**Sheffield Dementia Involvement Group**

**Thursday 5th March 2020**

**Report:**

**Experiences of**

**Hospitals and Outpatient Clinics**

**in Sheffield**

**Background**

**The topic for this SHINDIG was Experiences of Hospitals and Outpatient clinics in Sheffield.**

This topic was requested by a team of Dementia practitioners from the Sheffield Teaching Hospitals. Sally Byers and Amy Ashton attended tea and Talk (SHINDIG planning group) and explained that they are part of a new service. This is being funded for five years by the Hospital Charity with the aim of making Sheffield hospitals and outpatient clinics Dementia friendly. Their brief focuses on:

* The environment
* Information
* Getting too and around hospitals/clinics
* Staff and training

Sally Byers requested to meet with SHINDIG to gather people’s experiences and ideas and ensure people affected by Dementia have input into the work. she will take responses back from SHINDIG to inform the project.

This SHINDIG was attended by 36 people living with Dementia, family carers/supporters and was supported by 12 staff facilitators or visitors. People opted to discuss the topic in either in one of two groups with just people living with Dementia; in a mixed group of people living with Dementia and their family carer/supporter or in a family carer/supporter group only.

Questions and prompts were used to guide discussions and responses were recorded on flip charts. These were typed up and this report reflects the key responses to the questions asked about people experience of Sheffield Teaching Hospitals.

**Summary**

* People had varied experiences of Sheffield’s’ hospitals and clinics.

Some people had good things to say about their experiences whilst others had examples of where their experience might have been better.

* Some people’s first impressions of Sheffield’s hospitals and clinics were negative. Quite often this was due to poor communication between the hospital staff or admin and the person with Dementia and/or their family.
* There was a general agreement that all staff should have basic awareness training on Dementia so they could better understand and communicate with people living with Dementia.
* People felt that admin staff needed to know who they should send written correspondence to. Appointment letters were often sent to the person with Dementia. Sometimes it would have been better if their carer/supporter had received the appointment letter.
* Being treated with kindness and patience by staff was of huge importance to people with Dementia and their carers.
* Hospital stays were better when the person with Dementia was occupied and allowed to be themselves.
* People appreciated being able to stay with their loved one for longer during procedures or hospital stays as this added to a sense of feeling safe.
* Some people referred to feeling abandoned after an initial diagnosis and felt there was too long in between appointments.
* Most wanted to be kept informed and asked for their opinion.
* Some people felt there is often too much focus on what they can’t do and not enough on what they can still do. People would have appreciated information about activities and groups.
* ‘This is me’ is a document that gathers important information about a person with Dementia. They are available to help staff get to know their patients better. People were generally unaware of this document.

**Main Report**

**Have you been to any Sheffield teaching hospitals, services, clinics?**

The majority of people had used both the Northern General and Hallamshire Hospitals. A large number had used the Memory Service. Most people had accessed various outpatient clinics. A few people had used Western Park Hospital and Charles Clifford Dental Hospital.

**What were the good things about the experience?**

**Staying together**

A number of carers spoke about the importance of being able to remain with their loved one.

* *I was offered a place to sleep.*
* *They allowed me to stop with my wife.*
* *They let my wife stay in the hospital if they didn’t do I wouldn’t know what to do or where to go.*

**Understanding**

People spoke about staff understanding their needs.

* *Staff were excellent and explained what was happening.*
* *In B7 my husband did a lot of walking around and they didn’t try to stop him.*
* *Staff gave my husband time.*
* *Nurses were always there, quick response.*
* *I was allowed to sing, it put me in the world I was in.*

**Staff Attitude**

* *Sometimes they help the people...like help you to walk...you can think about what you are doing...do it your way, what suits you.*
* *Staff were friendly.*
* *Kind and nice and polite.*
* *They looked after me, kindness, love, they’d be patient with you.*

**What was not so good about your experience of hospital?**

**Lack of understanding**

A number of people mentioned poor practises which had a negative impact on them.

* *Sometimes staff don’t really want to listen.*
* *If you don’t ask no one comes to help.*
* *Staff asked my husband questions but he did not know what they were asking.*
* *Health care professionals always make an assumption about people with the diagnosis, assuming people with the diagnosis are always wrong.*
* *Dad didn’t bathe for two weeks, the nurse said he didn’t ask for one.*

**Managing non medical needs**

Some people living with Dementia were conscious of how their own behaviour when ill had impacted others.

* *I was delirious, the impact on other patients was brutal, they wanted me off the ward.*
* *Nurses say they do the absolute basics for people.*
* *Patients are left alone together which becomes distressing.*
* *Need more staff to take care of your non nursing needs.*

There was a general feeling that services including those that are Dementia specific still had a lot to learn.

* *Clinics are not set up to deal with Dementia patients.*
* *Admitted to the NGH for 5 nights and moved every night at 10pm just when dropping off to sleep.*
* *My friend was transferred from the NGH to the RHH at 2am.*

**The Environment: What were your first impressions of the hospital/Clinic Environment?**

Getting around hospital sites created problems.

* *Finding your building in the Northern General is difficult.*
* *Signage is not great.*
* *More staff, more information where to go.*
* *Leaflets need to be mindful of those who are colour blind, red signs are of no use to me.*
* *Tracks on the floor aren’t easy to follow.*
* *The Northern is very spread out, I dread it, if I go now I go in a taxi.*
* *The hospital is a very different experience if you live on your own.*

What people found helpful:

* *The ambulance staff.*
* *Everybody knew how to get to places using the lifts.*
* *Red frames around toilet doors.*
* *Reception at A+E are always excellent.*
* *I was asked to give some suggestions to wards, I like to get there at the right time...because I get easily confused.*

The H1 hospital bus was given the thumbs up by those who had used it. Others who had used public transport to get to hospital were less impressed:

* *They just dump you on the main road, they should go into the hospital grounds. The whole transport system is dysfunctional.*

**Comfort**

It was important that people could access food and drink during long waits. Vending machines being out of order and cafes being too far away prevented this at times.

**Information: What do you think about the way hospitals/clinics communicate with you?**

This topic resulted in strong feelings being shared which highlighted the importance of getting communication right from the start. Peoples stories emphasised how having to attend appointments could increase anxiety.

* *When you are not quite...with things, you need to meet the right people to give you enough time.*
* *We were given a 7am appointment but when I explained how difficult this would be the times were changed.*
* *First contact with the receptionist can be awful, this is so important. If I knew hospital staff understood people with Dementia I would be happier.*
* *I was told off for not using the bell, i didn’t know there was a bell.*
* *Sometimes instructions are too quick...anxiety produced, you are vulnerable.*

**Written communication**

There was frustration regarding appointment letters being sent to the person with Dementia.

* *There should be an option to send letters to the ‘carer of’*

Although efforts have been made in hospitals to use documents like ‘This is me’ in order to help staff get to know their patients. Many people were unaware that they existed.

People did share some positive experiences of communication from hospital services in general. Being text to remind you of a hospital appointment was felt to be a good idea.

* *Memory service was excellent, so lovely to both of us.*
* *They fixed my hearing aid straight away when I said I had a problem.*

There were a number of people who indicated feeling abandoned after an initial diagnosis or treatment.

* *Haven’t heard when my next appointment is, I feel at sea.*
* *You have early onset Dementia now bugger off, you felt like you were on your own in the dark.*
* *I felt deserted, see you in 12 months off you go.*
* *It would have been great to be invited back for more information about ‘what’s ahead’.*

There was reference to post diagnosis groups in the Memory Service offering reassurance. People also mentioned the Alzheimer’s Society and Dementia cafes as being good places to get information.

**Recommendations**

Some key recommendations can be made from this report:

* All staff in Sheffield teaching Hospitals should have some basic awareness training on Dementia.
* More consideration needs to be given to help people with Dementia find their way around hospital sites.
* Written communication needs to be sent to the right person.
* People with dementia want more focus to be placed on what they can do rather than what they can’t.
* Younger people living with Dementia have access to fewer services, this needs to change.
* People want support to be a priority.
* Distressing experiences could be reduced through better communication between staff and carers.
* Tools like ‘This is me’ are available to aid communication but are not always being used. Why is this?

**Conclusion**

This SHINDIG provided people with Dementia and their family carers the opportunity to share their experiences of using Sheffield Teaching Hospitals. The findings will be shared with Dementia practitioners from Sheffield Teaching Hospitals to inform their work on making hospitals and outpatient clinics Dementia friendly. The report will also be shared with Sheffield City Council commissioners.

For more information please contact SHINDIG co-ordinators: jo.wallace@alzheimers.org.uk or claire.jepson@shsc.nhs.uk