



Sheffield Dementia Involvement Group

SHINDIG 6

Tuesday 23rd September 2014

**Where do we want SHINDIG to go from here?
Ideas for the future and review of SHINDIG**

Introduction

The previous five SHINDIGs have focussed on topics that paid workers thought would be relevant to SHINDIG members. SHINDIG 6 aimed to be the start of passing more control over to SHINDIG members by seeking their ideas for future topics as well as exploring what works well and what could be improved.

Prior to SHINDIG 6 a planning meeting had included people with dementia and a carer; some initial ideas for future topics were discussed at this meeting and were used as discussion prompts for SHINDIG 6.

This report summarises the views and ideas from 14 people with dementia and 10 family carers who worked across 4 small discussion groups.

Ideas for future SHINDIGs

Assistive technology

Following on from SHINDIG 5 – where groups members ‘had a go’ with using iPads, there had been a suggestion that perhaps the group might like to experience and try out some ‘assistive technology’. This is aimed at supporting people to live independently and offer help with everyday difficulties faced due to memory problems. Comments from groups included:

IPads – interested in using

Clocks, calendars, mobile phones – technology gadgets – invite Nick from the Alzheimer’s Society to show us what’s available

“Allergic to technology”

“It doesn’t agree with me”

One carer liked her computer

SHINDIG on the move

The suggestion of 'SHINDIG on the Move' had been made by a person with dementia at the SHINDIG planning group. The idea was to visit other involvement groups for people with dementia to see how they operated. Comments from the group included:

Where would we go? How often?

Could it include singing and concerts?

Meeting other people? A programme of events.

Would be better on a coach so we could all stay together.

Liked the idea

No more than 2 hour coach journey away – going further or overnight would be too much

Our experiences of treatments for dementia

One group thought that it would be helpful to return to a past topic relating to experiences of accessing services and treatments offered for people with dementia. This group prioritised this topic as number 1. Comments included:

How people would NOT want to learn about their diagnosis

Revisiting important topics in future SHINDIGs – for example experience of GPs

What we do to look after ourselves

Another suggestion by one of the groups was to re-visit the topic of how people with dementia look after themselves and live their lives with dementia. This was voted as priority 2 topic choice

What kind of supportive services do we want?

This idea was highlighted as a future topic by more than one group. It focussed especially on support and help needed to live with dementia and also planning for the future.

People living on their own – it's difficult as there is a minefield of information. Is it easier when you are with someone?

Planning for our future

Concerns of the future, especially when a small family – what would happen to husband if I became unwell?

Words and labels used to describe dementia

The Dementia Engagement and Empowerment Project, who have helped to fund SHINDIGs this year, have had discussions with people with dementia about their views on the words and labels used to describe dementia in the media and society. Such words include 'suffering' with dementia, 'victims'. It was felt a future SHINDIG might want to discuss these words and labels.

Research

Some people from SHINDIG had been asked to share their views in a research project that was being submitted for funding by a researcher. All research requires that 'patients and the public' are involved in some way in the development of research ideas and bids. Group comments on this as a potential topic were:

We can't advise on research – that is up to the experts

Not aware of research much beyond 'medical cure' and drug treatments

People with dementia are the experts to advise on what research might be relevant

What is being researched? How do we know?

Can someone come and talk to the group? Perhaps DB, maybe PB?

Ask people to come and talk to the group.

What it's like to have dementia and helping others

One group spoke of the ways in which people who did not have dementia often reacted and responded to a person with dementia. Some of these ways were seen as patronising or ignoring the person with dementia. There was a suggestion that a future SHINDIG might discuss some of these issues and perhaps provide advice on how best to communicate and respond. Group comments included:

Communicating what it's like to have dementia and helping others without dementia to communicate better. Examples of being ignored, how others respond putting hand on shoulders from behind – 'neighbours – how they talk' – 'I turn my back and walk away'

Helping others to talk about emotions – perhaps a leaflet of 'dos and don'ts' Perhaps have workers 'role play' to generate discussion on what advice to give people

Adjusting to dementia, having to let go of some things, or being 'allowed' to make mistakes, how you feel about that

Using humour to try and see the funny side of dementia is important

What do health and social care professional need to know about dementia?

There was a discussion about some of the differences in communicating with health and social care professionals such as Doctors and Nurses and communication with staff from the Alzheimer's Society and SHINDIG. There was a feeling that sometimes health and social staff knew a lot about dementia, but less about what it feels like to have dementia. Comments included:

They ask the same questions over and over again

Who asks people with dementia what it's like?

People to talk about their experiences to bring about change / dialogue

Frustration on part of person with dementia and professionals – not able to always express self.

Our political demands

One final topic raised as relevant for a future SHINDIG related to the lack of attention paid to dementia compared to other conditions. There was a feeling that SHINDIG may have a role in raising the profile of dementia. Comments included:

Dementia – the lack of media attention compared to Cancer.

The Prime Minister is a Dementia Friend, seems to have gone quiet.

How to campaign and have people with dementia's voices heard?

Invite local politicians to SHINDIG to listen?

Maybe invite police to come and listen?

What do you value about coming to SHINDIG?

Groups were then asked to consider what they value about attending SHINDIG. A number of themes emerged.

Being with likeminded people

Able to talk to others who have same problems / questions.

Sharing of common problems

All talking about the same thing

There is purpose to meeting others in the group

The value of the small groups

Separate small topic groups is a good thing – good for them, gives them a break

First time at SHINDIG – liked the small groups felt like everyone could talk

Separate rooms – really important

The opportunity to share views and ideas

Hearing other people's perspectives is interesting

'Freedom of speech'

Open up more

Good to share experiences

Get tips on coping

Should be open to anybody who wants to speak

The supportive environment

It's alright here because people here know how to talk to people with dementia

Builds your confidence

Takes the fear out of it

Takes away the broodiness

Laughter – means a lot

How can we make SHINDIG better?

The groups were asked what things might help to improve SHINDIG, comments included:

How to advertise things about dementia better – for example the recent sponsored walk to raise money

The SHINDIG Planning Meeting; did not like this name at all. There was tea and biscuits, chat and lots of laughing – call it ‘Tea and Talk’

Conclusion

The discussions from this group will be considered in the next ‘Tea and Talk’ (planning) meeting and will be used to inform the format and the topics for future SHINDIGs.

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