

Sheffield Dementia Involvement Group

August 2024



Further influencing the Sheffield Dementia
Strategy

Background

In July 2023 SHINDIG was invited to discuss the term 'Dementia Friendly', and asked what they currently accessed in their local area to support them to live with Dementia. This information was used to influence the Sheffield Dementia Strategy. Before the new strategy is finalised, partner organisations wanted to check in with SHINDIG to make sure they are planning the right things. The following three topics were selected for discussion and each group were asked questions in a different order to ensure opinions were gathered on all 3 topics.

GP Dementia diagnosis

Support for carers

Getting support from local Dementia support services

In August we were joined by 17 people living with Dementia, 9 with a diagnosis and 8 carers/supporters. One couple chose to share their opinions via email, these have been incorporated into this report.

Summary

- GP's diagnosing Dementia could be beneficial if properly resourced.
- People asked, would GPs be able to prescribe and would this diagnosis be accepted by other services?
- A desire to maintain important roles, independence and honour wedding vows prevents people asking for help.
- Not everyone identifies as being a 'carer'
- After diagnosis having a named person to contact would be the ideal.
- The financial impact of needing care provision at home causes anxiety.
- Information about services needs to be provided in all formats as not everyone uses the internet.
- Service providers need to reach out to people living with a diagnosis.
- Stigma associated with Dementia and age create barriers to accessing services.
- DAS The Dementia Advise Service can be accessed before and after diagnosis

Main Report

Dementia diagnosis

If you had advanced Dementia, how would you feel about your GP (rather than the memory service) making your Dementia diagnosis?

The topic of diagnosis always triggers an emotional response from attendees.

Several of whom described negative experiences.

“We had to wait two years for a diagnosis and then were offered no help I feel we missed out for a whole two years”.

One couple used private medical insurance to speed up the process of diagnosis, another had considered this.

A person with a diagnosis described feeling

“Brushed to one side”.

A carer suggested that following diagnosis it would have been useful to have had a care plan advising her and her husband on when and why they should get in touch with services.

Another person sought help after recognising the same symptoms he had observed in his father. He was later diagnosed at the hospital and felt they had been dismissive. His GP had told him.

“I can mend your body but not your brain”.

This led to this person taking control of his own health by making lifestyle changes.

“We should be taking an all-round fitness approach”.

In one case a dentist had identified signs of Dementia and took the initiative to refer this person to their GP.

Most people agreed that GP’s diagnosing Dementia could be beneficial.

“If GP’s can diagnose people in care homes, why can’t they do it for people living at home”

“Yes, in favour of the idea it would save a lot of time and a lot of worry”.

“Yes it would be streamline and cost effective, that’s with my business head on”.

“Yes, as long as it can be resourced properly”.

“If GP’s are aware of the different forms of Dementia that would be extremely helpful. If a GP can refer an individual for CT or MRI and then understand the results, thus enabling a correct diagnosis it would mean not having to wait over a year to see a consultant to have the tests. It would also mean vital medication could be started much sooner”.

It was also highlighted that a GP may be able to observe changes in personality over a period of time and suggested that GPs could complete the MMSE.

(Mini Mental State Examination) on an annual basis to check on brain function.

People did raise important questions and concerns.

“Are we putting too much on GP’s? they are already overloaded and working into the evenings”.

“If GPs diagnose, will they then be able to prescribe and say if people can still drive”.

Do GP ‘s have the skills to diagnose and would their diagnosis be accepted by others?

“Sometimes intelligent people can pass ‘the tests’ even though they have Dementia. Most GP’s have a particular interest in different areas of medicine, so would it work with GP’s who didn’t have Dementia as their specialist area”

“Would Social Care accept a GP diagnosis of Dementia, is there a letter or a form that would need to be completed as proof”.

Carers and supporters, identity and help

How can we help more people think about themselves as carers, and encourage them to ask for support as early as possible?

Several people did not feel the term 'carer' applied to them.

"The word carer means someone is dependant on you. That idea can put people off".

"My wife is my wife her role isn't my carer, it's problematic living with me but we get by".

Some were fearful about other people getting involved.

"You think there is no-one who can look after your spouse better than you can".

"Once you admit you're a carer the whole system gets involved and takes over your life and you lose control".

Some spouses felt it was their duty to care regardless of the circumstances.

"When you get married you say you'll care for them in sickness and in health so it's just part of what you should do".

"I don't mind doing what I am doing because of my wedding vows".

Comparison to others can prevent people from reaching out.

"You always think there is someone else worse off than you out there who needs help more than you, so you don't want to take the help".

"I know I am a carer but I want to be independent and cope . I don't want to need assistance".

Two attendees referred to the inequity they had experienced between Cancer and Dementia services.

"It was his Cancer that gave me the support, not the Dementia. When you have Cancer, the carers can get help at home and treatments for free. They couldn't do enough for me. For Dementia there is very little for carers".

Having a named person to reach out to was deemed essential.

"After Cancer diagnosis I was told that the same person would support us throughout".

“I open up to the nurse, who you feel has more time. Nurses can start up a conversation easier and before you know it you’ve told them everything”.

“So many times after his Dementia diagnosis I have had questions but did not know who to ask”.

There was plenty advice offered by attendees

“The Dementia strategy should recommend referring a newly diagnosed person with dementia's carer for a carer's assessment. Professionals making a diagnosis should be aware of this service. A carer's assessment can help to start the conversation about the carer role, and diagnosis is the best time to do this. Without those initial referrals, you can go from diagnosis to crisis point. Better pathways would save money as the most expensive care could be avoided”.

One carer stressed the need to be specific about what a carer role involves.

“Ask them to complete a survey to identify all the things they do for the person with dementia and how many times/hours a week they spend doing these things”.

The use of images depicting roles that carers may perform was felt to be accurate and many could relate.

“Yes, to all of those pictures”.

“I do all of them for my partner who lives with Dementia”.

Some couples commented on the need to share tasks to help the person with a diagnosis feel valued”.

“I can still do some jobs around the house”.

The financial implications of needing support to keep their spouse at home was a huge concern for one couple.

“Even if people do identify as care-givers the help that is available is means-tested, so if one is above the threshold (even just a little) there is no help, unless you pay for it. There will come a time when I will need to pay someone twice a day so that I can just walk the dogs. Then have someone in so I can do the food shop once a week. I haven't a clue how we will manage financially when that happens. It is all very well asking for support, but if the person you

care for does not want help or someone else coming into the home there is no easy answer”.

Attendees thought the strategy should recommend a local Dementia Cafe as some have carers groups attached. Some people had experienced a loss of activity and social life since diagnosis.

“Empty diary syndrome, it feels like the world closed in bit. That was our biggest challenge”.

This led to discussion about the 40 memory cafes across the city.

“Is there a list available, how do I access it, can you send me one”.

One group discussed the role of a person caring from a distance and the need to inform them of what services might be available to them in their city.

The subject of Admiral Nurses was raised, and all attendees were made aware that a new service is due to commence in Sheffield. The two Admiral Nurses providing this service will be attending the next SHINDIG event on November 28th.

Another group spoke about past SHINDIG events where numbers allowed for groups to be made up of People with a diagnosis, Carers or a mix of the two. This group agreed that now our numbers have increased we should resume this approach to provide couples with time apart.

Getting support from local Dementia support services

Several people believed that they had to have a diagnosis before they could access services.

“Not having a diagnosis is a barrier”.

“I’ve only just found out about Dementia Advice Sheffield and that you don’t need a diagnosis to access it”.

One couple shared sensory, mobility and psychological issues which prevent access services.

“My wife is not comfortable meeting new people/situations/places. Noise and lots of people cause anxiety. There is the inability to get to and from coffee mornings. People not understanding her type of dementia. Visual problems

(due to dementia) results in not being able to take part in activities. Spatial problems (due to dementia) leads to not being steady on her feet”.

The stigma associated with Dementia can also have an impact on willingness to access services.

“The way dementia is portrayed in the media and the attitude of some healthcare professionals impacts access to support”.

“The public need to know and understand what to do if someone in their family has signs or symptoms. Everyone needs to be aware. That will help people. We need to increase society’s understanding of dementia in general and the steps involved”.

One person commented on age, being a factor which presents a barrier.

“We don’t feel a need to attend groups yet, my husband is young to have Dementia”.

Another carer shared having had a similar opinion.

“I felt the same but never looked back after going”.

Even with a diagnosis some people still felt at a loss in terms of what was available to them.

“You’re set adrift once you have the diagnosis. You’re on ‘their books’ till you die but there’s no-where that tells you what these services are and how to get hold of them”.

“I didn’t get any information when I was diagnosed”.

“I’ve just been left”.

What about people who don’t use the internet?

“I don’t go on the computer I can’t remember what to do, so online information isn’t any use”.

“Some people don’t use technology or have a smart phone”.

“Too many assumptions are made about people. If you can’t get on the net you’re at distinct disadvantage”.

Who should, point you in the right direction?

“I feel you need the GP to tell you what the services are. Getting in touch with your doctor is the problem, it’s frustrating not being able to get an appointment, that’s the first place you’d think to go”.

“There needs to be leaflets in GP surgeries”.

“When GPs do dementia reviews, they should check what people are connected into and connect them if they’re not already”.

“I rang The Alzheimer’s Society; I only knew how to because I volunteered for them in the past”.

One person stressed the need for services to be more pro-active in reaching out to people.

“If you have a diagnosis the services should reach out to you, not the other way around! It’s not my responsibility to contact them; *they* need to call me”.

Knowing which services to choose can be difficult

“Hard to know what services we could access as my partner's presentation changes so quickly; I don't know which services would be suitable for them. For example, for them to see someone in the late stages might be quite scary, currently we try to keep things as normal as possible. Important to respect the views of the person living with dementia when considering which services to access”.

Provision of appropriate services for the duration of a persons’ Dementia.

“Continuity of services is important, you can't just drop people when their dementia progresses, this can leave them in crisis”.

What are people accessing now?

Some attendees go to memory cafes and spoke positively about their experiences. Not only of the cafés themselves but the peer support created through attending.

“We go to the café at Freshville it’s very good. We went to a gong bath that was great, very relaxing. We also have a Whatsapp group and support each other and it is great for communication”.

Six SHINDIG attendees are now part of DRAISY Dementia Research Advisory Group South Yorkshire. Three attendees go the Sheffield Early Onset group run by Age Uk.

Recommendations from attendees

“We need a calendar for the city of all the different dementia cafes. Print it out in GP surgeries. Post it to people. Give it to people at SHINDIG. Post it out with the bin calendar”.

“Could there be signs/posters up at bus stops? Posters/signs in taxis? Physical posters”.

“Should have a dementia café in the town hall 3 times a week, then people could get information there”.

“There needs to be something permanent (a dementia drop-in/shop/base) in the middle of Sheffield for people with all disabilities to come to. They’d be spending money in town so it’s a no brainer”.

This SHINDIG gave people the opportunity to further influence the Sheffield Dementia Strategy.

Paper copies of a city-wide memory café list will be provided at the next SHINDIG on November 28th.

For further information or to request a referral form please contact:

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For past reports go to www.shsc.nhs.uk/shindig

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