



Sheffield Dementia Involvement Group

SHINDIG 1

Thursday 28th March 2013

Feedback on People with Dementia's Experiences of GP Services

Introduction

The Sheffield Dementia Involvement Group (SHINDIG) is a City Wide forum that is being facilitated initially on three occasions between March and September 2013. The group is being evaluated through Collaborations in Leadership for Applied Health Research and Care (CLAHRC – SY) Translating Knowledge into Action Theme and is part of a larger project and how to better involve people with dementia in service feedback, evaluation and planning.

At the March SHINDIG two groups of 6 people with dementia and one mixed group of 4 people with dementia and 6 family carers talked about their experience of GP services. Groups were facilitated by staff from the Alzheimer's Society, Sheffield Health and Social Care Trust, Sheffield City Council, University of Sheffield and Sheffield Hallam University. Conversations were enabled to flow freely, with prompts if people struggled in any way. This paper summarises what people said. An initial summary is presented of the things that people with dementia say is important when visiting their GP. This is followed by some more detailed comments and suggestions on the positive experiences and the challenges that people discussed.

Summary of things that people with dementia say is helpful when they are in contact with GP services

- It is important that the GP recognises / remembers that the person has dementia (no matter what the problem is that they are attending their GP for) so that the Doctor can make allowances for or minimise the problems associated with their memory
- It can help if the GP makes some notes during the visit that the person with dementia can take away in order to remind them what was discussed at the visit and any possible actions
- It can help if the GP practice can proactively prompt people with dementia to attend for reviews and flu jabs as they may otherwise not remember. This is especially important when there is no family carer to offer prompts.
- It is really important for the GP to know about the person with dementia otherwise it can be a struggle for the person with dementia to remember and have to explain their circumstances and past medical history

- It can help if one GP in the practice sees the person with dementia as they can better know the person, especially if this GP is interested, sensitive to the needs of people with dementia, listens and is respectful towards the person..
- If a person visits their GP worried about their memory it is important their concerns are taken seriously and that they are referred to receive a diagnosis if deemed necessary and if that is what the person wants.
- It is important to people with dementia that their GP practice remains local and accessible. Having a pharmacy attached is seen as a great benefit

Detailed Feedback on the Experience of People with Dementia regarding GP services

The following section provides the detail of what people with dementia said to support the statements presented above. There were many positive comments about GP services as well as some less helpful experiences voiced.

Positive Experiences of GP Services

A positive experience for a person with dementia attending their GP can be summed up as one where the GP recognises the person has dementia and supports the person though being respectful, making allowances for memory problems and maintaining notes for the person with dementia to take away.

It is important for the person with dementia to be known by the GP and for their memory problems to be taken into account no matter what the reason for their visit to be. It can be helpful to see the same GP each time as it prevents the person with dementia from having to explain their situation each time.

People spoke of liking GP practices to remain small and local and they appreciated it when a pharmacy was attached

Here are some examples of what people said to illustrate these points:

I tell them I have Alzheimer's and they immediately change – they understand; there is an understanding.

When I go they seem to listen very carefully

Doctors have a lot of respect for you

GP tries to minimise problems

*To be **known** (cared about as well as known) it is important that GP is familiar*

GP makes notes during the visit that I can then take away

Senior doctor at practice taken charge so sees that doctors each time rather than explaining each time

I see the same GP each time – that's very good

Pharmacy attached to GP is good and will deliver medication

Want GP practices to stay local and not too large. Don't want to have to travel far to GP

Challenges in experience of GP Services

Alongside the positive comments people with dementia identified a number of aspects of visiting the GP that were more difficult.

It could be difficult if the GP did not know or remember that the person had dementia. It was very important that the GP made allowances for the disabilities that dementia brings. People with dementia described one way that Drs could make allowances for their memory problems was to make notes during the visit for the person to take away as a reminder. Information sheets were also seen as being helpful. There were discussions about whether there should be an alert on the computer identifying the person has dementia, although not everyone liked that idea.

Some people with dementia described having missed appointments, reviews or flu jabs due to their memory. It would be helpful if GP practice could prompt people at regular intervals, or remind them that their appointment was due. Some people felt that they needed more time to explain things and that appointment times could be too short. Sometimes if there was a long wait to see the GP the person may forget what they were attending for.

There were a number of challenges for some people in getting their GP to refer them to specialist memory services and they did not feel that their memory problems or

other concerns were taken seriously. If people did feel they had not been treated well many did not know how they could make a complaint.

Here are some examples of what people said:

There is one really good Dr in the practice who understands dementia and who gives me time, but sometimes I prefer to see a female Dr and she is not as understanding about dementia.

I don't think GP remembers about my diagnosis of Alzheimer's – that affects whether they send 'reminders' or prompts for treatment (i.e. flu jab)

I want the doctor to remember I have Alzheimer's, even if I have gone for something else.

GP not always making allowances for memory problems

Waiting can be harder if you have memory problems – more likely to forget why your there and feel impatient and anxious.

I feel as though I don't want to take up too much time because there are always lots of people waiting

I can feel hurried – you can see the doctor watching the time

I had some difficulty getting my diagnosis

Took a long time to get diagnosis

Did not feel listened to when I went about wanting to stop a tablet (good surgery though – it was just that once)

The hospital doctor was helpful but my GP wasn't

Our GP has been difficult at times. He was reluctant to refer to Memory Clinic; I had to go and see him several times. I knew there was something wrong but he was not having me telling him. He can be off hand and on one occasion got very angry with us when we had been told by the hospital to go and ask him if my husband's appointment at the hospital (not for his memory) could be brought forward. But we have known him a long time, so we don't like to change

If it's a new doctor they don't always have time to read notes and family carer has to fill in

Waiting can be harder if you have memory problems – more likely to forget why your there and feel impatient and anxious.

We wouldn't know how to go about making a complaint (whole group)

These themes and comments were passed on to GP Steve Thomas who has a lead for Dementia in Sheffield and to Sarah Burt who is a commissioner for older people's services.

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