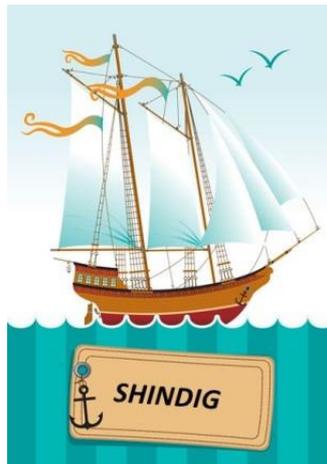


Sheffield Dementia Involvement Group



SHINDIG 19

Thursday 15th December 2017

Report:

**Advice to NHS and Social Care Staff
On Gathering Feedback from
People with Dementia and their Family
Carers / Supporters.**

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 to explore and improve the ways people living with dementia are involved in service feedback, evaluation and planning.

The 19th SHINDIG held in December 2017 was attended by 20 people with dementia and 15 family carers / supporters. The discussion topic was requested by Sheffield Health and Social Care NHS FT to help inform their service user engagement work.

SHINDIG members worked in small groups to discuss:

Advice to NHS and Social Care Staff on how to best gather feedback from people with dementia care services.

Discussions were guided around some questions on some of the ways that SHSC staff currently use to seek feedback. The findings of this SHINDIG will inform a report to SHSC service user engagement group and managers within services for people with dementia. Guidance will be shared with staff working with people with dementia in SHSC.

This report is available electronically at: <http://goo.gl/P9kJYb>

Advice to NHS / Social Care Staff On Gathering Feedback from People with Dementia (and their Family Carers / Supporters).

<p align="center">GOOD COMMUNICATION SKILLS</p> <p><i>“Be friendly and kind to everyone.”</i></p> <p><i>“Make sure you are looking at us, be clear, show interest and keep eye contact.”</i></p> <p><i>“We appreciate it when staff are understanding and take their time.”</i></p>	<p align="center">DON'T RUSH</p> <p><i>“Staff need to give us more time to understand and gather our thoughts.”</i></p> <p><i>“Staff need to talk more slowly and not rush us.”</i></p> <p><i>“We know staff are busy and have to be quick – but we need time to share and talk about our experiences.”</i></p>
<p align="center">DEMENTIA AWARENESS</p> <p><i>“Staff need to understand people with memory problems and have more awareness about dementia.”</i></p> <p><i>“Staff need to have good attitudes towards older people with dementia.”</i></p> <p><i>“It can feel frightening for us.”</i></p> <p><i>“We need ‘Dementia Friendly’ appointments.”</i></p>	<p align="center">BE FLEXIBLE</p> <p><i>“Try different ways to gather our views.”</i></p> <p><i>“You could use groups to 1:1s to suit different preferences.”</i></p> <p><i>“I’m unsure whether I would use a certain method – depends on the situation / circumstances.”</i></p>
<p align="center">CONSIDER FAMILY CARERS / SUPPORTERS</p> <p><i>“Some people with dementia prefer to have their family carer / supporter present, it makes it easier.”</i></p> <p><i>“Some people with dementia prefer to be alone or don’t have a family carer / supporter. They feel capable sharing their views alone.”</i></p> <p><i>“Many family carers / supporters (who attend SHINDIG) feel it is important that they are there to support the person with dementia they care for.”</i></p>	

Some Different Ways to Gather Our Views and Experiences

QUESTIONNAIRES

Questionnaires were not a popular choice of method for people with dementia to share their experiences. Some people with dementia could see their use and others found them difficult. Family carers / supporters largely felt they were not a good way to seek the views of people with dementia.



“A questionnaire would be useful to tell NHS staff how we feel / give feedback.”

“It’s a good start.”



“Potentially difficult for some people to understand / fill out a questionnaire.”

“OK but could become difficult”

Considerations

- *It’s better if there is some help to complete it – probably not a staff member.*
- *It needs to be given there and then at the right time.*

DISCUSSION GROUP WITH OTHER PEOPLE WITH DEMENTIA

This was an especially liked method for many people with dementia at SHINDIG (although not everyone). The benefits were seen in the mutual support gained in a group setting.



“We find it encouraging – we’re all in the same boat.”

“It’s nice to share our experiences with others.”



“Some people may feel under pressure or on the spot.”

“It should not be too large a group.”

Considerations

- *People felt they might be more likely to say negative things or express criticisms in a group setting compared to a 1:1.*
- *It may trigger ideas and questions by hearing what others say*
- *The group needs to have confidence in the facilitator.*

1:1 CONVERSATION WITH STAFF MEMBER

Talk with staff member about some aspect of providing feedback about care.



“It can be easier to share when it’s 1:1.”

“It could provide an immediate response to any specific issues raised.”



“People might be reluctant to speak out or say anything negative in a 1:1.”

“The person may feel anxious being asked questions in 1:1.”

Considerations

- It depends who you are talking to. It might be difficult to express negative views to a staff member involved in your care.
- Concerns over whether staff have time for 1:1 conversations due to being busy and short staffed.

BEING PHOTOGRAPHED

This idea was that a photograph may be a good way to capture the experience of a person, particularly when participating in an activity or group.



“Good idea.”

“I wouldn’t mind being photographed if it’s necessary.”

“A film would be good.”



“Does a photograph represent how you feel?”

“Some people would think the idea of being photographed as intrusive.”

Considerations

- People would need to understand the reason for photographing them to gather their feedback / experience.
- It needs to be carefully negotiated and done with consent / best interests in mind.
- You automatically smile when a camera is pointed at you, a film might be better than a one off snapshot.

THUMBS UP / THUMBS DOWN SIGNAL

This is a way of giving feedback in the moment to an event for example being asked about a meal – was that Thumbs Up = Good; Thumbs Down = Bad; Thumbs in the Middle = So so.



“Easy and instant.”

“Don’t mind being asked to show thumbs up or down if it’s in our best interests.”

“Yes it allows an immediate response.”



“Unsure how I would feel about thumbs up or down – depends on situation / circumstances.”

“Works better in a group than a 1:1.”

Considerations

- You can’t always express feelings through something as simple as a hand gesture, doesn’t capture the correct feeling – for example anger.
- It might feel a bit simplistic / patronising for some people.

OTHER COMMENTS / THOUGHTS / IDEAS

- Family carers/supporters generally had reservations about a number of the different methods and felt it was important that they were involved in any feedback activities with people with dementia. It is important to seek the views of the person with dementia in their own right whilst also appreciating the individual knowledge that family carers/supporters have about the person.
- Flexibility seems vital, choosing the method of capturing feedback that best suits the individual and is the best fit for the circumstances / situation.
- People with dementia and family carers/supporters feel that many health professionals do not fully appreciate / have full understanding about dementia and how it affects the person. This can affect whether they are enabled to share their views and experiences.
- A few people raised the issue of never getting any feedback after they have filled in a questionnaire or taken part in an involvement / feedback activity.

Thanks to all SHINDIG member for their hard work on this topic.

For further information about this report or SHINDIG contact Jane McKeown: jane.mckeown@sheffield.ac.uk or Jo Wallace: jo.wallace@alzheimers.org.uk