



Sheffield Dementia Involvement Group

SHINDIG 9

Thursday 18th June 2015

Support and Services needed to Live Well with Dementia

Brief Summary

Comments or feedback that can be reported to SHINDIG members are welcomed
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Introduction

The 9th 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.

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) together (10 people in total). A brief summary of the discussions is presented below and the full report is available upon request or at: <http://goo.gl/P9kJYb>

Brief 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.