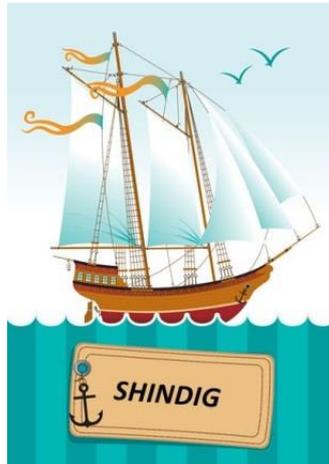


Sheffield Dementia Involvement Group



SHINDIG 20

Thursday 26th April 2018

Report:

What Support and Care is needed to Live Well with Dementia: Informing Sheffield Dementia Strategy



REPORT

This Sheffield Dementia Involvement Group (SHINDIG) topic was a request from Paul Harrison (Alzheimer's Society Operations Manager, South Yorkshire and Humber) related to work being undertaken by Sheffield Care Commissioning Group on a City Dementia Strategy and pathway. SHINDIG was specifically requested to seek the views and experiences of people living with dementia.

This SHINDIG took place on Thursday 26th April at the Quaker Meeting House in Sheffield City Centre. It was attended by 21 people living with dementia, 18 family carers / supporters and was supported by 18 staff / student facilitators or observers. The SHINDIG organisers decided, in order to broaden the demographic of people included, to seek the views of people with dementia using the following services: Dementia Rapid Response and Home Treatment Service (2 responses), the Alzheimer's Society Young Onset Dementia Day Centre – referred to as Our Place (7 responses which are indicated in blue italic text) and an individual with Young Onset Dementia whom we met through social media (1 response).

The questions asked were:

- What help, support or services do you currently receive to help you live with dementia?
- What works particularly well with the support or services you receive?
- What works less well with the support or services you receive?
- In an ideal world what would you like now that you are not getting in order to live well with dementia?
- Is there anything else you want to say about what you think help and support to live well with dementia in Sheffield should look like?

Responses were collated on flip charts and typed up. As is usual with SHINDIG reports the responses are grouped under what emerge as recurrent themes. Where possible these themes are not over-interpreted but rather used to organise and reflect the responses from SHINDIG members.

The themes reflecting what people said are reflected initially in a Report Summary and then more comprehensively in the Full Report.

REPORT SUMMARY

1: Support and access to information to live with dementia after diagnosis

- People need diagnosis to be clearly communicated in a sensitive way and be able to access timely support following diagnosis in order to come to terms with the feelings evoked.
- Services need to communicate clearly and accurately. Errors in letters and communication can lead to misunderstandings and lack of confidence in services.
- People with dementia would like a key worker or mentor upon diagnosis to guide them through coming to terms with and then living well with dementia and to signpost them to services.

- Information regarding support, services and care after diagnosis need to be more clearly and fairly communicated by services. Currently people find out about activities and services in an ad-hoc manner often from other people with dementia and their family carers / supporters.

2: Driving and transportation

- Services need to be sensitive and consistent in how people are informed they can no longer drive. The psychological consequences of having to give up driving need to be better understood and supported.
- Challenges in providing adequate transport and the support to use that transport may mean that even if services and opportunities to remain active and supported exist some people with dementia may not be able to access them.

3: Support for people to remain living supported at home

- Organisations need to work more closely across boundaries to ensure that people have access to the right support and information.
- Complex situations require close collaboration and complex solutions to prevent people with dementia moving into care prematurely.
- Support to remain living independently require the City and local communities being more dementia friendly and aware.

4: Maintaining interests and activities

- People want to be able to continue to pursue existing hobbies and interests or be helped to adapt to new ones. Some of these may be dementia specific and some may be in non-dementia specific settings but these may require dementia awareness raising.
- Activities and social events need to be viewed as essential therapeutic services.

5: Support from family, peers and friends

- Peer support is hugely valued and can help people appreciate they are not alone and to come to terms with their diagnosis.
- People with dementia need to be understood within the context of their families, friends and communities in order for all the necessary people to receive the appropriate support.

6: Stigma and dementia awareness

- A dementia strategy and associated pathway needs to take a whole society and community approach in order to ensure that Sheffield as a City can support people to live their lives well with dementia.

FULL REPORT

Themes that emerged from what people said

1: Support and access to information to live well with dementia after diagnosis

A key discussion topic was the importance of help and support to understand and cope with the feelings that dementia evokes in people. People spoke of some of those feelings:

- *The dementia slowly “grows on you”.*
- *Get frustrated.*
- *Trying to re-construct how to do things, but get so frustrated at times want to kill somebody.*
- *Trying to forget got dementia and get over it despite others telling me to live with it.*
- *Difficult to be positive about the diagnosis.*
- *Sometimes it gets you a bit mad when you see people getting up-tight with people and shouting at them.*
- *S said about her experience of diagnosis and coming to terms with the illness –“ I Want to tell a story but my mind can’t get to the point...”.*
- *I would be the first person to admit that I protect how I feel and to maintain my self-esteem.*
- *Share tears and knowing people are here to listen and understand is what I value about here (Our Place).*

People had mixed experiences of receiving support to come to terms with their diagnosis.

- *Questions about the cause remain unanswered.*
- *If you don’t want to take medication then you are pushed to the back by the Memory Service.*
- *It takes time to understand diagnosis - ‘pace’ and detail – there can be contradictory information regarding the diagnosis.*
- *Helps to have wife go along to 5 week course (at the Memory Service), it was good to discuss together when we got home, important to attend as a couple.*
- *The group were prompted about their experiences of hospitals and diagnosis, one person said “I just got knocked down” which he links with his diagnosis, another talked about a change with new Doctors and not being sure who they will see.*

Some ideas that people feel would help with post-diagnostic support included:

- *It would be good if after diagnosis, perhaps a month, someone came to you and had a word and pointed you in right direction.*
- *When first diagnosed need to be allocated a Mentor for the person with dementia and family carer to guide them through the process and remain throughout as a point of contact when necessary.*
- *Named Admiral Nurse, occupational therapist and physiotherapist.*
- *Something like the ‘A Good Life with Dementia’ (like the one run in York) should be available to everyone post-diagnosis (all ages).*

The groups discussed the need for better access to information about support and services. A recurring message is that people find out about what services are available in an extremely ad-hoc manner.

Improved access to information needed after diagnosis

- *Don't know what's out there.*
- *Council could do more to advertise what's available also to make publicity about people with dementia are people.*
- *Local press - need to publicise that people with dementia are out there, what services there are and how to access them.*
- *Found out more at the Alzheimer's Society café than at the Memory Service*
- *11 month to get appointment, we had the tests then "See you in a year", clinic initiated earlier follow up at my request but this was then cancelled so it was 11 months after diagnosis, what happens now? Confused.*
- *Signposting of support services, not everyone can use the internet or knows where to look, or as in my case had so much to deal with I was more concerned getting by day by day.*

Communication from organisations was important and not always to the standard expected

- *Timing of Memory Service 4 week course - starts at 10am – that's too early. Also the information was misleading; it said it was a Monday – so I nearly cancelled our carer – was in-fact on a Wednesday.*
- *Communication errors in letters from Memory Service.*
- *Lack of organisation, it felt like that, things that needed to be done were done but it felt like the medics were tip toeing around the topic (of diagnosis).*

Linked to this was the need for organisations to work together and not alone

- *Working together – not each organisation working alone – in isolation e.g. Sheffield United will fund various activities. Funding/PR – Special interest in older people and people with long term illness. Jigsaw – need to work together across the board.*
- *Sharing information across organisations saving on admin.*

The consequences of services not working together and communicating is reflected by the story of a person diagnosed with Young Onset Dementia (see Case Study 1).

Summary:

- Receiving a diagnosis in a timely, well communicated and supportive way is essential.
- People need time to process the diagnosis and have timely support to discuss their feelings and ask questions; it helps if services initiate this than expect people to ask for it themselves.
- Organisations need to work together and across organisational boundaries. There needs to be an equitable access to post-diagnosis support and groups no matter where your diagnosis is given or what age group you fall into.

- People need access to information about the range of support, services and activities. At present this information is given in a haphazard and ad hoc way, there needs to be a cross organisational city wide approach.

Questions:

How can we ensure that everyone receiving a diagnosis whatever their age or circumstances is offered post-diagnostic support?

What is the best approach to ensure that all people diagnosed with dementia and their carers find out about opportunities for support?

What is the best way support / information can be offered, given that people live a long time with dementia and their needs change?

Case Study 1: Story from H diagnosed 12 months ago with Young Onset Dementia

H was unaware of any courses or support services in Sheffield and there was no evidence of a referral being received by the Alzheimer's Society. Through social media H found out about a course in York.

When I was diagnosed as I walked out of the Consultant's room it felt like I was walking off a cliff into a deep dark hole, but to be fair my Consultant has helped me as much as she can. Support is mainly from my wife and family.

What support do you receive?

The Good Life with Dementia course (run in York) has improved my mental well-being, confidence, interaction with others and lead to a more positive outlook from my wife and I. The course is also leading to people joining Minds and Voices and taking part in research. Research gives me something to focus on.

What works less well with the support or services you receive?

Having to undertake a 130 mile round trip to York to access a post-diagnosis course. I have no other support services. I needed someone with me if I have gone further than the local shops but since going on the course I have started to go out alone a bit by taxi. Still haven't been on a bus since September.

What would you like now that you are not getting in order to live well with dementia?

Something like the 'A Good Life with Dementia' course should be available to everyone post-diagnosis. This could include short presentations at each session from for example OT, physio, dietitian, researchers, speech and language therapist.

Signposting of support service, not everyone can use the internet or knows where to look, or as in my case, had so much to deal with I was more concerned getting by day by day. Access to occupational therapist, physiotherapist, named Admiral Nurse.

Dementia services need to be brought up to same standard as cancer services. Support group for family members.

2: Driving and Transportation

A regularly discussed topic is the impact that having to stop driving has on the person. There appear to be challenges in how people are prepared for and / or are supported when their driving licence is removed.

- *How can I prove I can drive safely before my licence is removed?*
- *Sick of been told I can't drive.*
- *Driving is best way to get about.*
- *Loss of drivers licence, I'm now reliant on public transport (had to learn how to bus it), no test to check ability.*

It seems like for some people the immense psychological consequences of having to stop driving are not fully addressed. The account in Case Study 2 reflects this:

Case Study 2: B's Story – In discussion with Dementia Support Worker and friend

Earlier this year B was facing a driving assessment. B was very apprehensive about this in terms of the potential of failing the test losing his licence and that he may have to take the test in Derby and not Sheffield and in a dual control car, not his own. He was perplexed and mystified as to why he was being put forward for the test having only been diagnosed with dementia 7 months previously. No-one professional or family had raised any concerns about his driving.

This combination of lack of transparency of why he was being tested and the possibility of being tested in Derby added to the potential significant psychological and practical consequences of losing his driving licence.

It was not clear whether the DVLA only ask people for a test in response to a professional or family concern or whether they may call people up randomly. An Alzheimer's Society Dementia Support Worker advised B to discuss this with his GP, who it transpired had been the one to contact the DVLA.

After family intervention, the test was eventually taken in Sheffield. As B said with irony: "the day dawned wet and foggy"... but "...no excuses." He is pleased to recall that he did an excellent emergency stop but he also did surrender his licence that day.

B was devastated on the day but by the next day was saying "well let's get on with it...". His positive attitude has helped him engage with finding alternatives to driving, however as his friend J has said "although B takes things in his stride he has been upset and anxious underneath", he has been left with strong feelings of failure and has had trouble coming to terms with it, and understanding why after 60 years of driving without an accident he has lost his licence.

Two things have helped him to adjust since this: One was a letter from the DVLA thanking him for surrendering his licence; the other was at (this) SHINDIG where he met other people who had lost their licence, including some who had driven professionally for a living. This in particular made an impression on B and has helped him to accept the situation and given him an understanding and acceptable explanation when people ask him about his driving.

This story highlights the huge importance of how people are communicated with and told about driving and DVLA process. How this is done, and how people are supported in the process and with the outcome can have a significant effect. A suggestion is that the GP/other professional speak with person a week after the test, to discuss with the person and help them understand and adjust.

When a person can no longer drive then public and other forms of transport become increasingly important. A number of issues relating to transport were discussed.

- *Parking permits – hospital parking is difficult.*
- *Issues when you or your partner has mobility issues.*
- *Community transport – need more information about it (a repeated comment).*
- *Transport is a problem when you need to carry bulky items, for example golf clubs.*
- *Both staff and participants talked about bus passes and blue badges and that they are both hard to get and confusing about how to get them. This impacts on going out to places at 'Our Place' and when at home. There doesn't seem one easy place to find out about passes both for transport and leisure.*
- *I would like a private driver to take me places.*
- *There needs to be a one stop shop for all issues related to transportation, passes, badges etc.*
- *I've needed someone with me if I have gone further than the local shops ... I have started going alone a bit by taxi, still haven't been on a bus since September.*

Transport (or rather challenges with it) can be the difference between whether someone can make use of a service or activity (or not).

Summary:

- Being told to stop driving has a huge emotional impact on some people. Others with the right support are able to adapt.
- Transport issues are central to whether people with dementia can access services, support and life enhancing opportunities. A range of inclusive and appropriate transport services in Sheffield is currently missing.
- It's not just the transport, it's being helped from the house to the transport, being reminded the transport is coming and having a return journey assured that are issues that all need to be considered.
- It may be assumed that certain services or activities are not valued or required – when it might be that people just cannot access them.

Questions:

Do we need to develop guidelines for practitioners who are responsible for advising people with dementia to stop driving?

Do staff understand the complex emotional impact this may have for some people and ensure they receive the necessary support?

How can transport services in Sheffield be developed to meet the needs of a range of people who need them?

Whose responsibility is it to improve these?

3: Support for people to remain living supported at home

For all people living with dementia, being supported to continue to live independently at home was a significant desire and need. The challenges of this were increased for a number of people who lived alone.

- *I live on my own and get carers, they come in early to help and they bring me to 'Our Place' and Sheffield Community Transport takes me home. I have support (Alzheimer's Society Home Support) to do some of the things I enjoy - I went to revisit my home of birth and they take me shopping and to health appointments. (Person also recalled going to the library to do local history in the past with the support of home support).*
- *I currently receive carers. They visit me four times a day. My daughter used to do this but the carers are now helping as it was too much for my daughter.*
- *I would like a little more attention and interest shown towards me. I would like some one-to-one time with someone to take me out as I rarely go out these days and always sit looking at the four walls.*
- *No problems (with carers) really, sometimes they are a bit late and some are very young.*
- *One person has found it very difficult at first to accept people in the house and has had quite variable support from two agencies. (Comment from staff manager: both agencies had been unreliable and eroded her independence rather than supporting it).*
- *Lives at an Extra Care housing complex, is supported by regular visits from granddaughter and phone contact all the time because "I love her". As well as attending 'Our Place' has one day support a week from the Younger People's Home Support Service.*
- *They send regularly workers which I like because I can tell them something private.*
- *Have help with medication – in the morning – works well. They do a little bit extra and this goes a long way.*
- *B: also has home care, and friends, brother and people in the holidays – the care company is very good, bringing me to 'Our Place' on time and where I can enjoy socialising.*
- *A: It's different to home and before I was not expected to cook but I am supported to cook here and enjoy it. A expressed the importance of having walks with the dog.*
- *Living your life is really important.*
- *You can have a life with Alzheimer's with the right level of support and independence.*
- *One person in the Young Onset Dementia service has a personalised budget that is being honoured from long time ago if reassessed now would not get such a large package. Gets allocated time for social – 4 hours a week, shopping, 2 hrs home care and brought to the place, 3 x days and home care at night brother supports at weekend.*

Case study 3 illustrates how people with dementia and complex needs can be supported to remain in their own homes when services work well together.

People spoke of some of the things they needed when out and about in order to go about their lives.

- *Card from bladder bowel community "just can't wait" which you can take into a shop.*
- *Toilet key disables toilets.*
- *Good disabled toilets – facilities.*
- *We need a city wide map of where disabled toilets are.*

- *Befriender's need to also be able to respond to personal care needs if required during their visit.*
- *Food bank – somewhere to shop for food which is nearly at its sell by date, can buy food cheaply.*
- *Accessing the money and know what you want to spend it on.*
- *Access to buildings lifts etc., friendliness and welcome.*
- *Need more money and resources to make sure that we can continue to do things which are useful.*
- *S showed us the tracker she has attached to her keyring – “best thing ever...gives my brother his own life without worrying about me”. It helps with independence and peace of mind for family and friends.*
- *Got to try do things on my own – find own way on transport rather than accept lifts from others.*
- *Bus journeys on my own – feel like doing something to get away from it (dementia).*
- *Speaking to someone when dealing with internet.*

Case Study 3: Supporting S (who is a Younger person with dementia) to remain living alone at home

'Our Place' is a service provided by the Alzheimer's Society to support Younger People with Dementia (ie those diagnosed under the age of 65 years). Some people we support live alone whilst others have partners that still work and have children that are still at school. Each person has complexities that are individual to them, however often in common with each other.

We have supported S for a few years now from her initial diagnosis, where she was driving and still married. Since her diagnosis of dementia her husband left her, she was not allowed to drive anymore and she became isolated and increasingly more vulnerable. At one point S was almost sectioned and the NHS Dementia Rapid Response Team became involved. S was carrying round £1000 in cash around and she was going out of the house at night, not knowing where she was going. S was referred to a Community Psychiatric Nurse who is fabulous and got Personal Assistants involved in S's care. We at 'Our Place' also offered more days in the day centre to keep S occupied, stimulated and to lower the risk of her getting lost etc. S is on a Care Programme and all professionals meet regularly to review her care and wellbeing. The PAs bring S to the day centre after they have supported her to get ready for the day. This package of care works and I am sure S would be in care without it.

This is an example of where all services working together can support a person with dementia with complex needs to remain living at home as independently as possible.

Manager of Our Place in collaboration with S

Summary:

- Being supported to continue to live at home and live a full life as a citizen is immensely important and the right help and support that is empowering and reliable is crucial.
- Paid carers supporting people at home need to have an understanding of dementia, how it affects the person and have positive attitudes to working with people with dementia
- Supporting someone to live independently at home involves services working together in supporting the person to remain engaged in their community and in society more widely.

- Supporting people with dementia to live independently involves the wider City and community becoming more friendly and accessible to all

Questions:

How can services work together better to provide comprehensive care for people in their own homes?

How can we make sure that everyone involved in planning and providing services understands the complexity of designing a package of care that meets the individual needs of each person (and the important people in their lives) and ensure it is reviewed regularly?

Who needs to work with the wider City to ensure that people with dementia are understood and supported to live as independently as possible in their communities?

4: Maintaining interests and activities

A strong theme running across all groups and ages is that people want to be able to continue with the hobbies and interests that they have or maintain contact with activities that they have participated in since their diagnosis. Examples were given of activities that people found fulfilling:

Singing

- *Singing for the Brain (x2).*
- *Singing groups – need more– can't take away the joy, special time.*
- *Visiting a care home to play music and sing.*
- *I definitely enjoy the music at 'Our Place' – my kind of music (there were a lot of nods to this as all kinds of music is available). The people are decent and make a good connection.*

Sport and physical activity

- *Golf, it's therapeutic, the freedom to express yourself, not all clubs are welcoming, Tinsley course very welcoming, rely on friends for transport, Concord course nice for beginners, there is stigma in some clubs – want to look at your golf clubs plus how long been playing.*
- *Walking group – it helps me to feel tired, we meet to get the bus out of city, discovering new places.*
- *Swimming, (P would take us all out to Hathersage outdoor group).*
- *Slow walking, health walks including us if have dementia.*
- *One person talked about attending a women's walking group in the past and how it being women only was important to her as it created a positive atmosphere and she made lots of new friends.*

Arts and creative activities

- *Keep up old hobbies – mariachi, art.*
- *Creative dementia arts exhibition.*
- *Art, it helps keep your mind active, I still help to run the group and teach.*
- *Teaching flower arranging, sharing memories and knowledge with others.*

- *Theatres, you get a discount if you have dementia with a free tea, coffee and scone.*
- *Dances.*
- *Showroom and Light Cinema have dementia friendly showings.*

Groups where people can share their experiences of dementia

- *Love Shindig (x2) it's an opportunity to talk and learn from each other. Groups like Shindig help come down to a different level; we're all going through same thing.*
- *We need more meetings like SHINDIG.*
- *Support group Alzheimer's Society.*
- *Group meetings important with others with dementia.*
- *Very important to feel we always have these moments good to be in the same environment as people who understand (referring to 'Our Place' and this discussion).*
- *Feel contented by being involved.*
- *People with dementia need to speak up for themselves; we've got to draw people in.*

Vocational Activities

- *Getting interested in what's going on in local community – volunteering.*
- *One person was a building supervisor, one mentioned they would like to work, one doesn't miss work, one found it hard to stop working. One had to give up working. One involved in social work and safeguarding children.*
- *Being offered things you enjoy doing, gardening, repairs, what you used to do.*
- *For men especially to be able to continue with interests – adjusting to find new ones.*

Social opportunities

Opportunities to socialise were seen as important. There was the impression that it was not essential that these were necessarily dementia specific, but it was important that people with dementia felt included.

- *Opportunity to get "away from under feet of wife".*
- *Library – tea, quizzes, bingo stopped now, social.*
- *Friendly places – Upperthorpe library is very friendly open to all, good café good meals pay what you wish.*
- *Drop in places needed.*
- *Friendship lunches in pubs around Sheffield publicity on website.*
- *Dementia Cafes (x2) – enjoy the chatting + meeting people.*
- *The group were asked if they liked to reminisce – and yes they said they did enjoy talking about the past. General feeling that both general discussions, like the one we were having today, and one to one discussions are really important and enjoyable in themselves and to recall past memories. This is something they like about 'Our Place' the opportunity for conversation.*
- *Most people in the group said they enjoyed the opportunities 'Our Place' gave them for engaging in a variety of activities, such as weekly baking, gardening and art/craft at the place, as well as attending the weekly dementia friendly Sports session at Concord sports centre and other external events such as the Drink Wise Age Well 50 plus events. They felt*

a “friendly welcome is most important” when going along to thing and Drink Wise Agewell is inclusive and welcoming.

- *One person reflected: Sometimes I don't feel like joining in, but several people agreed that it was okay not to.*
- *More places for people to go like Darnall, sharing a lunch, doing things together, good people.*
- *Meeting up with others old workmates.*
- *Somewhere you can enjoy yourself.*
- *Specialised holiday places – does anybody know about these?*

Pets

Pets were important to a lot of people and this raises an issue of how services can support people to keep their pet when they receive a diagnosis or else have contact with animals if that was important to the person:

- *“Next door neighbour's cat always comes in when she knows I am here!” (Joke: “that could be a CATastrophe!”)*
- *I've always had a dog but not anymore as when I got a diagnosis I was frightened of having a dog if it was taken away from me. I can walk all over but dogs need looking after – it broke my heart.*

Research

- *Research gives me something to focus on*

Some of the activities and groups discussed were dementia specific and others were open to all people from the community. Discussions did identify certain places that were more 'Dementia Friendly' than others and there appears to be more investment needed in ensuring that places people frequented before their dementia are still welcoming once the person receives a diagnosis.

Summary:

- Activities that on the face of it seem like just social events can have an important contribution to the wellbeing of people living with dementia and their family carers / supporters.
- Activities and involvement opportunities need to be re-framed as having therapeutic benefit, integral to the care of people living with dementia.
- Being involved, included and asked to contribute appear to provide a focus and a sense of wellbeing in people.
- Pets can contribute hugely to a sense of wellbeing and be a source of comfort and friendship. This can be especially important to people who have always owned pets and to people who live alone.

Questions:

Whose role is it to help to develop community groups, churches, sports facilities to become more dementia friendly and how can this be incorporated into an overall pathway of care and support for people with dementia?

How can we better harness the voices of people with dementia themselves to take more individual and collective action?

Could there be opportunities to challenge the Universities to explore how their commitment to citizen engagement might provide opportunities for people with dementia?

What happens to people who do not enjoy socialising and joining group activities? Where and how do they receive their support?

5: Support from family, peers and friends.

People with dementia are often supported to live with dementia from a variety of family, friends and peers.

Family

A variety of family support was referred to. With spouse relationships there was often a sense of working as a team and wanting services to recognise that. For people living alone wider family networks were crucial.

- *Spouses support.*
- *I'm happy got a good wife.*
- *Family support.*
- *Family help – take people out etc.*
- *We work as a team and want to still do things together (x 2).*
- *I looked after my brother and now he is looking out for me – when I get this that and the other I didn't know what to do. Another person's family network is important to her with her brother and nephew – and she recalled a very important event when her nephew helped take her for a cataract appointment, this helped her but it also helped him understand about dementia and that helped the family to understand.*
- *On families, S said "No offence but thank God for them"*
- *I think that the DRRT carers are good and helpful, but feel that my daughter has lost her role as she used to provide the support for me (daughter commented that she relieved the carers are now in place as she can go out and leave her Mum knowing someone is visiting her).*
- *I would like to go and visit my relatives.*
- *Family was important to many people in the group.*
- *My ex left me!*

Peer Support

The value of opportunities to gain peer support is evident throughout the discussions, although is more fully represented under the previous theme number 4.

- *Peer support important – council not doing enough for us so need to love each other.*
- *Share tears and knowing people are here to listen and understand is what I value about here".*

Friends

- *Friends – some can't deal with it and visits from them become less frequent.*
- *Friendships: It's important to keep connections and make new ones through Alzheimer's support group, visiting friends.*

Summary:

- Family carers and supporters play such an important role in the care and support of people with dementia it's important that care for the carer / supporter is fully reflected in any pathway.
- Especially with people who live alone or with Young Onset Dementia a pathway needs to reflect the wider family and community context.
- Peer support, having a place to meet other people with dementia in order to share feelings and experiences and offer comfort and information is essential. Often peer support networks are supported / facilitated by workers.
- It is not unusual for people with dementia to report that friends have stopped visiting because of dementia. It's essential to look at how existing friendships can be supported and new friendships forged.

Questions:

How can family carers, supporters and friends be better supported to maintain positive relationships when a person develops dementia?

How can opportunities for peer support (for people with dementia and for their family carers / supporters) be better provided, understood and valued?

6: Stigma and Dementia Awareness

People with dementia are aware of the stigma that dementia can carry and are keen that training and awareness raising initiatives are in place to ensure that other people understand dementia and how it may affect the person.

- *Stigma attached.*
- *Radio – Putting on something about mental health and dementia.*
- *Training for workers, make sure they know how to help people with dementia.*
- *People listening, being helpful and understanding dementia.*
- *You have to say that you need help, and tell people to slow down and give you time.*
- *Location and timing is everything (sometimes services did not recognising this offering early appointments that made it stressful to get too and before people could use their bus passes)*

Summary:

- Stigma and lack of understanding of dementia prevails, even within specialist dementia services. For example offering appointments early in the morning can make it very stressful for the person to get up and be helped to get ready to attend.
- Many people with dementia can recognise the stigma and lack of understanding about their situation.
- People with dementia feel that dementia services are not given the same understanding and funding as for example cancer services

Questions:

What needs to be in place within a Dementia Strategy and associated pathway to ensure issues of stigma are recognised and overcome?

How can statutory services work more broadly with the media, schools, Universities, churches, community organisations etc. to challenge stigma?

Should initiatives like Sheffield Dementia Action Alliance, the Alzheimer's Dementia Friends and Dementia Champions be more fully integrated into a pathway?

Limitations of the Event

We have identified a number of limitations that exist in terms of seeking a wide representation of views of people with dementia to inform the Sheffield Dementia Strategy.

Firstly SHINDIG attracts people with dementia and their family members who are fit and able to travel to the City Centre. It attracts people who enjoy socialising. Although some people who live alone attend SHINDIG, it is largely attended by spouse couples. Consequently the needs of people who are more physically frail or isolated are not reflected at SHINDIG, neither largely are those from black and minority ethnic communities nor those who don't enjoy social events and gatherings. As facilitators of SHINDIG we did make some attempts to ask colleagues in other services (for example a nursing home, an assessment ward, Community Mental Health Teams, a day centre, Young Onset Dementia services) to contribute to this . Although we had some success with this initiative many colleagues were not able to help due to workload and the short timescales.

Secondly there was a challenge in seeking views on services, care and pathways. People with dementia do not necessarily view activities and groups that they attend as 'services' – so a Dementia Café is seen as a social place to have a cuppa, Singing for the Brain as a Singing Group etc.

Thirdly, 'support' may be not understood in the same way that organisations understand the word. So for example a dementia support worker talking to them regularly is seen as a good chance for a chat and to get advice and some help, but it's difficult to tell whether either people with dementia or carers necessarily see this as "support".

Finally the difficulties with memory that most people with dementia experience can impact on how a person recalls a service they are accessing. Our Place – the day service for younger people with dementia was well reflected as the focus of the discussion was actually at that service which aided people to recall their experiences there. Some people, who attend for example other day centres, were not able to recall them and so did not report on them. Additionally other services such as respite were not reported on as many people attending SHINDIG do not access respite.

This challenge was experienced by some staff facilitators, when the people with dementia that they supported with a range of services stated they 'had nothing'. Staff facilitators were mindful in trying not to influence discussions by highlighting services they were directly involved in delivering. With this in mind we offered SHINDIG facilitators who listened to and supported people with dementia on a day-to-day basis to share their vision for a Sheffield Dementia Strategy. Six staff responded and their views are summarised in Appendix 1 of this report.

Despite these limitations the questions that were posed prompted much rich and diverse discussion amongst people with dementia attending SHINDIG and these have informed this report.

Conclusion

People with dementia were pleased discuss their experiences of support and care to live with dementia, experiences in the present and suggestions for the future.

Remaining a citizen was a thread running through; being able to maintain interests, develop new ones, be part of the community, retain connections with family and friends and make new connections with others living with dementia was a loud and clear message.

Some of the major barriers to living a good with dementia related to transport, attitudes, stigma and dementia awareness. A Sheffield Dementia Strategy needs to reflect not only the co-operation of statutory services, it needs to encompass a City wide community approach.

People with dementia are less worried who provides what service and more interested in having support when they need it from staff who are dementia aware, sensitive to their situation, friendly and responsive.

A clear, consistent and equitable approach to information sharing about services and care appears currently lacking. This can lead to people missing out on accessing services that are available and creates inequalities in who knows about and accesses support and services – and who doesn't.

For a Strategy and associated pathway to be successful it needs to be co-produced and receive on-going evaluated from a range of perspectives (for example policy makers, managers, people living with dementia, family carers and statutory and third sector organisation staff and volunteers to who work with people with dementia on a day to day basis). Involving people with dementia in such work is essential but is time consuming and intensive. Through SHINDIG we have learned and continue to learn at each meeting new and better ways to enable people at different stages of dementia to contribute. Such opportunities for people with dementia to contribute to developing services / having a say need to be regarded in themselves as having therapeutic benefits. Such

opportunities help people to feel their views and opinions are valued, they provide a forum for peers support and provide people with right to remain valued citizens in society.

This report was collated and written by SHINDIG organisers: Jane McKeown Senior Nurse at Sheffield Health and Social Care NHS FT and Jo Wallace at Sheffield Alzheimer's Society. For any feedback or clarification please contact Jane on jane.mckeown@shsc.nhs.uk or Jo on jo.wallace@alzheimers.org.uk

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Appendix 1:

Some of the staff / volunteers who support SHINDIG have worked with people with dementia for over 30 years; many have a strong organisational memory. Here is a summary of the reflections of 6 of these staff based on what they see as important to people affected by dementia.

- Agencies need to work collaboratively with good communication between one another so that services are not duplicated or diluted. This will provide more clarity for services users, so that they are clear on who to go to for is triggered when someone receives a diagnosis – in a similar way to what happens for example in breast cancer services.
- There is a need for visual maps of pathways and resources / organisations.
- For one identified service to be the key agency following diagnosis. Maybe develop a dedicated Dementia Support Service combining health, local authority and third sector organisations. Perhaps an Admiral Nursing service.
- For a consistent approach in ensuring that every person receiving a diagnosis of dementia receives information about support, services and activities. The recent success story of organisations, communities becoming more dementia friendly and inclusive of people with dementia has resulted in a plethora of provision; this in itself brings greater need for an identified coordinating service to signpost, help navigate and support uptake.
- More clarity re the role of GP, CMHT, Rapid Response, Local Authority.
- For all Younger People with Dementia to be referred to a central and co-ordinating point of contact upon diagnosis.
- Recognition that Younger People with Dementia often have different needs and consequently more tailored services. The need for the to continue to provide quality Home Support and Day Care to people under 65 diagnosed with dementia in Sheffield.
- For the Memory Service to be clearer that patients can phone at any time for a review or advice if experiencing problems and that they are always there for provision of clinical support and that they have not been discharged (there still appears to be misunderstanding and people don't always know if / when they should ring.)
- Making sure people providing services and support are properly trained and prepared to offer the support that's needed; identifying good training and making it a requirement.
- A lot depends on the person who they are allocated to in Social Services and CMHT in terms of the quality and quantity of support they receive.
- Making sure that things are properly resourced – this means making sure that there is funding for services and support, and enough staff to ensure that it will work as intended.
- Having a place where people can 'drop in' and receive a friendly word, cup of tea, practical advice (particularly for family carers / supporters).
- More therapeutic courses/counselling for family carers and people with dementia.
- Fairer access to information, support, respite and emergency respite. There are some reports that people who are self-funding are given a list of numbers and are to arrange care for themselves.
- A lot of resource has been lost in terms of day care provision. Some Day Care provided is innovative and personalised and attractive to people with dementia; other Day Care runs on a more traditional communal and activity based model that is perhaps not in keeping with current practice or culture this seems less of an attractive option to people with dementia.

- More sitting services seem needed and include staff to be able to offer basic personal care if required, for example helping someone to use the toilet or with incontinence.
- There is a great need for enabling services, such as companionship, accompanying, buddying.
- Closer and innovative working between statutory, voluntary and commercial sectors would be welcome, particularly between the care home sector and wider services and community.
- Challenges for some people with dementia being admitted and / or discharged from hospital and transition pathways could be improved.
- It's essential to provide things that allow people to stay connected to the world, with who they are, and what they want to continue to do. Providing as much 'support' as people need to allow them to continue to do these things.
- People consistently say that SHINDIG is one of the places that they enjoy, that they think is useful and that they learn from. This demonstrates that people enjoy social time, a good lunch and feeling valued because they are taken seriously, at the same time as being known, having a bit of fun etc.
- Making sure things are accessible – this means making sure that there is funding for transport if necessary and for support workers to accompany people to things if necessary and also means that the things provided are tailored to suit the needs of individuals
- Better resourced quality community transport is required– with support to help people get ready, be reminded and get to and from the house to the transport safely. There are worrying reports of people not taking up services such as day care because there is not adequate safe transport.
- Blue badges and bus passes are a huge issue which impacts on where and what people can do. Many people with dementia, especially younger people are turned down for these as there is a lack of understanding about dementia. Better access to the Plus bus pass where carers go free; this is especially relevant where paid staff may need to fund their own travel to accompany the person with dementia. When staff use their own cars, not having access to a Blue Badge can impact on how they support the person they are transporting.
- Better understanding of how life is with dementia, and better resources to help the community to learn.
- Consideration of support for people who are not 'joiners' ie don't necessarily enjoy group and social activities but still need support and information.
- For people with dementia and their family carers / supporters to feel valued; feel taken care of and understood, and feel that they are able to respond to friendliness with friendliness. It is important that services get to know people with dementia within the context of their life in order to be fully understood.
- A recognition of the skills required to support a person with dementia and their family carer in a truly person-centred way. Skills in understanding the complexity of how dementia affects each person differently, knowing the person, pre-empting their needs, intervening at an early stage to prevent distress, understanding the complex dynamics playing out between the person and family members, making each person feel special, unique and valued as a human being.
- To perhaps implement a dementia audit into services, statutory and voluntary so that they really consider in their service how they put the person with dementia at the heart of it and everyone can learn from one another.