



# **Sheffield Dementia Involvement Group**

## **SHINDIG 9**

**Thursday 18<sup>th</sup> June 2015**

**Support and Services needed to Live Well  
with Dementia**

## **Introduction**

Sheffield Dementia Involvement Group (SHINDIG) is organised jointly between Sheffield Health and Social Care (SHSC) NHS FT and Sheffield Alzheimer's Society. The group meets 4 times a year and has an identified topic for discussion at each SHINDIG.

The 9<sup>th</sup> SHINDIG, held in June 2015, invited people with dementia and family carers to discuss the support and services they use and need to live well with dementia. Four members of SHSC Specialist Directorate management team attended to hear what was discussed. 19 people with dementia and 14 family carers attended.

Discussions were held in four small groups, two for people with dementia (7 people in each group), one for family carers (9 people) and one group for people with dementia (5 people) and family carers (5 people) making a group of 10 people altogether. A number of prompt questions were put to each group and these helped to guide the conversations. Responses were recorded on flip charts and these were typed up and form the basis for a number of themes under which responses were reported. This report summarises these group discussions. A brief summary of the discussions is presented initially as an executive summary. The report then presents the discussions and summary from people with dementia in full followed by the discussion and summary from family carers of people with dementia.

## **Executive Summary**

### **The support and services people living with dementia need to live well with dementia**

- 'Services' are understood by people with dementia as a whole range of support, activities and people that help them to live with the condition; this may include family, friends, the local community and third sector organisations as well as health and social care services.
- People want to be able to maintain their interests and hobbies and their inclusion in society, some groups and activities enabled them to do this. Some people had ideas on opportunities for improving this that were not currently available.

- People were keen to share their experiences of receiving a diagnosis of dementia, but also share hints and tips that helped them to live with the condition. There were suggestions that it helped if health services provided written information following a visit as it would help recall.
- A strong theme was the desire to maintain independence and remain at home. Some people were able to look to the future and consider the need for more services to enable them to remain independent and at home; people who lived alone seemed especially aware of 'the future'. Some people preferred not to look to the future.
- A common theme was the need for a much greater understanding and awareness of dementia in local communities and in society as a whole.
- The needs of people who live alone can be quite different to those who live with a family carer (usually a spouse). Services need to understand these differences.

### **The support and services family carers of people living with dementia need to live well with dementia**

- Carer support was identified as an issue, specifically there is a need for carers to be listened to, heard and reassured that they are doing a good job.
- Groups were valued as a place to mix with others in a similar situation but it was difficult when groups such as the memory service groups ended with nothing to replace them.
- It was felt that there was an inconsistency in the information and advice offered to carers of people with dementia, it appeared difficult to know how to find out about services and how to access them. The increasing emphasis of information being available online was difficult for some people. Dementia cafes were felt to be a good place to access information.
- Experience of services identified some area for improvement and there were some suggestions such as having an identified worker, or staff taking more time to talk to the person with dementia and family

member rather than relying on 'tests' to assess how the person was progressing.

- Family carers identify a lack of awareness of how dementia affects the person with the condition and / or their family as a difficulty in society and even within health and social care services. There were some suggestions such as people with dementia being identified to staff when admitted to hospital and for more openness about having dementia.
- Family carers had concerns about the future and how to best plan for it. The need for more support and information in future planning was identified.

## **Full Report**

### **The support and services people living with dementia need to live well with dementia**

#### ***Support in the home***

People spoke about the value of having someone call in regularly to support them in various ways. Visitors may come from a range of organisations and services, not exclusively health or social care services for example: Alzheimer's Society Dementia Advisor supporting people living alone; health services Community Psychiatric Nurse (CPN) or Occupational Therapist (OT); a care worker to help prompt with taking medication; a private cleaner; family members; members of the local community.

*"A man calls every day to make sure I take my tablets – sometimes at 7.15am some mornings! I find it useful – it stops me worrying about taking my tablets."*

*"I have [name] (from Alzheimer's Society), if she's a service, I depend upon [name]." (more than one person agreed)*

*"Visits from CPN and OT."*

*"Support following hip operation came from the local community – it was initially a struggle but was OK with family help."*

#### ***Groups and activities to attend***

A range of groups and activities were discussed as of being valued and of support. Some of these were specifically for people living with dementia, for example, groups at the Alzheimer's Society, SHINDIG and related SHINDIG activities, dementia cafés, memory service groups. A valued part of the dementia specific groups was the atmosphere that enabled people to feel comfortable:

*"Alzheimer's cafes – comfortable being there – acceptance, enjoy being there."*

*"SHINDIG – beneficial because you make friends, it's a nice place to go – that matters."*

*"All together in the same boat – gives you confidence."*

*"It makes you realise there is hope – gives you hope. Used to have a role (job) after retirement loss of role – it takes ages to get simple tasks done. Can get down – accessing services helps to get your life back and helps with fighting dementia."*

*"Alzheimer's Service – lots of help and support - Boyden House (younger people with dementia service) really good."*

*"Alzheimer's Venture walks thoroughly enjoyed."*

Other community and non-dementia specific groups and activities were also referred to such as church coffee mornings, 'Knitters and Natters', suggesting that for some people specialist dementia support is not always needed.

*"Knitters and natters – enjoy artwork, it's something I enjoy it helps me socialise and relax."*

*"Coffee mornings at local church in - Crookes taken over by students many of us have lost elderly neighbours."*

Some people valued the support of groups so much that they had their own ideas and suggestions for other groups.

*"Would like a drop in centre – a dementia friendly social club. Provide a warm, caring and friendly atmosphere. There must be more people with dementia we don't know about. A drop in centre may help with this – reduce loneliness."*

*"Looked into having a younger people's social gathering but haven't been able to due to health and safety."*

*"A place for dementia people to meet and chat would be helpful – a safe environment."*

### ***Maintaining hobbies and interests***

Support was referred to very much in terms of remaining part of society and maintaining activities, interests and activities. Support was seen as: *'People to be supported to enjoy the things they like doing and can do.'*

*“Dementia gym sessions facilitated by dementia aware staff (can be a struggle with sequencing and organising of equipment)”*

*“A place for hobbies (eg model making) would be useful.”*

*“Doing exercises / physical and mental stimulation- ie car maintenance is helpful, keeping busy, maintaining enthusiasm and having achievements.”*

### **Support and services in the future**

Some people were reluctant to consider the future, but others were happy to discuss it and had thoughts about what they might need.

*“Don’t think about it”*

*“The uncertainty of the future.”*

*“I worry about going into a care home.”*

*“Want to stay in own home preferably.”*

*“Looking to move into sheltered accommodation as I know things will change in the future, I’m scared of being at home now since my neighbour died.”*

*“Help available with transitions – ie transition into nursing home.”*

There seemed to be a difference in terms of support depending whether people lived alone or with a family member:

*“Support when you live alone can be difficult.”*

*“My wife is a support – she comes with all the information.”*

*“Husband or wife – part of a ‘unit’ – or a ‘substitute’ if you live alone.”*

### **Services for receiving a diagnosis**

People discussed some of the challenges they had faced in either being referred to the memory service or clinic in the first place, or their experience of receiving the diagnosis with memory services or the memory clinic.

*“After diagnosis the consultant in the hospital didn’t make it clear what I had, how it would affect me and what services were available. It was not until the Alzheimer’s Society came to see me did I realise – felt like a new born baby – didn’t know what was going on. The Alzheimer’s Society have*

*put me back on the right track - gets rid of the down side and brings out the sunny side."*

*"Until a diagnosis is given nobody believes you and what is happening. Nobody listens even though you know something is wrong. It took a lot of persistence to get the GP to make the neurology referral. When diagnosis was made it was later than I would have liked – I knew something was wrong."*

*"Services need to look at the depression that goes with dementia."*

*"It would be really helpful for people to take information away from memory service following diagnosis – to enable recall."*

*"You sometimes have to fight to get transport to get to health services such as the memory clinic." (another person said they were happy with the transport arrangements they were given).*

### ***Personal Experience of having Dementia***

People spoke about their own varied experiences and emotions of having dementia and the impact it had on their lives and how they felt.

*"I'm angry – I want to keep my independence – why did this happen to me?!"*

*"It annoys me having to ask for help."*

*"I hate the word Alzheimer's, I'll never come to terms with it – I prefer to say I'm getting old."*

*"You don't get better – you get worse."*

*"Don't like the card that says 'I have dementia' it's like saying 'I am demented.'"*

*"Infections can affect the memory – you can forget to eat."*

*"Lose freedom with dementia. Liked to be free spirited and decided was going to spend a few days in Paris – family wouldn't permit it due to dementia. Difficulties knowing the difference between day and night."*

*"Poor eyesight can affect things."*

Despite the reported challenges of living with dementia one group member reflected on a positive aspect:

*“There are advantages – there are so many ‘repeats’ on the TV, but with dementia you forget you have seen them.”*

People also spoke of the ways they try to help themselves to compensate for memory difficulties:

*“Phone (calls it a ‘gooseberry’) difficulty using at first but got used to it.”*

*“Asking for help (eg insurance broker for car parking difficulties) makes life easier.”*

*“Keep checking and double checking – date, time etc.” (others agreed).*

*“Get into routine and habits help to assist with forgetfulness, when other things occur with the routine – that’s when the blips occur.”*

*“GP is very helpful and provides written recall information which I keep with my medication list.”*

*“Simple important little things help prevent mistakes and enable better living.”*

### ***Awareness of dementia in the community and society***

People did not always refer to support in terms of services or people, it might be more understood in terms of how people in the wider community and society understand dementia:

*“Continued and better understanding and awareness.”*

*“Dementia friendly communities are very important.”*

*“Orange wallet for a bus pass – bus drivers know that a passenger may need more help – it gives you legitimacy.”*

*“It’s easy to say what it’s like but with all the will in the world you can’t say that. The more people talk about dementia the more people understand.”*

*“By carers having a better understanding more help can be given. Have a better understanding of what’s important.”*

## **Summary**

'Services' are understood by people with dementia as a whole range of support, activities and people that help them to live with the condition, this may include family, friends, the local community and third sector organisations and not just health and social care services.

People want to be able to maintain their interests and hobbies and their inclusion in society, some groups and activities enabled them to do this. Some people had ideas on opportunities for this that were not currently available.

People were keen to share their experiences of receiving a diagnosis of dementia, but also share hints and tips that helped them to live with the condition. There were suggestions that it helped if health services provided written information following a visit it would help recall.

A strong theme was the desire to maintain independence and remain at home. Some people were able to look to the future and consider the need for more services to enable them to remain independent and at home; people who lived alone seemed especially aware of 'the future'. Some people preferred not to look to the future.

A common theme was the need for a much greater understanding of dementia in local communities and in society as a whole.

The needs of people who live alone can be quite different to those who live with a family carer (usually a spouse). Services need to understand these differences.

## **The support and services family carers of people living with dementia need to live well with dementia**

### ***Carer Support***

There were examples of where carer support was received but some concern that support available did not always meet individual needs. Carer support needs identified related to being listened to and being understood.

*"Biggest thing is everyone is different but all need support to continue what they enjoy doing."*

*"We'd be lost without the Alzheimer's Society."*

*"Support – someone to talk to – to reassure you are doing everything OK for your partner."*

*"A listening ear to ask questions to."*

*"As a daughter – try to support Mum as well as dad with Alzheimer's."*

*"Community transport."*

*" 'Making Space' sitting service – time limitation (3 hours) long enough for person with dementia but carer 'clock watching' due to bus times."*

*"Not always listened to by professionals."*

*"You can go a long time waiting for support."*

People spoke of the value of groups for support and information, but there were instances where groups had stopped which had left a gap.

*"Meeting other people experiencing dementia."*

*"Memory clinic events – now stopped (Grenoside and Longley centre)."*

*"There is nothing to replace the groups which have come to an end (Memory service)."*

### **Information and advice**

The importance of information and advice was a key theme along with some difficulties in receiving the necessary information about what help and services are available and how to access them.

*"Community support workers at GP surgeries – support with a range of things eg benefits."*

*"Dementia cafes – useful, maybe helpful to have other people from different organisations there to give more information eg Ageing Better."*

*"Received legal advice eg LPA, probate."*

*"OTs can help with home safety / adaptations."*

*"Confusion about what's available. How do you access it?"*

*"Not everyone has access to information on the internet."*

*“Memory service discharge you with very little information and tell you to go back to your GP.”*

*“Frustrating to be given a diagnosis of Alzheimer’s and not be offered any help.”*

### ***Experience of health / social care services***

Carers in the group took the opportunity to share the challenges they faced across services with some suggestions about possible improvements.

*“GPs, experience of GPs varies.”*

*“A feeling that social services don’t want people to get what’s available.”*

*“Memory clinic – don’t get anything from them – do tests – same one every time – they don’t reflect what’s really going on. If someone remembers the test, the results will be a high score but the person may not be managing in reality. They need to take more time to **talk** to the carer and the person.”*

*“Services and information – fragmented and not consistent across the city. Having the same person to deal with would give a lot more consistency.”*

### ***Awareness of dementia***

Family carers spoke of the need for services and society to have a better understanding of dementia and the ways that it affects people. There was a feeling that sometimes health services did not always display awareness of dementia and how it affected the person’s ability to communicate.

*“Dementia not recognised as a disease! Groups – people unaware of various groups – spread awareness.”*

*“During cataract operation for person with dementia – lack of understanding and communication to the patient.”*

*“Letters sent to people with dementia from the NHS when they can’t understand the contents.”*

*“Getting on day by day. Lack of family awareness, lack of social services awareness and NHS awareness.”*

Some possible solutions to the difficulty in awareness of dementia were offered.

*"Hospitals should have an 'alert' to say that someone has dementia on their records."*

*"Awareness is the key!"*

*"It's better to be open about having dementia."*

### **The Future**

The family carers raised a number of concerns and uncertainties relating to the future. There appears to be a real concern about how to best plan for the future and knowing who can help with this.

*"The uncertainty of the future."*

*"Yes it's always in the back of your mind."*

*"Carers feel they have to stay healthy for their partner."*

*"Told they can't sell their house in case they need to pay for more care in the future."*

*"I think what will happen if I'm not there to care – talk to family."*

*"Services will get involved if there is no-one to care for the person at home."*

*"Support to plan for the future – who? GP, Alzheimer's Society, family."*

*"Talks about this at dementia cafes would be helpful."*

*"Factsheet with local information on how to plan ahead."*

### **Summary**

Carer support was identified as an issue, specifically there is a need for carers to be listened to, heard and reassured that they are doing a good job.

Groups were valued as a place to mix with others in a similar situation but it was difficult when groups such as the memory service groups ended with nothing to replace them.

There was felt to be an inconsistency in the information and advice offered to carers of people with dementia, it appeared difficult to know how to find out about services and how to access them. The increasing emphasis of

information being available online was difficult for some people. Dementia cafes were felt to be a good place to access information.

Experience of services identified some area for improvement and there were some suggestions such as having an identified worker, or staff taking more time to talk to the person with dementia and family member rather than relying on 'tests' to assess how the person was progressing.

Family carers identify a lack of awareness of how dementia affects the person with the condition and / or their family as a difficulty in society and even within health and social care services. There were some suggestions such as people with dementia being identified to staff if in hospital and for more openness about having dementia.

Family carers had concerns about the future and how to best plan for it. The need for more support and information in future planning was identified.

## **Conclusion**

This report presents the discussions and the summaries from a topic about the services that people with dementia and family carers of people with dementia receive and need in order to live well with dementia.

The report has grouped the discussions under general themes – using the words from group members to illustrate the themes. No attempt has been made to formally interpret or analyse these findings. It is anticipated that service providers and researchers may learn from and make use of the discussions to inform future developments.

**Comments or feedback that can be reported to SHINDIG members are welcomed by: [jane.mckeown@shsc.nhs.uk](mailto:jane.mckeown@shsc.nhs.uk) 0114 2263950 or [beverly.graham@alzheimers.org.uk](mailto:beverly.graham@alzheimers.org.uk) 0114 276 8414**

**The SHINDIG webpage is available at: <http://goo.gl/P9kJYb>**