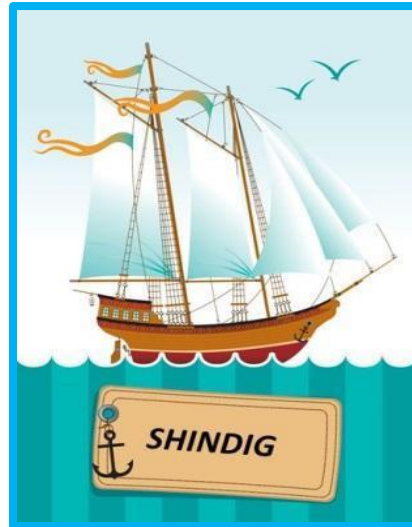


Sheffield Dementia Involvement Group



SHINDIG 24

Thursday 7th March 2019

Report:

Information, advice and support services:

Experiences and needs.



Background

This Sheffield Dementia Involvement Group (SHINDIG) topic was requested by Sheffield City Council commissioners, who were in the process of exploring the re-design of information, advice and support services in Sheffield. The ideas were endorsed and tested out with Tea and Talk (SHINDIG planning group). A range of questions posed by the commissioners were adapted in response to Tea and Talk feedback in order to promote discussion within the main SHINDIG.

This SHINDIG was attended by 18 people living with dementia, 12 family carers / supporters and was supported by 16 staff facilitators or visitors. People opted to discuss the topic either in one of two groups with just people living with dementia; in a mixed group with people living with dementia and their family carer / supporter or in a family carer / supporter only group. Questions and prompts were used to guide the discussions and responses were recorded on flip charts. These were typed up and this report reflects the key themes that arose from the responses, each theme is supported by responses from group members. These tend to reflect the views of people living with dementia first and then the views of family carers / supporters.

Findings

1: The range of places that people currently access information, advice and support.

People described a range of places that they access information from, these included: Alzheimer's Society; Age UK; Darnall Dementia Group; Memory Service and Memory Clinic; Citizen's Advice; Chapelton Advice; Sheffield Carer Centre; libraries; family; Occupational Therapists; GPs / care navigators; Patient Advice and Liaison Services; Buddies; Faith groups.

- *Enjoy Darnall Dementia Group – wonderful, lots of support, calming and supportive, but there is a waiting list. Worried about closure and lack of funding.*
- *Carers group – need to have one where person with dementia isn't there – good at Darnall Dementia Group and Central Café Church.*

People did value the opportunity to drop into a centre – for example Age UK in town. People who had accessed the Alzheimer's Society for a number of years talked about missing the opportunity to just drop in when the office moved out of the City Centre.

- *Age UK very good also Alzheimer's Society (AS), although AS not as responsive and good since move from the City Centre, not very accessible any more.*
- *Having an accessible location accessible by car, tram etc. in central location.*
- *Not allowed to go into AS anymore, feel detached, answer machine. In times of crisis need for a 'private' room to actually talk.*

Another key source of information was from other people with dementia and other family carers / supporters, through groups such as SHINDIG, Dementia Cafes and peer support groups.

- *Enjoying coffee mornings and cafes, find them useful but only some can attend.*
- *People may or may not want to join a group – but in fact it helps when you join a group.*
- *Peer support is the most important – learning from your peers is more valuable than listening to a professional.*
- *Being in peer support groups is more relaxed – no-one will tell you you're wrong.*
- *Peer activities reduce self-consciousness – it doesn't matter if you make a mistake.*
- *You get to find out about benefits and support – most information we find out comes from groups like this rather than going asking for advice.*

2: The importance of information, advice and support services having an in-depth knowledge about dementia and how it affects people.

People with dementia and family carers / supporters described how important it was that services providing information, advice and support understand dementia and the ways it affects people.

- *We need a dementia specific service.*
- *It's difficult to get people to understand what it's like to live with dementia.*
- *SHINDIG makes it easier to accept having dementia because people listen and understand. People here are not scared of having dementia.*
- *There is a stigma surrounding dementia, some from society and some from professionals.*
- *Alzheimer's Society provides a service where dementia is not stigmatised or feared.*
- *Realising that dementia means you have to slow down and not jump to conclusions – it is important that those around you recognise this.*

- *Professionals can patronise or assume that a person with dementia understands – it's important that they check understanding.*
- *Information, advice and support workers need to have worked with a lot of other people with dementia and be very supportive to new members.*

Associated with this is the need for information, advice and support services considering the environment / atmosphere to make it conducive for people living with dementia:

- *They're good at listening at SHINDIG.*
- *It' needs to be friendly – that means a lot to people living with dementia.*
- *Environment is important – one to one and quiet environments make it easier to stay calm – business and noise can increase confusion.*
- *Meeting people is important and it's relaxed and social.*
- *It's good we can go together as a couple.*

It was emphasised that information, advice and support services need to recognise and support the emotional aspects of living with a diagnosis of dementia:

- *Being diagnosed with dementia is frightening.*
- *Dementia can result in lack of confidence initially – time improves confidence.*
- *Attending cafes and groups improves confidence.*
- *Need to have a lot of acquired knowledge, it can be very scary and can't just 'go away and make a cup of tea'.*
- *Carer stress cannot be under rated.*
- *Need to have a place to talk to other carers and how to cope, very beneficial to carers without person with dementia.*

3: The sorts of information, advice and support people would find helpful

People described the range of topics that they would find helpful to receive information, advice or support on:

- *Support and information is needed about the changes dementia can bring – maybe from GP?*
- *Course on living with dementia was good.*

- *Research into things that can improve the life of someone living with dementia – diet / exercise.*
- *Research into living with dementia is limited and slow but is starting to appear on NHS and Alzheimer's websites.*
- *Information about the progression of dementia is wanted by some individuals and not by others.*
- *More information about mindfulness and caring for yourself is needed.*
- *Information is needed about socialising – eg cafes.*
- *Dementia diagnosis = learning.*
- *Services should support people with care plans, rights and wishes.*
- *Legal rights.*
- *Hospital discharge rights.*
- *Have a private chat over a cuppa.*
- *Help with filling out forms.*
- *Crisis help at any time of day or night.*
- *A list of things / government help that they are entitled to.*
- *There can be BIG changes after diagnosis for example having to stop driving.*
- *You can give up driving voluntarily, driving is a big issue that can be shared.*
- *People with dementia can work with students / researchers for example the University life story work group.*

4: Information, advice and support services for people with dementia are lacking in equality compared to those for cancer services

Some people with dementia articulated clearly their disappointment that information, advice and support did not appear to be given the same priority as in cancer services:

- *Information lacking in dementia versus cancer services. When the council / CCG offer services for people living with cancer – are they offering a comparative service for people living with dementia?*
- *Need to campaign and demonstrate the inequality between dementia and cancer services – we need a stronger voice.*
- *It's not obvious that you are suffering with dementia 'You don't look like you have dementia', people are dismissive - It goes against our rights even if we lose capacity we still have legal rights.*
- *A lot of people feel in the dark about Alzheimer's compared to for example cancer or stroke.*

5: Information, advice and support needs to be tailored to individual needs – one size does not fit all

There was no *one* way that people thought information, advice and support should be offered. Information needed to be tailored to individuals in terms of their personal circumstances, their preferred way of receiving information and delivered at a pace that was not upsetting.

Personal circumstances

Here people spoke about their personal preferences and that services needed to understand different needs of different individuals in order to tailor information provision.

- *People living with dementia have very different experiences.*
- *It helps for the person giving advice to know you and your situation.*
- *People access information in lots of different ways depending on their individual needs.*
- *Sometimes we need something general and sometimes something specific.*
- *Any information should be up to date and geared to the individual.*
- *Would be useful to have some continuity – someone to go to who knows you to say “this is happening ...” that would be reassuring.*
- *There are a couple of groups now in Sheffield for people with young onset dementia – these are social and about enjoying yourself – you don’t learn more about dementia – it’s more about what you like doing – people need to know what our interests are.*
- *Not everyone wants more information – it’s about enjoying life now.*
- *Some are able to wait every month until next café – but may not be able to in the future.*

This was even more important when people had particular types of dementia, for example, according to SHINDIG members, up to date and accurate information for people with young onset dementia seemed to be missing:

- *At diagnosis the memory clinic (RHH) didn’t have any relevant up to date information to give us on Young Onset Dementia. There needs to be up to date information available – there is very little out there for younger people with dementia.*

- *Memory service (NGH) had packs of information all about people over the age of 65 – need specific information for younger people for example regarding PIP.*

Preferred way of receiving information

People suggested some of the different ways they would like to receive information; this was very varied and depended on what access people had to different forms of technology. Their preferred way of interacting was sometimes dependent on the type or nature of the information to be received.

- *Some don't like the internet and prefer 1:1.*
- *Face to face is important for sharing information.*
- *Information and advice services need to be more than just a website or leaflet.*
- *There needs to be audio information for people who can't read.*
- *Recordings can be played over and over – a telephone call might not be remembered.*
- *Podcasts.*
- *Audio files on MP3 player – people need help loading it on.*
- *Some people with dementia cannot / do not use computers – makes it difficult when everything is online - Digital support is needed for people living with dementia.*
- *Peer support and dementia cafes are an important information source.*
- *YouTube – some content is really useful.*

Pacing

People talked about the importance of receiving the right information at the right time so as not to feel overwhelmed.

- *Improved information services would be preventative (if they are effective and accessible).*
- *It is vital before a formal diagnosis - needs information before when it's just 'memory problems'.*
- *Needs some information immediately after diagnosis.*
- *Staging is important – the right information at the right time. Don't need everything at once (as happens in the Memory Service) it leaves your head spinning.*

- *More information needed as it (dementia) progresses – some may progress quicker than other so different information is needed at different times.*
- *Some people have power of attorney – people want different levels of information – important not to force it.*
- *Had some information from the GP on what might happen later – we asked GP for that information.*
- *Some people are afraid of looking too far ahead.*
- *Has felt overwhelmed at the time straight after diagnosis with information but not so much afterwards.*

There were some calls for information, advice and support to be offered in a more proactive way by services:

- *It would be useful to have a visit a few weeks after diagnosis to explain for example the benefits – maybe if someone came from the Drs.*
- *Didn't realise you could just ring the Memory Service for a chat – it feels like it needs to be more serious to ring – would be good to have some information – maybe scenarios – of when to ring.*
- *Some people might not like ringing – do services check on people if they have not heard from them for a while?*
- *There should be some 'outreach'.*
- *It's frustrating when calls are not returned.*

6: Challenges in accessing information, support and services

People spoke about not always knowing who to contact for what.

- *Finding information about services and activities can be difficult.*
- *Need a list of useful numbers!!*
- *Need a directory of up to date information.*
- *'Help Yourself' directory was very useful but doesn't exist anymore and leaflet in council tax letter.*
- *The Memory Service (NGH) did not explain how they worked (to phone nurse helpline if concerned and they decide where to send you).*
- *Important to be signposted to the right person for the information they need – people don't always know who they need to talk to.*

People living alone or with limited family support felt they had increased challenges:

- *It's harder on your own – we have different needs to those with partners / family.*
- *It can be difficult if you have limited direct support to do activities you want (even with some family support).*
- *What the carer thinks is best is not always what the person with dementia wants.*

Access to services was sometimes seen as an issue:

- *Medical professionals identify problems but not the potential causes of things to help.*
- *I find it difficult to speak with a specialist Dr (at the memory service), the GP can't know everything – it's a gap in information services not being able to speak to a specialist Dr.*
- *Rapid Response Team good but you can't just ring them.*
- *Hospital staff need to be experienced in dementia care.*
- *Some have rang memory service but not much success – but there is a nurse helpline that is very responsive – good at keeping contact.*
- *I got information from AS when person first diagnosed, can't do that anymore as can't drop in anymore and they don't answer the phones.*

Summary

Key messages from this report appears to be the wide range of ways that people currently access information, advice and support, from a range of organisations and from one another.

There is an emphasis on information, advice and support services needing to understand dementia and how it affects individuals. There is also a sense of sometimes needing some general information about dementia, but on other occasions needing tailored and personalised information by someone who understands the person's unique circumstances. There was also a sense that information needed staging and not all provided upon diagnosis. More proactive information, advice and support provision would be welcomed especially in the weeks following diagnosis.

The quality of information provided is important, in that it is accurate and up to date and is available in a range of different ways that does not exclude people who do not routinely engage with digital technologies. Some people gave Cancer Services as an

example of a Gold Standard in terms of information, advice and support and something to aspire to in the dementia world.

Challenges included access to information, knowing who to contact and when, especially when information, advice and support was needed in a crisis and additional challenges for people living alone who may not have a family member to help.

Potential imitations of the Report

This report needs to be read with an understanding of the context and a few associated limitations.

People who come to SHINDIG tend to access support from the Alzheimer's Society in Sheffield and most likely the memory service or the memory clinics in Sheffield. They may or may not access a wider range of support and services. People who attend tend to enjoy group social situations and so their views do not necessarily reflect those of people with dementia who prefer to share their views more privately or individually.

SHINDIG is attended largely by white people, largely spousal couples, although a few people who live alone or who are supported by non-spousal family members or volunteer staff to attend. People are generally fit enough to be able travel independently to the group.

Some people do not always recognise when they are receiving information, advice or support. For example a conversation at a dementia cafe or follow up from an issue raised at a peer support group may not be recognised as information, advice or support, but may be perceived as a social event or an enjoyable chat.

A final observation is that some conversations focus on past service changes. A few people remain extremely disappointed and upset at the changes in the location of the Alzheimer's Society office that took place a number of years ago or the changes to the memory service access. These changes and the associated emotions remain prominent in conversations, making it more challenging for some people to focus on the discussion of current services.

This report confidently reports the conversations that took place with the 30 SHINDIG members who attended on the day.

Feedback, questions or follow up relating to this report can be directed to Jane McKeown or Jo Wallace. Contact details can be found at: <http://goo.gl/P9kJYb>