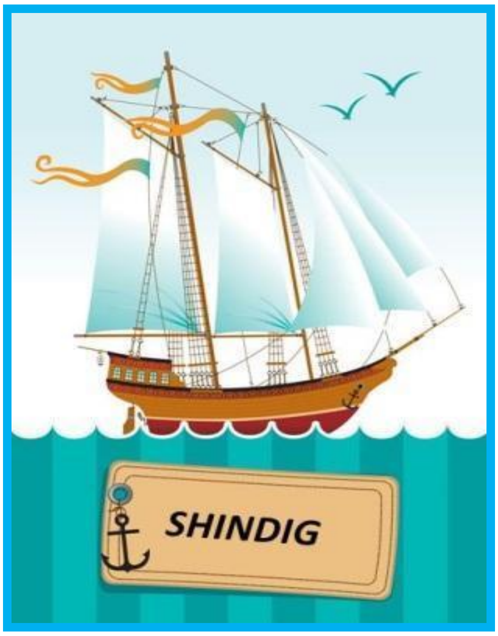
Sheffield Dementia Involvement Group



February 17th 2022

‘Planning for the future’

Background

Sheffield Dementia Involvement Group, also known as SHINDIG, is a forum where people that are living with Dementia can meet to discuss topics of importance to them.

A number of topics were brought to SHINDIG by the Sheffield Dementia Strategy Group. These were discussed amongst our planning group to establish which was felt to be most important. It was agreed that the topic to be discussed first would be;

‘Planning for the future’

Questions relevant to this topic were taken to ‘Tea and Talk’ SHINDIG’s planning meeting to be tried out. Then were adapted accordingly.

Representatives from both The Carers Centre and Memory Service were invited to attend and share relevant information.

Memory Service colleagues were particularly interested to hear about attendees’ experiences of the Memory Service and what their thoughts are regarding the information they are given at post diagnosis appointments.

This SHINDIG was attended by five people living with Dementia and five carers. Four people withdrew on the day due to ill health. A new couple joined us which led to our existing members adopting a very supportive role.

When attendees were asked in 2021 how they felt SHINDIG could be improved, there was a consensus that we need to reach a wider and more culturally diverse audience. This, coupled with the progression of Dementia of our members and Covid-19, our numbers reduced significantly. In response we began connecting with other groups to recruit new members and initiate conversations. Following our main SHINDIG event in February we attended four other groups. One group was attended by people living with Dementia and two groups had a mix of people living with Dementia and carers. The fourth group was a carers group. On each occasion we used the opportunity to promote SHINDIG and on two occasions took questions to generate a conversation on the current SHINDIG topic ‘Planning for the future’.

We did notice that in some groups people seemed less comfortable speaking about Dementia. Both the people living with a diagnosis and carers. This has led us to consider the stigma attached to the word Dementia and the method by which we introduce topics going forward. Could we be more creative in how we initiate discussions?

What was evident was that people were keen to speak about ‘living’. The things that they do to stay well and how they remain actively engaged in life.

Summary

Discussions about planning for the future should start as soon as possible.

People need informing about LPA (Lasting power of Attorney).

Groups/Memory Café’s should be prescribed at the point of diagnosis?

Attending groups is an essential part of staying well.

DNAR (do not attempt resuscitation) is a sensitive subject and should be handled tactfully only when the time is right.

Services need to link up and communicate better.

Services need to consider the language they use. Refer to a person’s choices rather than wishes.

Receiving their diagnosis can be a relief for some people.

Dementia is difficult to see, and stigma still exists.

People are using technology to for practical and leisure purposes.

Main report

Planning for the future

When is the right time to have these conversations?

There was a consensus amongst the group that conversations should start as early as possible.

“I personally could make a decision now, the earlier the better. I think it is better to bring it out into the open and then re-visit it. You don’t need to say straight away, open it up and come back to it when you know the person more”.

One person shared that we should all plan for our future regardless of any diagnosis.

“These subjects should be raised at our 40-year health check for everybody. Not linked to Dementia, when we are fit and well”

Some topics were felt to be more sensitive than others and discussing them led to an emotional response amongst the group.

“My husband went into hospital, the doctor wanted me to agree to DNAR (Do not attempt resuscitation). I wasn’t ready for that, I didn’t have LPA for health (Lasting power of attorney), very regrettably”.

People didn’t feel it was appropriate to discuss DNAR initially but agreed that LPA should be raised straight away at the point of diagnosis. It was also suggested to have a person as a reserve LPA in case anything happened to your spouse.

“Wait for post diagnosis to begin conversations about death. LPA is not as negative as DNAR”.

One person recently diagnosed had spent time with his wife making plans but did acknowledge there could be financial implications for some people.

“My wife is a Civil Servant, so we had already spent a lot of time looking through the booklets. We had done the LPA and it is to be recommended because it’s sensible. It does cost a lot, not everyone could afford it”.

Within the groups, attendees were keen to advise each other. One person pointed out the need to get LPA for both health and finance.

The conversation led to people reflecting on their individual experiences of diagnosis. For one couple it was helpful to have had a member of staff from the Alzheimer’s Society with them as they received the diagnosis. Another person expressed frustration that services had not been more linked up when his wife was diagnosed.

“It’s wrong to have two separate services, why isn’t there more co-operation between services. Very disappointing”.

One person shared how he has now been discharged from the Early Onset Service and given the choice of seeking further support if he and his wife feel it is necessary.

“I was monitored for a few years, my father had Early Onset. I have now been signed off because there hasn’t been any progression. My wife and I have been advised to decide when it is right to request a GP referral to the Memory Service”.

For some people living with Dementia, receiving their diagnosis offered some relief. It helped them to understand why they had been behaving in certain ways.

“I kept on getting into trouble, now it made sense why I was doing those things”.

How did you tell family/friends that you had Dementia?

People were generally open about their diagnosis, and most didn’t experience any difficulty in telling loved ones.

“We started having conversations with friends and family as soon as I was diagnosed. We did it with jokes because that’s how we are in my family. They took it well”.

“My wife has always been ok with telling people”

“What does it matter? They haven’t got it. Why should they be afraid”?

“My husband told people himself and they reacted apologetically. He felt that there was nothing to be ashamed of.”

One person did acknowledge experiencing some negativity when he shared his diagnosis.

“I struggled for so long, making mistakes. When you share it with people you find out who your true friends are.”

What was evident from discussion was the reaction of the wider community and how this could impact on both the person living with dementia and carers.

“I am a person who is used to being listened to. What has impacted on me is I notice that they started talking through you. They’re not listening. That has developed”.

The theme of Dementia being difficult ‘to see’ came up several times. People shared that a lot of society still perceive people with Dementia as being old and disabled.

“The receptionist asked for my date of birth, and I hesitated and looked at my wife. What are you asking her for she said? I felt embarrassed and my wife was furious”.

“People didn’t believe it because of my age. They think we can’t do things. We can, we just do things differently and may need some support”

The group spoke about an ‘inequity’ of resources and understanding.

“If a person has a physical disability, they get more help. Dementia is worse than a physical disability as it is an invisible disability and harder to explain. People often say, you don’t look like you’ve got Dementia. I say do you want me to wear a badge”.

What information do you need to help you plan and how do you want information to be provided to you?

Some members of the group were aware that you can make advance statements to express your individual preferences and decisions while you have the capacity to do so. However, there was concern that these could be overruled at a later date in hospitals or when in 24-hour care settings. The need to use appropriate language when having these conversations was felt to be important.

“You keep referring to a person’s ‘wishes’, it is not about ‘wishes’. These should be a person’s ‘choices’ that are respected and adhered to. The choice should be that we are able to take control of our lives. Dementia is an organic disease; we can still make choices and decisions to make changes”.

One person felt that people should be made aware of opportunities to attend relevant groups at the stage of diagnosis.

“I believe that there should be a referral process at diagnosis so that people should attend a memory café. They would meet other people and it would be part of their rehabilitation”

Other members of the group echoed this.

“It’s the best thing we ever did”

One carer felt that this approach could put people under pressure to go into a social setting, suggesting that it’s not for everyone. Most people agreed that initially they had felt nervous or doubtful about joining groups. However, all were glad that they had. The value of having opportunity to spend time with other people was evident in all of the groups that we spoke to this quarter.

“I was terrified when I first came but this has given me a new outlook. Everyone is so happy and there’s a feeling of camaraderie”

“The centre is like a lifeboat”

It was helpful having two members of the Memory Service present for this SHINDIG as they could update attendees on current practise within the service and listen to recommendations. It is hoped that a representative from the Memory Service will be able to attend SHINDIG events going forward.

The group shared the things they felt should be added to the information pack provided by the Memory Service.

“Information about personal trackers, devises and how to use them on your phone. Like the ‘find your friend’ app”

One person mentioned using a tracker in his pocket when he goes out cycling.

“This way my wife doesn’t worry as she knows where I am”

“I fell out of bed and was there for a long time, could things like Alexa or Google home help?

“Information about lifestyle and exercise. By taking charge I feel more positive about it and feel better” https://foodforthebrain.org

“Playlists for life” https://www.playlistforlife.org.uk/

One carer recalled being given a lot of information at an initial appointment with Memory Service and felt it would have been better to get this at a post diagnostic appointment. Another person had appreciated the hard copy format of information.

“Having something physical to look through as well as all the websites that are available”

One couple stressed that they preferred face to face communication and learning about things by ‘word of mouth’.

“When it’s on paper we don’t know what it means. It’s better to have a chat as I can’t remember what I’ve read. I feel very strongly that person to person is better, having conversations is better. Just a couple of words with someone at a memory café is what I need”.

There was a discussion about the need for people living with Dementia and their partners/carers to have time to speak to professionals separately. It was acknowledged that this can be arranged at the Memory Service and is preferable for some people. This needs to be shared as some attendees felt their partners wouldn’t ask for separate appointments unless prompted to do so.

The current assessment process at the Memory Service does allow time for the person living with Dementia and their carer to speak separately. The group were also made aware of the helpline being run by the Memory Service.

The group recalled how having separate groups was previously part of the SHINDIG model. Having three types of groups, people living with Dementia, carers and a mixture of the two proved beneficial as it allowed people to open up. Unfortunately, due to lower numbers following the Pandemic we are currently unable do this.

What do you do to stay well?

Wise words from one of our original SHINDIG members.

“You only live once, you have to do what you can, while you can”

Comments highlighted the importance of peer support and being around people who understand.

“Keep talking and discussing things, being able to discuss without feeling judged”.

People spoke about the practical things they have put in place and how they keep their brain active.

“I keep a diary every day now, otherwise it would be gone. I have a list of 50 people. I go through them in my head one by one, recalling how I first met them”

Having opportunities to socialise and make connections was important.

“We attend two memory cafes, two day-centres, SHINDIG and Darnall Dementia Group. Through that we have picked up more friends. We started to meet new people which is so important because my wife is a people person”.

Using music was felt to enhance mood and occupy.

“As soon as I am up and about, I listen to music”

One carer shared the value of having technology like an Alexa device that can be operated easily by his wife, allowing him to manage other tasks within the home.

“My wife uses the Alexa every day, she asks for Cliff Richard while I get on with my jobs”

Some attendees shared how they use their time to educate others providing resources for people living with Dementia and advocating for them. One attendee is involved in the planning of a conference later this year.

“Keeping busy helps me, getting involved in things like the research, I run a radio station”.

I feel the following illustrates the value of groups like SHINDIG. One person joined the group for the first time with a very recent diagnosis of Alzheimer’s Disease. He left SHINDIG later that afternoon with plans to become a Co-Researcher in a music project and help educate NHS staff at a team away day.

Conclusion

This SHINDIG enabled people living with Dementia and carers opportunity to discuss the topic of planning for the future. The attendees were at different stages in their individual journeys, but this enabled them to share experiences, advise each other and circulate relevant information. There was a strong sense of people supporting each other and positive relationships being forged between services and individuals.

Our next event will take place on Thursday the 5TH May at Quaker Meeting House 1-4pm

For further information about SHINDIG please feel free to contact

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