



# **Sheffield Dementia Involvement Group**

## **SHINDIG 2**

**Thursday 27th June 2013**

**Experience, Advice and Tips on how to  
Live Well with Dementia  
From Experts by Experience**

## **Introduction**

Sheffield Dementia Involvement Group (SHINDIG) is organised jointly between Sheffield Health and Social Care NHS FT and Sheffield Alzheimer's Society. The group was formed as part of a project hosted by Collaborations in Leadership for Applied Health Research and Care (CLAHRC – SY) to explore and improve the ways people living with dementia are involved in service feedback, evaluation and planning.

The 2<sup>nd</sup> SHINDIG held in July 2013 invited people with dementia to share their experience, advice and tips on how to live well with dementia. The report is largely based on the words spoken by people with dementia which are organised under some overarching themes.

## **Dealing with the Diagnosis**

People Living with Dementia describe a whole range of emotions on receiving their diagnosis; here are some of their experiences:

*“The official diagnosis was a relief as knew what it was”*

*“I still don't believe I have dementia”*

*“I cried when first diagnosed – now think ‘Well you just have to get on with it’ “*

*“I was scared when first diagnosed”*

*“I just cried-I never thought I would be like that-funny isn't it? Now I just think I have to get on with it”*

*“It seemed a frightening prospect at the time”*

People describe different opinions on whether it is helpful to let others know they have dementia:

*“Tell people about your situation, so they know what you are facing”*

*“For example getting on the bus and telling the bus driver ‘I’ve got Alzheimer’s’ helps, also to other people if ‘lost’ when trying to get somewhere”*

*“Be open about it, your experience helps others in the same situation; they understand and can help you.”*

*“I don’t like people knowing I have Alzheimer’s disease.”*

*“You need to make the decision if you want to inform other people about your diagnosis or keep it to yourself; it’s a personal choice.”*

The emotional side of the condition continues and people describe a variety of feelings, some of which change over time:

*“I feel awful sometimes but today it’s wonderful”*

*“I didn’t like it-was scared. I never thought I would be like I am –you think, go away and come back another day. Singing helps me a great deal... even by myself”*

*“Keep yourself going – it will get easier.”*

*“Having a positive attitude to yourself so that you can improve things”*

*“I don’t know what all the fuss is about”*

*“You have to be realistic make the most of what you can achieve and hope others will follow, be positive about the illness, or you can get stuck in a big dark pit”*

### **Timely Information - Giving and Receiving**

The importance of having information in a timely way was discussed

*“The Alzheimer’s Society visited house when first got diagnosed, less overwhelming this way.”*

*“Leaflets and books about people living with dementia helped.”*

*"It's important to get to know as much about what you are facing in order to help your friends and family to support you."*

*"The more they know the better."*

*"The more factors we know of value the better – need to build knowledge."*

*"In order to 'face things together' (with carer) need to know what you're facing"*

*"In order to help people you need to know yourself"*

### **Socialising with Others**

People living with dementia provide lots of advice and example of how maintaining a social life can be very important to them. This might involve socialising with family or friends.

*"Make yourself talk to people."*

*"Don't worry and mix with people"*

*"I use email to communicate with family and other people with dementia"*

*"You need people who understand around you."*

*"Enjoy life as a couple"*

Another important side to socialising was mixing with other people with dementia and the support and friendship this could provide:

*"1st Friday of the Month group, you report what you've done that is positive"*

*"Mixing with people in the same boat"*

*“Dementia Cafes – fun activities, nice food and friendly people – ‘everyone in the same boat’ ”*

## **Keeping Active**

Keeping active in some way or another was a common topic of conversation for people living with dementia; their advice and tips include:

*“Walk and get out every day”*

*“Dancing and singing”*

*“Singing is positive as it’s something most people can do”*

*“Enjoy ‘Singing for the Brain’ group”*

*“Singing helps even at home”*

*“Having a ‘never ending’ garden!”*

*“Going to the local history group, outings and books to borrow.”*

*“It comes in handy to play the viola”*

*“Playing the piano at functions”*

*“Important to keep up with hobbies and activities”*

*“The Grindstone Pub” and “Fish and Chips”*

*“Keeping busy by doing jobs around the house”*

*“Physical activity is very good to do, swimming, walking” (everyone agreed!)*

*“Keep busy and take every day as it comes”*

*“Still play golf, have to get there on the bus”*

*“I’ve already got the next project planned!”*

## **Being able to Adapt**

There were many examples where people living with dementia spoke about how they had adapted their lives to adjust to having dementia:

*"You need to apply yourself to the problems you face – like you would a job. Find things and involve people to deal with them."*

*"Got to keep positive all the time. Try and ignore things you're not so good at."*

*"Can't be grotty' accept a memory not there that day but will come back another day"*

*"Don't think of problem being 'solved' think of it being 'helped'"*

*"Changing and sharing roles, Husband no longer drives so Wife will do more driving now"*

*"Adapting to new situations such as transport, home"*

*"Moving into sheltered housing – we weren't sure we were making the right decision but we are glad now we made the move now"*

## **Support from Family and Services**

People with dementia describe the people and services who help them to live well:

*"If we didn't have some of the people around this table' ..... they are very important"*

*"Owe quite a lot to people present"*

*"People being around through process from diagnosis that are more than happy to help"*

*"Community Psychiatric Nurse support 'wonderful'. "*

*"Would be 'lost' without my carer." (many of the group agreed)*

*"I felt lucky when got involved in the (Alzheimer's Society) group – felt 'wonderful' as you can say what you want"*

*'Coping with Forgetting Group' helped realise there were more people with dementia and 'all in the same boat'. Would like to have carried on longer than 6 weeks. Felt comfortable talking in the group."*

*"Keysafe is good" (a small box with door key in attached to outside wall, only Trusted people have the code number)*

*"Get help from the Alzheimer's (society)...quick!!"*

*Writing things down helps – the community psychiatric nurse helps work out what needs to still be 'done' "*

*"Need communication between Alzheimer's Society and medical services" (particularly for follow up around time of diagnosis)*

*"Life stories book – people can look and know about 'where you're from' – life history, medical needs, family."*

### **Wise Words**

*"Keep yourself going; talk to other people with dementia; enjoy yourself; family is important; be realistic and look at what you can do"*

**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**