



Sheffield Dementia Involvement Group

April 2024

Staying Put

‘Holding onto our independence at home’.

Background

The theme for April was Staying Put, Holding on to our independence at home.

Our discussions were in two parts.

In part 1 we used images of 'dementia unfriendly rooms' to prompt discussion. These were created by Age Scotland from 'A carers guide to creating a dementia friendly home'.

In part 2 the group were introduced to and asked to comment on a brand new tool, 'Me and my home' developed by Occupational Therapists Dr Clare Craig Charlotte Sutcliffe and Designer Helen Fisher.

Aprils SHINDIG was attended by 7 people with a diagnosis of Dementia and 9 carers/supporters. Amongst which were 7 new attendees. The three discussion groups were deliberately selected to enable a mix of established attendees with new attendees. Our observers this time were a clinical Psychologist from Sheffield Assertive Outreach Team and a volunteer from Sheffield Afro Caribbean Mental Health Association.

Summary

- SHINDIG attendees have existing knowledge of what works and what doesn't within the home.
- Roles at home change as Dementia progresses.
- Small changes can keep people involved in daily tasks.
- Looking after your body is good for your brain.
- Changing the environment can be disorientating.
- Familiarity is good, keep things in familiar places.
- Contrasting colours are so important.
- Avoid furnishings with geometric shapes, stripes, shiny surfaces.
- Occupational Therapists can really help at home.
- Accept what is offered to you, you may need it later.
- Attendees need longer to view written information prior to discussions.
- The booklet 'Me and my home' could help people plan for the future.
- The booklet was informative, well made and people liked it's layout and use of language.
- People felt they could re-use it.

Main report

Dementia 'unfriendly' Images

Each group were given a3 images of four rooms within the home and a garden. They were asked to spend a few minutes looking at the images then to share their observations.

The groups had no problem in identifying what could be problematic in each room. Particularly things that could result in injury from tripping or falling.

One group described the rooms as;

“Extreme, with not enough light. too much use of the same colour and the patterns are overwhelming”.

“It’s an accident waiting to happen, too much clutter. Things left out all over it’s overcrowded. There are too many cables and papers piled up. When I trip, I feel humiliated”.

One person acknowledged that it sometimes difficult for the carer to make changes in the home. Particularly if it is going to affect how the room looks. She acknowledged that it is important to consider the person living with Dementia.

The kitchen image led to conversation about changing roles. Carers commenting on the increased responsibilities they now have and the loss they feel.

“He used to do all the DIY in the house, it’s come as a shock as I’ve never had to get an electrician out”.

“I miss him putting the bin out. The car was his domain too, we missed the MOT because he used to do it”.

“Even the post is now my responsibility, he will pick it up and pass it to me”.

“The hardest part is it’s all on me”.

Some couples have made small changes so they can still share tasks within the home.

“We’ve just got a perching stool so he can prepare the vegetables and wash the pots”.

One person with a diagnosis has made significant efforts to remain healthy and active.

“My father had the same Dementia; I was next of kin. I learnt a lot about what was to come. I was utterly determined I would fight it as long as I could. Research affirms that if you look after every other part of your body, it’s brilliant for the brain”.

This person shared how he continues to have a productive life living as independently as possible.

“I still do family finance and driving, the heavy jobs. My wife gets surprised that I find a way to do things. I may become a carer for my wife, I aim to keep active and well enough for her”.

A group of carers spoke about their husbands using puzzles to occupy themselves. Sudoku seemed to be popular along with crosswords. Having a daily paper was also good for some people. One carer shared:

“He can still spell but can’t remember what’s happened a minute earlier”.

To which ‘he’ replied

“S-H-U-T U-P now I’m going to get a C-R-A-C-K”.

Existing Awareness

The group demonstrated a wide range of knowledge in terms of how the environment affects a person living with Dementia. Those diagnosed several years ago were able to share experience and tips with the larger group.

“Colours and patterns can be confusing; stripes and geometric shapes can feel like hallucinations. Curtains and carpets with patterns can be misinterpreted”.

“You need time to process things, you may need a picture as well as words to tell someone where something is”. Have pictures of the

contents of the cupboard. Some of these things may not be an issue now but might be in the future”.

Some people among the group rely on their spouse to get clothes out for them and were happy to continue with this routine. One person joked how he completely dismisses a new pair of trainers as he just doesn't recognise them as his own. He would continue to where his old ones unless prompted not to by his wife.

Making changes within a familiar environment can be detrimental.

“When you decorate a room, it might not be recognisable to a person living with dementia who has become familiar with the old décor”.

The act of making changes can be extremely disorientating and lead to increased dependence and frustration. A possession that has been moved could be perceived as having been lost or stolen, causing unnecessary stress.

“It is Important to keep things in their known place and not change things around unnecessarily. No two days are the same. You learn strategies to remain in control of what you can do to retain independence. Learning how to work with what abilities you have”.

One group discussed simple steps to help a person use their bathroom, which could also transfer into other rooms and spaces.

“Painting a contrasting colour line around a light switch and door frame can be helpful. Having a contrasting colour toilet seat from the toilet bowl. Handrail in contrasting colour to the wall on stairs. A toilet roll holder in a dark colour so that the roll is visible”.

One person spoke about the complexities of moving house and what helped them.

“The best thing that could have happened was a visit from an Occupational Therapist, the OT service was superb”.

A carer agreed.

“We had recently moved, and my husband had many falls. The OT input was greatly appreciated. He struggled making what I call ‘false steps’ which led to falls. I was told to put red electrical tapes on the steps to make them stand out which helped”.

A new carer shared how they are learning and adapting.

“I read something about plates, it’s harder to see food on a white plate. We now have red plates”.

The same person commented on their new bathroom considering how they may have made a mistake given what was being recommended by peers.

“I chose black and white floor tiles and a stripey blind with a zebra on it”.

Wise words

“Whatever you are offered, take it, you might not need it now, but you might be glad of it in the future. Accept any help offered. If you suddenly realise you need some help, you will have to wait. Look after yourself if you are caring for someone. You might not manage if you don’t. Remember you can hire wheelchairs from the Red Cross.

As at most SHINDIG events, gadgets like Alexa continue to be championed.

“Alexa can remind a person to take tablets, lock the door, have a drink, can also make a phone call. Which could be useful in the case of a fall”.

The subject of the garden led to a new attendee living with a diagnosis beginning to speak.

“I go in the garden, I don’t mind gardening, she has to fetch me in, it blows my hair all over. I just enjoy doing it, the fresh air”.

My home and me card/booklet

One group commented that it would have been useful to have the booklets on the table before the discussion, so that attendees could have had time to take in what they needed to see before the discussion started.

People felt that it was useful to have tips and liked the fact that they were in bold, so stood out.

“Having the questions to explore is good”.

The font size throughout was felt to be appropriate and people appreciated the use of language.

“You’re not talking down to the person with Dementia”.

“The wording is clear and strong without being too wordy and without being patronising”.

People began sharing what they already do.

“I would be ticking bright coloured towels and clothes”.

There was some confusion about the view finder,

“What is it for, is this a bookmark”?

“I thought you could look through it at your own room”.

One person commented on the title of the tool.

“What if you live with your wife? it should be our home and us”.

In terms of the aesthetics and layout.

“Pleasing to the eye, simple enough with not too much detail”.

“I would move the logo to the bottom right corner”.

Most people liked the colours used in the booklet, but one person felt they were not bright enough. She acknowledged as an artist being drawn to her favourite colours. This person would also like the book to have rounded corners.

Some felt that the tool was something they would re-visit.

“I feel like I could look at it again, I missed that the first time”.

A carer whose spouse has died commented that the tool would have been useful for them both.

The group acknowledged that the tool may become more relevant as their Dementia progresses.

“It will help awareness for me in the future”.

“It may not be relevant now but could be good to come back to in the future”.

The materials used to create the booklet were important.

“I like the fact that the book has a binder so you can fold it back. You won’t lose your place and it’s strong”.

People felt that the checklist was useful.

“We might not have thought of things, it will be helpful to make a note of the things we can do now, before the problem arises”.

Reading through the checklist led to all groups sharing more tips.

LED plug-in lights on the landing so that there’s enough light to see by in the night.

Inside locks can be opened with a coin from the outside if necessary.

Soap can be mistaken for food.

Whiteboard or blackboard to help person remember dates.

Labelling is no help if we can't read things.

Hot and cold taps- don't have boiler heat setting too high so burns can't happen.

Overall the booklet received a 'thumbs up' and people liked the fact that it generated a range of conversations.

Conclusion

Aprils SHINDIG gave people living with a diagnosis of Dementia the opportunity to discuss their home environment. They were able to share existing tips to maintain independence. The groups also explored the new tool Me and my home which aims to help people prepare their home in order manage the impact Dementia may have.

Any other business

Among discussions ideas for future SHINDIG topics were shared by attendees.

Exercise to keep healthy.

Care Homes, how are they classified? are they Dementia friendly? how are staff trained?

Resources in and around Sheffield.

The question was asked what is the best way for professionals to help people and let them know what's out there?

"Face to face. Conversations are always better than leaflets and written information. The best help is for professionals to speak to both the person living with dementia and their carer together, and then separately, so that a truer picture can be formed".

Closing comment

“If you have made a mistake there is no need to be ashamed or feel guilty. It’s not possible for a human being to know everything and how to do it all. The beauty of this group is that you can open up and everyone in the room understands because they’re going through the same things”.

For further information please do not hesitate to make contact.

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