need to observe body language and facial expressions to better understand her relative.

“When I’m with him I’m watching every move, eye movements, arm movements, posture”.

She went on to highlight how small details can make a big difference. Her dad who is now in care is Serbian. His name ends with the letter ‘O’. On the sign on his door it ends with the letter ‘A’. She stressed that the ‘O’ was masculine while the ‘A’ is feminine. Her dad is no longer able to correct this error but may still be aware when being addressed with a woman’s name.

Several people commented on the value of observation and drawing attention to the things around them. Sharing moments where words are not necessary.

“A ladybird landed on his arm, we stopped, watched together for ten minutes, beautiful small moments”.

“We go for walks, I point to the trees, a bird, it’s enjoyment”.

The use of touch and sensory experiences were also recognised as valuable ways to communicate and connect with people. As were activities like singing and dancing.

“Hugging”

“He’ll grab my hand and giggle at something. Puts my hand against his face. He adores stroking cuddly dogs”.

We want to communicate the importance of SHINDIG to others, what is your advice?

This question initially led to the groups reflecting on personal experiences, recalling feelings of isolation following diagnosis.

“My relations and friends disappeared when we had the diagnosis”.

“We don’t see our friends like we used to”.

“We never had children, so it was just me and her”.

“It was very hard for us at first, we did coffee mornings, just being able to talk to people. That’s how you find out about things like SHINDIG”.

Then came the relief of finding a group like SHINDIG.

“It’s been good for us, it helps to meet a lot of other people, a lot has come out of it, we have learnt a lot, I tell people about it”.

“Making friends, interacting with other carers, sharing stories. Feeling safer, all together”.

Our newest member commented

“This is the first time I have been and its brilliant. At first you don’t know what you want but what you want is kindness. You don’t say it but that’s what you want”.

The groups offered numerous suggestions on how best to promote SHINIDG to a wider audience. Several people felt it should be shared at GP level. On YouTube and Twitter. The idea of attendees making a short film was suggested. People agreed they would be willing to take part in this.

“Telling our story”

It was felt that we need to reach out by visiting other groups and organisations. Building links with Dementia Link Workers and speaking about SHINDIG at relevant forums. One attendee stressed

“People are out there hunting for something like SHINDIG”.

Part Two

Family Phone

Grant began the session with a presentation about the inspiration for the Family Phone:

Family Phone is a proposal for a new app that would make it easier for people living with dementia to use and answer the phone. Grant's experience with his own grandfather was that as he became unable to use the phone, this meant that he and the rest of his family had to visit twice a day to make sure he was alright. This became very frustrating for him and reduced his independence significantly.

Grant went on to elaborate further.

"Less and less people are having landlines, my parents for example, so we were trying to think what would work for them when they are older.

The first problem for my grandad was not recognising who was calling as the name wouldn't come up. The first 10 minutes were then spent trying to figure that out in the conversation which is stressful for both of us.

Solutions are out there but they often involve an expensive tablet at £30-£40 a month that would then not be that useful.

We are looking at an App for your current phone so there is no need to buy a new device"

Before discussion took place the Lead facilitator checked that everyone knew what an app was. Grant described it as the following:

An option on a smart phone that has certain functions, for example, maps.

The Family Phone has a simple interface with three options for people to call; a photo of the person, and 2 functions, press to call or press to answer.

What do you currently use for communication? Mobile phones, computers, zoom?

Attendees listed the following.

“I use zoom on an iPad”

“I use the landline mostly”

“iPad it’s ok, easier than a computer”

“I use a mobile for incoming calls, a landline for outgoing calls because the mobile is very quiet, and I can’t hear it”.

“We have video calls on iPhone and quite a few Zoom calls on a laptop. We only use the laptop for this”.

“When I receive calls on a mobile, I tend to mute or cancel the call by mistake so I hand it to my wife”.

One carer shared that his wife could no longer use the phone and it had become a source of concern. She would worry about losing her phone then accuse him of taking it. Another carer felt the app would be good for those already familiar with technology. She had tried an iPad with her husband, but he had struggled to use it. However, he does now speak to family on face time when it is set up for him. Another person mentioned the visual impact of Apps on phones, recognising that they soon become crowded with different icons which could be very confusing for someone living with Dementia. The message was to keep it simple.

Grant then showed the group a handout with three images to gage opinion on how the phone screen should look. Offering a verbal description of the Apps functions.

“The printout you have shows the screen you would see, which would have a carousel of images.

People can choose the photo, if there is more than one photo then it could cycle through.

It instantly makes it friendly and familiar; you can have different pictures of the person at different ages to help with recall. It could say this is Melanie your daughter”

Do you think it is clear what you need to do to make/answer a call? What would you change to make it clearer?

The following suggestions were made:

Press to answer, press to call
Use a larger font to make it easier to read
Suggesting it say Press to call plus the name of the person you want to call?
Add a person’s name and their relationship
Providing colour contrast options in the settings as some colours work better for people than others.
Again there was a consensus that too many options could cause confusion.

Grant asked the group if the App needed to be customisable and all agreed it should.

He was advised not to make it too complicated in terms of setting it up.

Grant also asked if it would help if when the phone rings there is a video of the person calling?

One carer stated that when the phone rings her husband does go to answer the phone, but he no longer knows how to answer it.

Another person shared that swiping to answer is difficult and felt that having to press to call and press to answer would be easier. He also advised making the button icon bigger and clearer, so it is easier to see.

One of our students shared observations of her own relative.

“My grandpa uses voice activation on the Facebook portal but couldn’t understand what was going on when we used an iPad in the hospital. He didn’t know what it was, he didn’t recognise the faces”.

Someone shared having an issue with unsolicited spam emails and asked if the App would have security features.

Grant stressed it will only be possible to call between phones that have the App when it is set up there will be a Unique ID provided so that the carer can set it up on their phone and the users phone.

Would it be better to have press to answer and then an option for video call?

One couple felt it would be better if it goes straight to video call, as the person living with Dementia likes both Facetime and Zoom.

There was a consensus that the App needs to be customisable.

“Set up to suit the person and what they are able to do and understand”.

“Can you personalise the size of the text and image according to what will work for the individual?”.

“I think it would be good to be able to change those features depending on what works for each person at any one time”.

One carer pointed out that he finds it hard to set things like this up.

“It’s got to be easy for the carer to customise it, I find web sites with help desks difficult. I need easy instructions and no complicated computer phrases”.

How about having audio, or recorded video for example a family member giving instruction?

“Hey Granddad, it’s me Grant I’ve been trying to call you, press the green button”.

This was felt to be a good idea and worth trying out.

How about voice commands. Does anyone use Alexa?

A number of people agreed Alexa was easy to use and a good idea.

This led to conversation about alerting someone in an emergency.

“I’ve been falling out of bed, and I can’t get to my pendant alarm. My wife was sleeping in the other room, and I couldn’t wake her for help”.

Grant suggested that the Family Phone could potentially assist people in such situations. Then discussed a variety of other potential functions such as falls detection and being able to push a call through if there were no answer and people were concerned. Location tracking could also feature. The group felt this would be useful. One person recalled a frightening situation involving her husband going out to the shops in the middle of the night.

Recommendations

- Dementia education is still required to aid communication as people still feel they are treated differently.
- Virtual methods of communication are here to stay and should be explored.
- SHINDIG needs new members and people living with Dementia need SHINDIG.
- Word of mouth is not enough there is a need to spread the word using the different methods suggested.
- An App to aid telephone communication needs to be customisable, easy to use and have useful features that will maximise both independence and safety.

Conclusion

November SHINDIG was a successful event and people were glad to be back face to face at Quaker Meeting House. The event offered attendees opportunity to discuss the topic of communication and advise on the development of Family Phone. A new application that aims to make it easier for people living with dementia to use and answer a smart phone.

Our next event will take place on Thursday the 17th of February at Quaker Meeting House 1-4pm

For further information about SHINDIG please feel free to contact

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