Sheffield Dementia Involvement Group

25th of August 2022

The 'D' Word

Use of language in Dementia

Background

While visiting different community groups post lockdown, facilitators noticed differing attitudes towards the word Dementia. It was agreed to explore the use of language in dementia. This topic was brought to the Tea and Talk planning group in July. Facilitators introduced the use of images to generate discussion as well as verbal questions. In July Tea and Talk took place at a new venue. Lab4living at Sheffield Hallam University have kindly agreed to host us at the White Building in Fitzalan Square for our quarterly planning meetings.

In August SHINDIG attendees were invited to share their opinions on use of language relating to Dementia and view tools and imagery used to assist and represent people living with a diagnosis.

In addition to verbal questions, facilitators had five sets of images which were used to direct and aid discussion.

Following a facilitator development session in May changes were made to the format of the SHINDIG event.

- Volunteers were asked to arrive at 12:30 to enable time for a briefing.
- Ten minutes was allocated at the end of the group discussions for (any other business/sign posting)
- Thirty Minutes was allocated at the end of the afternoon for facilitator de-brief.

In August we were joined by 16 people living with Dementia, 9 people with a diagnosis and 7 carers.

Summary

- For many the word dementia has negative connotations.
- Some images used to represent dementia are offensive. People preferred softer images that incorporated nature.

- If we tell people, we have dementia it can both help us, and educate them.
- How can our diagnosis be communicated across services, we're sick of repetition?

- What's the difference Dementia, Alzheimer's, Early Onset? Too many terms cause confusion.
- Sometimes professionals avoid using the D word.

- Groups like SHINDIG can inform, educate and challenge stigma.
- Attitude and lifestyle can make a big difference to length and quality of life.
- Alzheimer's Society help cards are discreet and are used by SHINDIG attendees.

- Images used to represent people living with dementia need to be varied and celebrate what they can do.

- No-one wants to see images which suggest lack of ability and loneliness.

- Films about dementia can be educational if done accurately.

- The dementia choir documentary represented people with living with dementia in a positive way.

- Images used to promote SHINDIG should be about connection, hope and a safe space.

Main Report

Questions

What word or words do you use to describe your diagnosis?

Some people felt that the word Dementia has negative connotations.

"You can't make it a nice word, it's like the big C used to be in the 50's and 60's."

"Assumptions are made if using the word dementia."

"When I was first diagnosed no one wanted to use the dementia word, avoiding it."

"It took my husband a long time to say it, he was that young It was a shock that he could have 'dementia' in his 50s. I try to avoid telling people that I don't know I think it's unfair to him."

"You don't want to admit it because you lose friends."

One carer highlighted the importance of a person's attitude towards their diagnosis and life style.

"My wife and a good friend were diagnosed at the same time. He saw it as a death sentence. Stayed in and kept to himself. He died four years later. In contrast, with us everyone knew from day one. She stayed active and she's still here fifteen years later."

There was a consensus that people were generally more accepting if the person with a diagnosis was older.

"It's easier when you have white hair, no shock horror."

Two people shared how different terms can cause confusion.

"I think dementia sounds far less severe that Alzheimer's Disease. People will talk about dementia, what's the difference?"

“People ask me is it Alzheimer’s Disease or just dementia? There are so many different types.”

One person felt SHINDIG could help to reduce stigma.

“I am grateful that there are groups like this that are trying to do something about it.”

A few attendees felt that there was no need to tell other people. while others shared the importance of acknowledging their diagnosis and how this could be beneficial.

“I describe my diagnosis as Alzheimer’s. That’s what it is, the quicker I get on with it. Your life is not over because of the diagnosis. I’ve been fortunate not to receive discrimination, sometimes misdiagnosis as mental health problems.”

“I do use the word dementia. If you’re struggling its nice for people to be kind when made aware of the dementia. Telling them allows time for both, it sometimes gives me enough time to pause to think.”

One person spoke about the shift in their relationships with family members.

“The family are becoming more accepting and understanding. They provide life stories and recordings to help me.”

This person chose to use term ‘memory loss’ to refer to their diagnosis.

Others had adopted a humorous approach.

“A touch of dementia is how I describe it to people.”

“I say I am not like everyone else; I’ve got what I’ve got and I’m keeping it.”

“I refer to my silly head.”

One attendee stressed the importance of kindness, regardless of any diagnosis.

“We’re all human, you get one life. If you are nice, you get niceness back”.

Is there anything else you use to let people know you have dementia?

The group were shown the following images.

"My husband used to wear a medallion attached to a lanyard. It said he had Alzheimer's and had his name on it. I had it made".

Sunflower Lanyard

Not everyone was familiar the sunflower lanyard, but most had seen people wearing them in public. One person felt it gets 'overused and abused'. While another shared how useful he finds it. An example was offered how it was used it in a hospital setting in case two people became separated.

Badges

One couple discussed how they would rather people know and be happy to wear a badge. Others preferred a more discreet approach, Suggesting wearing a badge that could be shown as and when required. People liked the fact that the forget me not came in sticker form and acknowledged that the image can indicate accessible environments.

The conversation progressed to how communication tools like these can aid people living with Dementia to travel.

“Tui have something called assisted travel and have taken care of me in the airport”.

“If notified they will help you onto the trains”

One group discussed the benefit of SHINDIG for sharing tips and information to help each other.

This led to a conversation about managing money. A new attendee spoke about her preference of using cash rather than a bank card. As this allows her to keep track of her spending. She was unable to purchase refreshments recently at a café that was card only. This caused embarrassment and lead her to ask.

“Should I have told the cashier I had dementia?”.

Solutions were offered such as having a cash card which has on it a specified sum of money.

Help Cards

Several people were familiar with, and frequently used the Alzheimer’s Society help cards.

“I found out about this by word of mouth, it can be kept in a phone case”.

“I have Alzheimer’s prompt in the back of my phone it’s brilliant”.

“You can get your card out when you need them or put them in your pocket”.

“My husband used it in airports”.

“I use it in shops when I don’t understand the special offers”.

One person took out the card he uses on the bus.

“Please be patient I have a hidden disability, please let me know when I reach my stop”.

He did add that at times bus drivers have been snappy and asked

“Are buses supposed to be Dementia friendly?”

Bus users amongst the group were aware of the large forget me not stickers on Mainline buses. One person shared that staff are only required to attend dementia awareness training every two years.

Most people agreed that the cards were a quick and easy way to inform others about their diagnosis. One person did raise the following point.

“When you get into difficulty and feel stressed do you have the wherewithal to get your card out”?

What language has been used by professionals when discussing your condition?

“My father had Alzheimer’s Disease, but they called it ‘weak executive control’ he was prone to confabulation. When I was diagnosed I asked is mine weak executive control or early stage? And they said just said yes. The GP advised me to deal with my affairs. Two years later I had not got work”.

Although this individual was required to give up work, he shared how an early diagnosis resulted in him being able to take control and use diet and exercise to influence mental and physical health.

“I got an early diagnosis, the beauty of that is that you can still get involved in things like food for the brain. I did all I could to counter every health issue. I’m doing what I can for other parts of my body because that looks after your brain as well”.

Several people could not remember the conversations they had when being diagnosed. One person recalled seeing his diagnosis in a letter.

“I received a letter before being spoken too”.

It was acknowledged that a professional’s background may affect how they discuss dementia.

“Culture and religion can affect opinions; some cultures don’t even have a word for dementia”.

Some people felt that it is easier for both professionals and people living with dementia to discuss physical health issues.

“Easier to say you have physical disability”.

In one group a GP was present who shared that some people are reluctant to discuss their symptoms. It was felt that this is due to fearing the consequences.

“People will think that they will be ‘put away’ I am relieved to know that isn’t common”.

“In the early days that would have been the case because there weren’t ways of detecting it early, so people would be sectioned”.

It was agreed that GPs shouldn’t shy away from discussion but perhaps be led by the person with the diagnosis.

One attendee who has regular hospital admissions due to physical health issues was keen to share two significant experiences.

“They didn’t know I had dementia; she just left the tablets on the table. Then asked sometime later why I hadn’t taken them. I’d forgotten”.

Not only was this person frustrated by the lack of awareness relating to his own needs. He also pointed out the potential risk to others.

“Anyone could have had those tablets”.

He went on to share that his experiences in hospital have generally been good but feels there is still room for improvement.

“More awareness and more education in hospitals”.

“One morning as she checked on us a nurse said”

“Just as well we didn’t’ have a dementia patient creating all night. It made me think about how I am going to be treated in the future. They often say you don’t look like you have Alzheimer’s you look too young”.

Attendees were keen of offer suggestions as to how professionals could make improvements. An issue that came up in this and previous SHINDIGs was the need for a system that shares a person’s diagnosis between services.

It was deemed important to place more focus on what a person can do not what they are unable to do.

If a consultation involves a phone call it was suggested to ask if a partner was present to ensure information was shared and documented.

The topic of Power of Attorney was mentioned as something professionals should raise.

How do you feel about these images used to represent Dementia?

There were strong reactions to this set of images. Some were offended while others related to the images.

“I hate to think these images would be used in a book to represent dementia”.

“The rubber is hard to look at, as I am still the same person”.

“That says it all really”.

People used words like disrespectful, negative, and upsetting to describe how the images made them feel. One carer commented that she wanted to run after and collect all the leaves. Another person suggested that the leaves represented

“life’s memories flying away”.

Several people regardless of whether they liked the images felt that they could be used to educated others.

“Direct in a way”.

“Could represent deterioration nicely”.

“If you are trying to get someone to understand”.

More people related to the natural images which they felt were more pleasant to look at and acknowledged loss over time.

“Nicer to look at more natural image”.

“Bits dying off as time goes on”,

“Sometimes that’s my brain”.

“My executive function is blowing away”.

The images led people to speak about their own behaviours and consider how they fluctuate throughout the day.

“Word searching, know the words are there, but can’t put finger on the right word”.

“Sometimes I feel like this image but sometimes I don’t.”

“Some people have moments of lucidity and then disappear again”.

How do you think dementia has been represented in film/television

While looking at these images one attendee complimented the approach of using images to aid discussion.

“I do find it fascinating the way you are handling this topic”.

There was a shared view that the media often perpetuates negative attitudes towards dementia.

“People are always shown in a nursing home”.

It was acknowledged that charities need to share the negative narrative to raise money. This led to a conversation about research.

“There is too much money used to research the wrong things, too much duplication. If I had a pound for every time I’ve been approached about ‘how the pandemic has affected me’”.

It was felt that films could raise awareness if done well. Some people had no desire to watch them while others showed interest.

“Still Alice is the best it’s true to life, my wife doesn’t watch them, but I like to see how accurate they are”.

“My family, watching it helped increase their awareness”.

“I wouldn’t go to see any of them myself”.

“I try to avoid watching films like that”.

One person spoke about learning a lot from reading personal accounts by people like Wendy Mitchell.

Several people had seen The Father and although found it difficult to watch were able to relate to it.

“It was really good, that’s what I do, similar struggles”.

“The father confused me”.

“It was meant to”.

Vicky McClure (centre) with members of the dementia choir *(BBC1)*

The image of the Dementia Choir a project initiated by actress Vicky Mclure was met with a very positive response. Most people were aware of it or had watched the documentary. People shared how they had found it a represented people living with dementia in a positive way. They also commented on the documentary having an emotional impact on them.

“It was kind”.

“It was most moving”.

“We all shed a tear”.

One person began to reminisce about their own time in a choir.

“I used to be in a choir at Norfolk Park, I went through a period of writing poetry. I read some of them and it stimulated older members who could do it from memory because they learnt it by heart as a child. What it stimulates can trigger all sorts of memories”.

The following images resulted from a Google Image search using the word Dementia :

People did not like these images and felt they represented sadness, regret and being unable to cope.

“Negative, thinking about what he could have done”.

Some commented on the people being so old. One person indicated the images showed one aspect of dementia but not the whole picture.

“Image is how it is but not how you are”.

This image was felt to be more positive, the woman sits alone appearing thoughtful but seems content.

“Positive”.

“Happy to just sit on bench or something”.

“I like to sit and listen to music”.

This image was deemed positive. It generated conversation about how people spend their time and how they engage with others. It was nice that this image made someone think of Sheffield dementia cafes.

“We have plenty of cuddles”.

“Absolutely loved dancing and listening to music”.

“This is common in memory cafes”.

People liked this image and thought the group were having fun. The image represents people living with dementia from the dementia enquirers group. One attendee kindly shared detail about each member and what they have achieved since being diagnosed.

“Four different positives, they have all done something new since diagnosis, including learning to swim and writing two books”.

This image was felt to represent an acceptance that dementia can affect people at any age. Although it was felt positive in terms of challenging stereotypes. It was also upsetting to some of the group.

“He/she is so very young; it breaks my heart”.

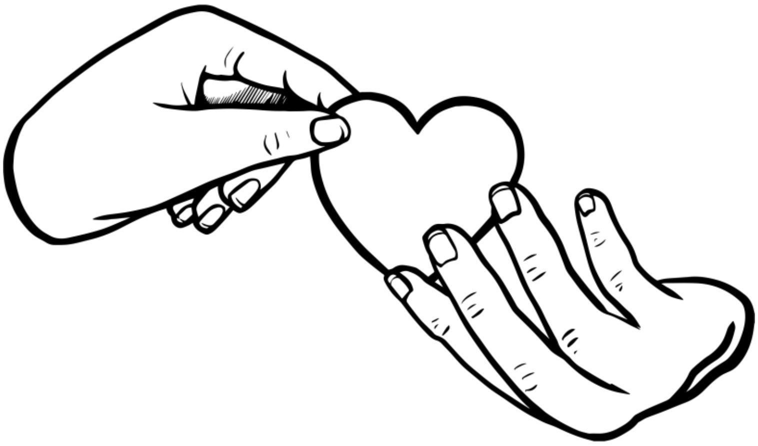
People felt all three images were positive because people were engaged in activities. They were busy, smiling and enjoying themselves. One carer suggested how her husband would be represented

“None of those images represent my husband, a better example would be a man sat at a computer”.

Illustrator images

The following images are some of those created by artist Emma Kitchen to promote SHINDIG. These were shortlisted by the Tea and Talk planning group last year who met with Emma via Zoom to discuss and adapt her artwork.

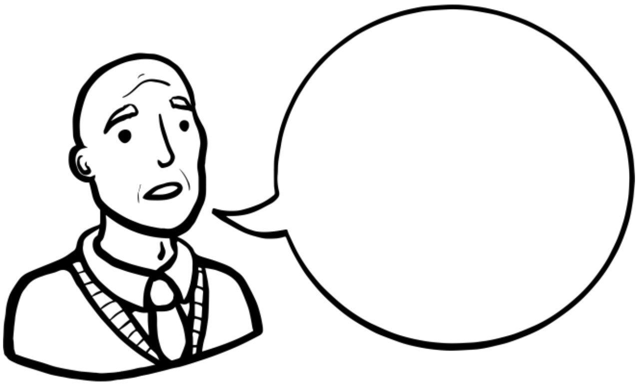
Not all discussion groups had time to comment on the images in August. Below are some of the comments we were able to gather.



This image was perceived by one person to represent two people squabbling over a biscuit.

People felt that this image was reassuring and felt good.

“Holding hands means a lot, it’s a nice gesture, its human”.



“Blank canvas, a bit like me empty with what to say sometimes”.

“It would be good to insert a message”.

People felt that SHINDIG would be better represented by an image that depicted a group of people.

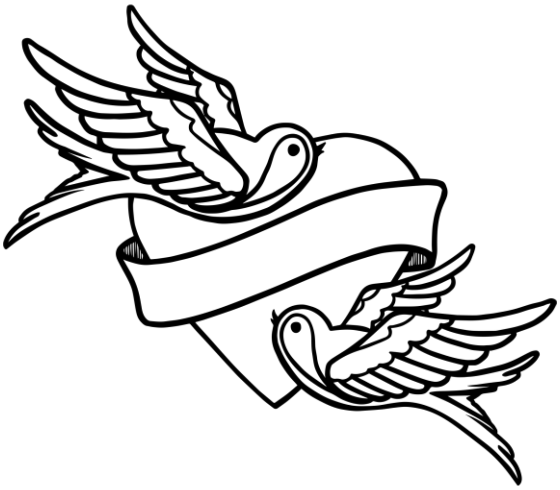
This image proved popular, largely due to the word hope.

“Hope is everything”.

“Next generation, hope for a cure”

“I like the use of the word ‘hope’

One person didn’t like the fact that it looked like a tattoo.



This was felt to represent SHINDIG as a safe space.

People immediately recognised the boat as an image that represented SHINDIG. The idea of ‘all being in the same boat’.

“I like that”

“Nice kind people do anything for you whatsoever

Conclusion

This SHINDIG gave attendees the opportunity to share their opinion on the use of language relating to Dementia. Attendees shared the words and terms they use to inform others about their diagnosis. They commented on a series of images intended to represent people living with dementia and explored tools aimed to inform others.

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