**Sheffield Dementia Involvement Group**



**December 3rd 2020**

**I know what I like**

**Looking at our tastes and preferences in everyday life**





SHINDIG is a collaborative project between Sheffield Health and Social Care NHS Foundation Trust and The Alzheimer’s Society. Our aim is to provide a forum where people living with Dementia, their family and supporters can have their voice heard around a particular topic. Topics relate to living with Dementia and health and social care services.

This SHINDIG was attended by 6 people living with Dementia and 7 carers. Apologies were received from 5 people due to illness or other commitments. There currently remain 25 people interested in attending virtual SHINDIGS. Some people recently contacted have declined to continue due to not being keen on the virtual approach or not being able to use the technology required. Changing health situations have also been given as a reason to end involvement by some couples.

The theme for December SHINDIG was brought to us by Marney Walker. Marney is an occupational therapist. Her work involves advising on the design of housing to make sure that homes are easy and safe to live in as we age. She is interested in how design can help people living with dementia to continue to do what they would like to be able to do in their everyday lives. Her research is looking into the importance of being able to choose the things that suit our personal tastes and preferences. Marney is based at the **Lab 4 Living Research Centre** at Sheffield Hallam University. **Lab4Living** specialises in design research that supports health and wellbeing.

**Summary**

* For some people the objects they liked often reminded them of family and loved ones.
* Objects that were shown to the group lead to people sharing stories. This often resulted in laughter and new knowledge.
* What people had chosen to have in their homes often celebrated where they had travelled and what they have achieved.
* People took pride in showing each other things in their home that they had made themselves. For example furniture and paintings.
* By seeing inside each others homes we learned about what people had done for a living and what hobbies they enjoy.
* Some objects were valued because they made daily life safer and easier and maintained independence. For example a mug with a lid that was easy to carry.
* Many people held on to things that had been given to them as gifts even if they didn’t particularly like the object. The kind act of giving was highly valued.
* People kept some objects for decades as they triggered important memories and sentiment.
* Some objects were simply too precious to use. These were usually objects given by the younger generation as gifts.
* Being able to make choices was deemed extremely important and described as both freedom and a human right.
* There was a consensus that choice is currently very much restricted as a consequence of Covid19

**Main Report**

**Attendees were invited to talk about their tastes and preferences in everyday life. People had been asked in advance to have their favourite mug or an object they really liked with them. Facilitators encouraged everyone in the group to show their mug/object and say why they liked it.**

**The group commented on their mugs/objects**

One person had brought a re-usable coffee mug with a lid, he explained that he loves coffee in the morning and likes to take it back to bed. He spoke about the practical benefits of his chosen cup.

*“It’s too hot in an ordinary cup I would spill it. With this cup, with it’s lid, I can take it back upstairs and have coffee in bed. I use two walking sticks so carrying an ordinary cup is too difficult. I take it up my upward slide.”*

Similarly, another mug was shown with a ceramic lid.

*“It’s for when you are in the garden and don’t want bugs getting in your coffee”*

Another person always picks a mug that he decorated himself, it was brightly coloured and had his name on it.

For one lady it was the design and colour of her cup that was important.

*“Roses are my favourite, a nice pink. Cuddly toys I love them. I lived with Grandma and she had flowers all over her house. This is when my love of flowers started.”*

One person Showed a mug that read ‘*the Atlantic bridge over the ocean’* and said he got it when on a Highlands Heritage holiday. This resulted in the sharing of an amusing story:

*“After the 45 rising Scots were banned from wearing kilts. Islanders would keep a pair of trousers in the pub on the island so they could put them on if crossing the bridge and then swap them back later”*

The same person talked about liking objects that told a story of where you’ve been.

The Sharing of favourite mugs lead to people sharing other aspects of their homes. Things that held real value to them and that they were proud of.

We were shown a dresser made by someone’s ancestors and told about a big wooden box that had been made into a cottage and a farm and given to a little girl. One couple showed us a really colourful splash back behind their cooker which had made from photos that they had taken of flowers and other colourful objects.

People spoke about how they had adapted their own homes.

*“I learnt how to wall paper the ceiling by watching videos on YouTube. The things I like around me are those I’ve made or done myself. This gives me a sense of pride. When I got married I bought a ten bob tool kit and still use it”*

*“My husband used to paint pictures and do woodworking. He had a studio in the cellar. We sent pencils to Swaziland and other bits to start art. He would not sell his paintings for more than a penny”*

A carer spoke about her husband’s skills at work

*“He used to work as a very good decorator and has done the decorating for everywhere in this house. This wall paper was put up in 1966. He used to sign all his walls before papering them”.*

There was a discussion about people painting or papering over and over, creating layers. One person described stripping wallpaper in their house in the 1970s and uncovering drawing pins from the 1940s used to attach blackout material.

Some people had mugs that were far too precious to use, they held great sentimental value. This often related to who had given them or what images or text was featured on them.

*“Here’s mine, worlds best nan. We’ve both got one but he doesn’t use his as he doesn’t want to break it”.*

**The group were asked if there were other things in the house that they liked for similar reasons.**

A ‘family forever’ cushion was then held in the air, it featured a photo montage of a grandchild as a baby.

*“He sit’s and talks to it all the time and says she waves and smiles at him”*

This person then squeezed the cushion, giving it a hug and smiled.

Objects frequently had connection to family and familiarity. At times they reminded us of what we are missing as a result of Covid 19 and lockdown.

*“This willow mug is from a set we use for everything. We bought them when we moved here 20 years ago. I like them because they are all same and we like the story of the willow pattern. We use them every day, for breakfast, dinner and tea. We would miss them, we associate them with get-togethers”.*

For some people objects had been with them for years. They triggered significant memories which clearly brought comfort and joy.

*“My grandson made this wall hanging when he was 10 years old, it says nanan and granddad”*

*“My mum made this Dusty Bin was for me to match my bedroom”*

*“My camera is always with me. It has lots of daft things on it. The old pantry downstairs has a lot of junk in it. I used to dance and found a Gold medal from 1951. I was really chuffed when it turned up”*

*“I have a sewing box which was given to me as a present during the war. 70 years I have had it. Brings back childhood memories”*

*“ This decanter and glasses are from Venice I cherish them. I have a cabinet full of memories. They become more cherished over the years. I can’t throw them away”*

**Attendees were asked how important it was for them to be able to choose the things they liked.**

*“It’s very important, it’s part of freedom”.*

*“ Yes, it’s a human right”*

*“You only live once so choice is important”*

*“Take away choice and I would not be very happy”*

*“Something that is important to you stays with you”*

*“Choices include health issues and where you live”*

*“COVID has meant I can’t go and buy stuff. It has taken choice away”*

**People were also asked how they felt about others making choices on their behalf?**

“Sometimes it’s ok, not others”

This lead to conversations about clothes and colour preferences. Strong opinions were voiced and there was a lot of shared humour.

*“I like blue. I knitted my husband a blue sweater but his father would not let him wear it because he was a United fan”.*

*“I bought a green suit but my wife said I shouldn’t wear it as green is unlucky”*

*“Never would I wear red. I like sparkly things, I don’t like dark colours”*

As with objects that held special memories people had also held on to items of clothing.

*“I have the dress I first wore when I met my husband. I can’t throw it away”*

*“I still have my trench coat, It brings back some memories”*

People tended to prefer making their own choices but would at times take into account their spouses preferences as well. Choices relating the home and decor were perceived as the wives role in some couples it where as others made joint decisions.

*“We would choose together we liked old fashioned furniture”*

*“Usually a joint decision then I say ‘whatever you like’ my wife used to make all her own dresses. We worked on Doncaster market”*

Two individuals offered practical advice on how they organise their clothing to make things easier.

*“I have a system for clothes I put clothes in one end of the wardrobe and shuffle them to the other side depending on the season. It stops me having to think first thing in the morning and saves my neurons”*

*“I used to work with a lady who would work out all her clothes for the week on Saturday evening and they looked so lovely all lined up in the wardrobe”*

**Have you noticed a change in your likes and dislikes?**

When asked if taste and preferences have changed there was a mixed response while one group all agreed that

*“You get more fixed in what you like and don’t like when you get older”*

In another group it was suggested that change is inevitable and a positive thing.

*“Tastes change, what appealed 20 years ago doesn’t now, especially in how things look. There is a distinctive look to each decade like 70’s 80’s. I’m a bit of a hoarder and have boxes of stuff that can’t throw away. They might come back into fashion. Its nice to be able to have a change”*

It was recognised that other people don’t necessarily know what ‘we like’ and several people spoke of receiving things they would never have purchased themselves. However there was a consensus that such items should be kept as the gesture of being given a gift was valued.

*“Someone bought me an animal print cardigan last Christmas, it’s not really me but I wear it when I see her as don’t want to hurt her feelings. Sometimes things doesn’t match your personality, someone else sees you differently don’t they”*

*“A friend got me a present saying ‘you’re going to really love it’ but I couldn’t stand it! And now I can’t get rid of it! My house is full of things I haven’t got the heart to get rid of because they were given to me”*

*“Everyone’s different, if people give you something it’s a gift, kindness, I would keep it. Its like the dolls house, its about kindness we put love into what we are doing, like we’re doing here in this group”*

**Does being able to choose the things we like make a difference to how we feel about ourselves?**

Accepting compliments about the Christmas jumper he had chosen to wear allowed one person to speak about roles that were of value to him. Recent work with university students had triggered positive memories of him dressing up in different costumes to entertain others.

*“I used to dress up as father Christmas for the last ten years. The life story work with the students has brought this all out. I would like to thank those students and staff. I also used to do clowning for my grandson”*

**Recommendations**

* It should never be assumed that people living with Dementia are unable to make choices about their preferences.
* Objects that people like can be used to generate discussion and positive memories.
* The objects we possess can also be used to maintain connection with loved ones.
* Colour plays a huge part in making choices about what we wear and how we decorate our homes. This should always be taken into consideration.
* Objects within the home can help us maintain our sense of identity and celebrate our achievements.
* Consideration needs to be given to the practical aspects of the objects we use. Can they do the job safely?
* Some objects can be used to comfort as they are not only pleasant to look at but also to hold.
* Can virtual access to our homes/possessions via zoom help us get to know each other better?

**Conclusion**

This SHINDIG provided opportunity for people living with Dementia, their carers and supporters to share opinions on what they like. Through three small discussion groups we explored the importance of being able to choose the things that suit our personal tastes and preferences.

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If anyone would be interested in being further involved in Marney Walkers research or have any questions or comments please contact her at:

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