



## **Sheffield Dementia Involvement Group**

**July 20<sup>th</sup> 2023**

**Influencing the Sheffield Dementia Strategy**

## **Background**

At our July SHINDIG we were joined by 9 people living with a Demetia diagnosis and 8 carers/supporters. Amongst attendees 5 were new to the group. In July people were invited to influence the Sheffield Dementia Stategy. Our plannning group 'Tea and Talk' met in June to negotiate which commitments from the strategy we would discuss in July. It was acknowledged there was a lot to choose from so we agreed that discussion groups would focus on the following two commitments:

Sheffield will become a Dementia friendly city.

For people with Dementia, support in Sheffield will be more personalised, local and accessible to help people remain independent for as long as possible.

## **Summary**

**Should we have to let people know about our diagnosis?**

**A 'Dementia Friendly' approach would suit everyone.**

**The attitude and body language of staff in public places is crucial to a persons experience of going out.**

**Physical limitations often prevent engagement and remaining involved.**

**There is not enough provision for carers, particularly those who are bereaved.**

**Documents like an abreviated 'This is me' could be a useful tool for getting to know a person.**

**People like to have a challenge and opportunity to help others.**

**It is important to have self awareness and plan more complicated tasks in advance.**

**'Dementia Buddies' should be endorsed.**

**Parking and access to certain places is a barrier to engagement.**

**It is essential to see people 'living with Dementia'.**

# Main Report

## What do you think is meant by the term ‘Dementia Friendly’?

Group one was presented with the scenario of going out for a meal and asked what things they would need to take into consideration.

Prompts included: staff attitude and communication, environment, layout, colour, flooring, signage, seating, paying the bill and finding the toilets.

The following menu (In its actual format of A3) was used as a prompt to generate discussion. Selected due to an actual experience by the Coordinator of SHINDIG. Who would like to stress that the staff and food at this establishment were both very good.

The design of the menu...well...decide for yourselves.

The menu is for 'The Hickory's Meats' and is divided into several sections:

- APPETISERS:** Includes items like Chicken Wings, Chicken Fried Chicken, and various sandwiches.
- BURGERS & SUBS:** Features 'Everything Under the Sun!' burgers, including the Hickory's Burger, Hickory's Veggie Burger, and Hickory's Double Cheeseburger.
- MAINS:** Offers dishes like Country Steak, Hickory's Prime Rib, and Hickory's Chicken.
- ON THE SIDE:** Lists items such as Hickory's Potatoes, Hickory's Mac & Cheese, and Hickory's Biscuits.
- BRUNCH:** Includes Bloody Mary, Pancakes, and Breakfast Patties.
- THE SMOKEHOUSE:** A dedicated section for smoked meats, featuring Texas Style Brisket, Hickory Wood Smoked Pork, and Hickory Wood Smoked Chicken.
- DESSERTS:** Offers Hickory's Fro-CO, Mac 'n' Cheese, and Hickory's Waffles.

The menu also includes promotional offers like 'SMAP OUT YOUR FRIENDS!' and 'Sprinkle some MAGIC!'.

During discussion, people spoke of the dilemma of needing people to be aware of a Dementia diagnosis yet at the same time not wanting to stand out.

“How do we convey to someone that we need help for example getting to a seat in the cinema”.

“How do you let people know without putting a badge on, how do you make people aware without having a label”.

One person shared that he only lets people know when necessary. Offering the example of being in the airport going through security.

“It is far too stressful to become separated from my wife”.

“I just want to be normal. Should just expect a level of courtesy”.

Some people were worried about the consequences of wearing a badge or lanyard.

“Other people think you’re getting special attention, some people limp, pretending, to make it feel more legitimate”.

People were aware of signage that indicates ‘Dementia Friendly’ services or environments but questioned them.

“Buses have dementia friendly logos, but they are not always”.

“Invisible illness, people are not always kind and considerate. It’s not a Dementia friendly world”.

“No good having Dementia friendly badges if staff aren’t trained properly. Just lip service”.

“Everything should be accessible to everyone, but it comes down to money”.

Carers commented.

“People with a diagnosis aren’t as stressed as partners. Thinking, what if”.

“Suddenly we are the person who has to do everything, if we forget, it’s forgotten”.

One person referred to ‘tracking’ to provide ‘peace of mind’ and continued independence for the person with a diagnosis.

## **The menu**

Initial comments related to the size of the lettering. People felt it was far too small and too busy.

“I’d need better glasses to read that”.

Having all the choices on one page was not helpful.

“I would feel forced to choose too quickly without having time to look properly”.

For some people, looking at a menu and taking their time to make choices is part of the overall experience of going out to eat. A menu like this could prevent them doing so independently.

“Floor coverings don’t matter to me; I like to browse the menu”.

“I wouldn’t go if I couldn’t read the menu”.

“I wouldn’t choose, I’d let someone else pick”.

One person reflected on what Dementia is taking away.

“With each little compromise it’s chipping away at my independence”.

Viewing the menu led to discussion about colours and problems reading the text on tablet boxes.

“Red and orange on white is hard to see”.

People shared opinion on going out in general and what puts them off.

“It can be too noisy, shouting in the streets”.

This group felt that staff tend to be of the younger generation and wouldn’t understand them. One person described the menu as:

“Very modern, it’s for the app generation”.

When asked what would make going out more dementia friendly. People felt that attitude of staff was the most important. Being served by knowledgeable staff who showed respect. Also, of importance was being able to locate the toilet in an unfamiliar environment. People felt it was common sense to make things dementia friendly as this would help everyone.

“Businesses should realise that there are many people with disabilities. There’s a good catchment of them coming out to spend money. People with Dementia come out to groups then go out together to get a cup of tea”.

**Group two** were given a copy of ‘**This is Me**’ a document produced by The Alzheimer’s Society and Royal College of Nursing. It aims to help health and social care professionals build a better picture of who a person really is. Helping them to deliver care that is tailored to a person’s needs. The group were invited to complete part of the document in pairs.

This group had four new attendees.

During introductions a new attendee made a statement which was felt to indicate his initial reaction to being at SHINDIG.

“I had such a warm feeling being here and it will make the next four years much better...mistakes can be corrected, and it is always worth getting up in the morning”.

None of the people living with Dementia or carers had seen this document before. It was felt that it could be used as a tool to get to know someone better.

One attendee who works as an agency carer had seen a similar, abbreviated form which includes a photograph of the person, a short history and a list of likes and dislikes.

Another carer felt the form was useful even if you missed bits out but felt that its effectiveness would depend on staff having the time to read it.

Filling the form presented some challenges.

“We didn’t have enough room to fill in everything”.

“We had hardly started, it’s brilliant but not manageable at that intensity”.

“It covers some very wide areas of a person’s life, and some questions were difficult to answer. For example, the one about routines and ‘I would like you to know’ this section seems too vague...know about what?”

A couple of people felt that questions about personal care could be,

“Tricky”

Another person shared that she would tell people what was important to her.

“The food I like and to be left alone at times”.

The people with Dementia in this group felt that they would need someone else to complete the form for them.

“I would like my daughter to fill it in”.

“My wife would fill it in in two minutes”.

One of our new attendees began to describe what was important to her and experience of a recent diagnosis.

“I think they’ve found some cures for this. I think it’s help for folk. I’m independent, I like to do things by myself. I never thought I had it until recently. I went to the hospital for tests and realised I must have had small strokes. I’m not particularly bothered about it to be honest. Can you tell if a person has Dementia when you meet them?

This person was informed that you meet one person with Dementia you’ve met one person with Dementia. Although people may experience similar issues, everyone is unique. The group were asked if having Dementia had changed anything.

“No, because I live on my own. It’s not the stigma because lots of people have it and don’t even know they’ve got it. Half the folks I live with forget things. We get up in the morning and we think, what day is it”.

One person shared how it is physical health that prevents her doing what is important to her.

“I’d like to get back to normal. Dashing here there and everywhere”.

She referred to doing charity work with the Salvation Army.

“They sell things and do things that help people and that’s good. The breathlessness slows me down. I get help three times a week (paid carer) and my daughter comes”.

A carer whose lost her husband shared how she values her ongoing connection with a memory hub and the carers involvement network.

A new carer wasn’t aware of the support available for carers.

“This is our first toe in the water”.

Her husband shared his views of the afternoon.

“I have an appreciation of all of you, this afternoon makes me think that things need to be done in a different way”.

### **Group three**

#### **What do you currently access or do that helps you live with Dementia?**

Attitude was felt to be an important factor to living with a dementia diagnosis.

“I’m still me, things have just changed a bit. One thing I have learned is to never give up”.

Planning in advance was offered as a method of managing more complicated tasks.

“I do research before a trip out, as it’s easy to lose track of things otherwise. I’ve even got myself to London and back”.

Being actively involved, sharing knowledge, and learning from others.

“From coming to these groups over many years I’ve seen that the people who do the best are the ones who stay involved”.

“I like coming to SHINDIG because I can still learn from other people”.

“I don’t go to a day centre because I get involved in all these other things, research, volunteering. I’m involved in a project to advise researchers about driving and dementia. I will be presenting about it at a dementia conference”.

Self-awareness, knowing your ability and limitations.

“It’s helpful to know what I should and shouldn’t volunteer for. Like I shouldn’t volunteer for something that needs too much of my brain. So, I volunteer at a care home and an older people’s club at church. My wife said I could volunteer if it didn’t involve her. That sounds mean but it was good for me. I’ve learnt to be ultra independent”.

“As a challenge to myself, I do the weekly shop. It is a challenge as I lost my sense of direction and need mental arithmetic to get the best deals”.

People in this group reflected on some of the challenges faced by carers.

“It’s hard for partners, they can break down. It’s a big thing”.

“There is nothing much in place for the person left behind”.

“People still have valued things to give even after their partner has died”.



One carer remains actively involved long after the death of her husband.

“I’ve made a lot of friends at the dementia cafes; I love mixing with people with dementia. It’s nice for me to help. Some are further along the line, all are lovely. Most of them know what I’ve gone through, and we’ve all experienced the same thing”.

Having a Dementia buddy provides purpose and support.

“Coming to SHINDIG led to me getting a dementia buddy and getting involved”.

One of the most valuable outcomes of SHINDIG is the peer support which takes place at each event and beyond. Those who have been recently diagnosed are frequently taken under the wing of more experienced attendees who, support, inspire and acknowledge the reality of the situation.

“I have a recently diagnosed dementia buddy who I can advise on what helps me and hope it helps him too”.

“Dementia buddy scheme, you should push it and endorse it. SHINDIG was the start of it for me. You come in a bit green, get invited to a café. Next thing I know I’m off to a dementia conference in Glasgow. It’s someone to give you little tips and a heads up on what’s coming”.

One person advised speaking to city centre ambassadors if you get into difficulty in the city centre.

### **Is there anything you need?**

One person identified the importance of first impressions, the impact of facial expression.

“I like smiling faces, otherwise I get anxiety that I’ve done something wrong”.

Another person shared what she finds problematic while out and about.

“My thought process mean I have difficulty with tram crossings. Roads are fine but tram lines are hard. They are also on about closing the ticket offices. You won’t be able to go and ask a question”.

A further person relies on technology but also struggles with it.

“I had a lot of trouble with my laptop. I rely heavily on it for online Dementia meetings. Technology is valuable but we’re reliant on it and it’s disruptive when it doesn’t work. Who can we ask to fix it”.

The issue of automated telephone messages also causes difficulties particularly for people living on their own.

“I now struggle to use the phone; I can’t remember what they’ve said to me too many choices”.

Parking prevents people from accessing what they need too.

“If we want to stop in some places, it’s the distance that the disabled Parking is from where we want to go. For instance, the National Trust, Yorkshire Wildlife Park, they have moved the car park. I complained and they said we have scooters you can use. I said what about attendant-controlled ones.

“At the Botanical Gardens there is no onsite parking. There is a drop off point but who’s going to look after the person who has been dropped off?”.

“I can’t go to the Young Onset Group at Norfolk Park because it’s too far from the Tram or the Bus Stop”.

“People who haven’t had the experience can’t perceive how difficult it can be”.

### **How can you influence change?**

“You must start at the top, with the council, the trusts, the commissioners”.

“Walking into a room and seeing people living with dementia is so powerful rather than people dying with dementia”.

“I worked for Sheffield Health and Social Care; I was a governor. I know within the trust who to contact. I was always polite and diplomatic, but I was known as the Yorkshire terrier with a bone, and I wouldn’t let it drop until I got something done. I am used to speaking at a high level. I have written to the newspaper about the Ticket Offices closing. I don’t know whether it will make any difference, but I have done it”.

## Conclusion

This SHINDIG offered people living with a Dementia diagnosis and carers/supporters the opportunity to influence the Sheffield Dementia Strategy. We adopted a slightly different approach in July, each group discussing different topics. We asked people to share opinion on the meaning of the term 'Dementia Friendly'. We asked them what they are currently accessing to help them live with Dementia. One group explored the 'This is me' document produced by the Alzheimer's Society. Another was asked how they would like to influence others. Time allocated at the end of each discussion group enables facilitators to sign post and share appropriate information.

For further information please do not hesitate to make contact.

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For past reports go to [www.shsc.nhs.uk/shindig](http://www.shsc.nhs.uk/shindig)

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**Next SHINDIG will take place on October 5th**