



Sheffield Dementia Involvement Group

SHINDIG 3

Thursday 19th September 2013

Experience of and feedback on Memory Services in Sheffield

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 3rd SHINDIG held in September 2013 invited people with dementia to share their experiences of memory services.

This report uses the term 'memory service' to include any healthcare setting in Sheffield where people may receive assessment and diagnosis for dementia. The report summarises the group discussions.

Experiences of memory services in Sheffield

The following section identifies the key themes that emerged when 19 people living with dementia and 4 family carers were invited to share their experiences of memory services in Sheffield.

Summary

1: The 'Journey' through services of people living with dementia

People with dementia do not always find reflecting specifically on one service and the staff related to that service meaningful; they are more able to reflect on their experience of a range of services they come into contact with through their 'journey' in living with dementia.

2: Receiving a diagnosis

Receiving a diagnosis does not necessarily happen at one moment in time and in one service and is often experienced as more of a process. People living with dementia react uniquely to hearing their diagnosis; some people describe it as a relief, a 'reason' for what they are experiencing or a starting point for finding out ways of coping with the challenges; for others a diagnosis brings shock, disbelief, frustration, stigma and fear.

3: The way the diagnosis is given

Some people describe receiving their diagnosis in a letter, or feeling it was given with little thought to the impact it would have on the person. Others describe sensitive communication on the part of staff, which is valued.

4: Follow-up and feedback

Some people described that follow up appointments between receiving a diagnosis and being able to further discuss and ask questions did not always seem timely. Some carers felt excluded when they were seen separately from their relative and given no feedback about what was discussed. Some people living with dementia also expressed this as a concern as they were unable to recall what had been discussed with them. There can be a lack of feedback on the results of memory testing.

5: Information giving

Information following diagnosis is seen as important for some, but too much information given all at once can feel overwhelming and confusing.

6: Support following diagnosis

A range of activities and events that supported people following diagnosis was valued by many but appeared 'patchy' as to how people found out about support opportunities. A suggestion was that a regular newsletter may improve communication.

Groups or workshops attended through memory services were highly valued, but there was loss and disappointment when the time limited groups ended. Carers appeared to have more opportunities for maintaining contact with peers when a group ended than people with dementia did. Peer support and meeting with others 'In the Same Boat' was seen as important for people with dementia and family carers.

Positive atmospheres were described as: friendly, understanding, supportive, warm and pleasant, good chocolate biscuits, positive and 'normality'. Positive staff attributes included: friendly, efficient, committed, dedicated, blurred roles, professional, patient, generous. Most of all it was important to the person with dementia that they were 'known' by staff and were not expected to repeat their story time and time again.

Detailed Findings

1: The 'Journey' through services of people living with dementia

We found that it is not always meaningful for people with dementia to reflect specifically on one service and the staff related to that service. People with dementia are far more able to reflect on their experience of a range of services they come into contact with through their 'journey' in living with dementia. For some people receiving a diagnosis of dementia was associated with other healthcare problems and the difference between specific services becomes a blur.

Consequently the themes emerging from discussions with people with dementia about memory services inevitably include their experience of dementia and dementia services; however these remain highly relevant to all care providers as common messages prevail.

2: Receiving a diagnosis

Receiving a diagnosis does not necessarily happen at one moment in time and in one service; for many it was more of a process. For some people receiving a diagnosis was confirmation of something they had been expecting. It was often initiated through information they had found out for themselves or something their GP had been preparing them for. This is relevant as it may be many months between concerns first being raised and diagnosis being given.

People describe a range of places where their diagnosis was confirmed, such as: memory services; neurology memory clinic; GP and psychiatric out-patients. Some family carers described the challenges in getting their concerns heard by their GP and in some cases depression was diagnosed before dementia was considered; they felt that their long term knowledge of the person they were concerned about sometimes disregarded.

The reaction of people living with dementia to hearing their diagnosis, unsurprisingly, varied between person to person. Some people describe receiving a diagnosis as a relief; a 'reason' for what they are experiencing or a starting point for finding out ways of coping with the challenges.

For others a diagnosis brings shock, disbelief, frustration and fear. For some people this is temporary and learning more about the condition and finding ways to cope helps; for others the frustration, anger and fear continue.

“Happy with the amount of concern given to us, daunting that we have ‘Life Membership’.”

“Wanted a new head, it felt like Thump, Thump, Thump.”

For some people the diagnosis brings stigma and the name ‘memory service’ can seem to increase that stigma.

“Don’t like the title ‘memory service’ pushing right in front, in your face. A confronting title when had to come to terms with”

Having to give up driving was often described as a great loss and there was a call for better communication between the DVLA and healthcare staff.

“Biggest loss was giving up my car ‘shock’ and giving up freedom”

3: The way the diagnosis is given

People’s memories and experience of how the diagnosis was given vary. Some describe finding out about it in a letter, or feeling it was given in a cold and matter of fact way with little thought to the impact it would have on the person; others describe sensitive communication on the part of staff. One person felt they would have preferred that their family were informed initially allowing the family to break the news to the person.

“Made to feel one of many, all I had was a letter with one paragraph and then nothing (vascular diagnosis).”

“Would rather my family would have been told rather than me and let them tell me.”

4: Follow-up and feedback

Some people felt after their diagnosis they were left with a long wait to ask questions or discuss the diagnosis; follow up appointments did not seem timely.

“Felt there was no contact with the memory service between being given diagnosis and next visit.”

Some carers felt excluded when they were seen separately from their relative at the memory service and then not given any feedback over what was discussed; some of the people living with dementia also expressed this as a concern as they were unable to recall what had been discussed with them.

“When carer and person with dementia are seen separately there is a feeling questions / answers can be missed.”

People spoke about the amount of questions that were asked and the lack of feedback on what the responses they gave to the questions amounted to.

“Often see different people, nurse / doctor, they ask lots of questions which don’t always get fed back”

5: Information giving

Information given about dementia and diagnosis needs to be tailored to the individual’s needs. Some people felt it would have been helpful to have taken away information following diagnosis; for other people the amount of information they took away was overwhelming and confusing.

“Going home with written information about my diagnosis would have helped with the shock I received.”

“Too much information can make it seem a jumble”

6: Support following diagnosis

People spoke of a range of activities / events that they felt supported them; these include: Alzheimer's Society peer support groups, dementia café's; 'singing for the brain'; information and support with Ros and Bev from the Alzheimer's Society particularly being mentioned, Sheffield Dementia Involvement Group (SHINDIG).

"A lot of support can be gained for the person with dementia by spending time with 'people in the same boat' for example singing groups, cafes..."

There was a feeling there was no consistent approach to how people found out about support opportunities, it seemed with a 'word of mouth' process amongst one another or if you were fortunate to be linked with the Alzheimer's Society. A suggestion was that a regular newsletter may improve communication.

"Couldn't we have some kind of newsletter so that information can be shared?"

There was also a concern that services were being cut and people had no influence or voice over the changes.

"Concern over cuts in services – it's alright and coming to talk about what we want and what is needed but SHINDIG doesn't have the authority to stop service being cut – a worrying time."

A few people mentioned groups or workshops they attended through memory services. One person living with dementia highlighted the positive experience he had of an all-male 'Coping with Forgetting Group', but also shared his loss and disappointment when the time limited group ended. This was in contrast to a carer's experience of a 'Caring and Coping Group', which upon ending continued in an informal way with carers continuing to meet socially.

"Group for people with dementia at memory service was really valued but great concern when it came to an end. Was all men together could relax, share stories, build friendship and enjoy one others' company - but then it just stopped."

Peer support and meeting with others 'In the Same Boat' was frequently referred to. Being with people who understood what it was like and where you could share experiences and learn from another was seen as very helpful (for people living with dementia and for their carers).

"Went to a workshop – enjoyed because was with people like myself good knowing I was NOT ALONE."

Support could be gained from the atmosphere that was created at any event or service. Positive atmospheres were described as: friendly, understanding, supportive, warm and pleasant, good chocolate biscuits, positive and 'normality'.

"Needs warm, pleasant environment with generous people with enough information to know what they mean."

Positive staff attributes included: friendly, efficient, committed, dedicated, blurred roles, professional, patient, generous. Most of all it was important to the person with dementia that they were 'known'; there was a frustration at seeing different people and having to re-tell their stories over again.

"Called to different places, different people – having to repeat the same story – they need to know you – I want their opinions but they can't help me to cope if they don't know me."

Conclusion

Although people with dementia were able to reflect on their experience of services it was more difficult for them to remember specifically which service they had attended. However there are still very valuable insights that service providers can consider.

These themes may give some ideas on what individual services might like to specifically explore more with people with dementia and family carers who attend.

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