healthwatch
Nottingham & Nottinghamshire

Dementia Discharge experiences

Sherwood Forest Hospitals NHS Foundation Trust

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Commissioned by

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Executive Summary

In June 2019 Healthwatch Nottingham and Nottinghamshire (HWNN) were commissioned by Sherwood Forest Hospitals Trust (SFHT) to interview people newly diagnosed with dementia and their family members before and after discharge. The project aimed to find out the gaps in information and support for people living with dementia, and how these can be addressed to improve outcomes.

Healthwatch interviewed six patients, eight family members and one friend; of these two patients, six family members and one friend were interviewed again after discharge. Of the patients in this study (and there is some overlap here), two were readmitted to hospital (one for an unrelated matter), three went to care homes and sadly, two died.

When people are newly diagnosed with dementia in hospital, relatives say they want to know more about the condition and then, what will happen to the person, for example, whether they might go to a care home. The findings from the interviews showed many good examples of support for people newly diagnosed with dementia at SFHT, for example, patients and relatives talked about the information they received, having a personalised care plan and meeting with social workers to arrange support after discharge.

Whilst the people who had received information found it useful, not everyone had received it and at least one person would instead have preferred to speak to someone. Two family members had experienced problems with discharge, one had not been told that their relative was going to a care home and one said they waited six hours in the discharge lounge for the ambulance home. Once home, many family members reported being overwhelmed by caring for their relative, and that they had received no further communication or that they felt they had been passed around the system when they had requested help.

Family members are also often elderly with health problems themselves. Given that they are the main caregivers for most patients and are also 'living with dementia', support for family carers is essential. A follow up visit to check that people have the information and contacts they require would be useful. They also need access to navigating the range of support which they may need from the wider health and social care system, including GPs, carer support, respite and sitting services.

Introduction

Healthwatch Nottingham and Nottinghamshire (HWNN) were commissioned by Sherwood Forest Hospitals Trust (SFHT) to interview people newly diagnosed with dementia and their family members before and after discharge. The aim of the project was to find out the gaps, in information and support for people newly diagnosed with dementia, being discharged from the Kings Mill Hospital site. This included whether people had received the information pack and whether this was useful. Fifteen patients and/or family members were interviewed, eight of these twice.

The two questions the project aims to answer are:

- What are the gaps in how we support people living with dementia, at the point of discharge and when they are back home/in the community?
- How could we improve information and services to enable people to feel more supported, and improve outcomes for people living with dementia post-discharge?

Background

SFHT commissioned this project because they were in the process of undertaking a review of the dementia service and recruiting a dementia specialist nurse. This project will be used to assess the support SFHT provides to newly-diagnosed patients, inform the role of the dementia nurse and identify recommendations to develop a dementia action plan.

The project complements a similar study carried out by HWNN about the experiences of family members of people living with dementia who were at Nottingham University Hospitals.

Nationally, about 25 percent of hospital beds are occupied by people with dementia. Their length of stay is often longer than for people without dementia and there can also be delays in supporting them to leave hospital[1].

Dementia: A state of the nation report on dementia care and support in England 2013 states that people with dementia are more likely to be re-admitted to hospital and more likely to die than other patients admitted for the same reason. Of the patients in this study (and there is some overlap here), two were readmitted, three went to care homes and sadly, two died. This appears to be in line with the national picture.

Kings Mill Hospital took part in the Royal College of Psychiatrists *National Audit of Dementia Care in General Hospitals 2018-19* which included views of carers on patient care. Kings Mill scored well on all seven measures including carer communication (70.9%) and carer rating of patient care (81%). These scores were, however, slightly lower than the last audit in 2016-17.

Our approach

Experiences were collected, by interview in hospital, and then again about six weeks after discharge. SFHT and HWNN developed the questions together. SFHT also identified suitable people to take part, gave them the project information leaflet and notified HWNN when people were available. HWNN Engagement Officers carried out the first interview at Kings Mill and the second one either at the interviewee's home or by telephone. Criteria for interviewing people were:

- Inpatient of Kings Mill Hospital
- New diagnosis of dementia
- Patient available for one interview in hospital and another 4-6 weeks after discharge
- One family member or friend available for two interviews (as above)
- Going home or to residential care

HWNN agreed to interview ten patients and their family members.

Questions before were repeated after discharge to discover any differences. The questions focussed on:

- Whether people had received the green information pack, whether they had found it useful and if any other information could have been included
- Whether people had contact details for dementia support organisations
- Whether any other information or support was needed at home after discharge

The information pack that SFHT provides includes:

[1] https://www.dementiastatistics.org/statistics/hospitals/

- NHS/Alzheimer's Society dementia guide
- RCN/Alzheimer's Society *This is me*[2] leaflet
- Practical guides from Age UK
- Local support information, e.g. Newark Dementia Carers' Group and Forget-me-not support group

Summary of findings

Due to the logistics of organising the interviews, patients being unwell, and changes to discharge dates, the number of interviews in the study includes: six patients, eight family members and one friend. Of these, two patients, six family members and one friend were interviewed twice. The interviews took place between August and December 2019.

A table showing the demographics of the people interviewed is included at the end of the report. The main points are that:

- All the people interviewed were aged over 60, and 11 out of 15 had a disability
- Five out of six patients were male
- Eight out of nine family members/friends were female
- Three people were from outside Nottinghamshire

The findings are discussed under three headings.

1. Whether people had received the information pack, whether they had found it useful and if any other information could have been included

Patients interviewed said they had not received the green information pack, either saying *'No'* or *'I can't remember'*. One patient also said: *'To be honest, the more I know the more I don't want to know.'* One patient said they did have some leaflets.

Five family members confirmed they had received the pack and the HWNN Engagement Officer also gave a copy to one family. One family member had filled in *This is Me*, the information leaflet designed by the Alzheimer's Society for their relative. In the second interview, others said they hadn't had time to look at the pack yet, or thought it was for the carers who would come in at home. One said: *'I think it's the right amount [of information] when given time to go through it.'* Generally, those who had received the pack said they had enough information; one person said they had received too much information from various people: *'a 12 foot high pile … loads but it's just trying to get through it.'* One said: *'I would prefer to speak to someone, I'd probably understand it more'*.

Those who had not received the pack were more likely to say that they didn't have enough information and some of these had also looked on the internet. One person had spoken with the doctor and said: *'Well it's enough for now because at least I know that he's got vascular dementia, but it's where do we go from here?'* One other person said they had received no information as they were friends, not relatives, of the patient.

People did find the information useful; however, where patients were discharged home, family members were struggling to find time to read it. One said: *'I find the*

[2] https://www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me

facts and I seem to go backwards and forwards… "I must do this" and "I must do that." I get diverted and by the time it's bedtime, I'm tired out.'

2. Whether people had contact details for dementia support organisations

The green information pack includes a booklet from the Alzheimer's Society, leaflets from Age UK and contact details for local support groups. Family members mainly spoke of Social Workers as their sources of help. *'I've got a lady coming in from Age UK, I think the Kings Mill Social worker organised that. Bless her.'* The HWNN Engagement Officer also gave two family members details of the Carers' Hub. One family member said: *'It would have been good to have information that supported me as a carer.'* Two other family members said they did not need other support.

3. Whether any other information or support was needed at home after discharge

When someone has received a diagnosis of dementia, they and their families need different types of support, depending on how advanced the condition is and whether the person is being cared for at home. Family carers are often the most important source of support for those living with dementia, and it is vital that they themselves are supported. Several themes emerged from the second interviews which highlighted the barriers and possible solutions to meeting support needs at home.

- Discharge from hospital – One person said that their relative was discharged to a care home without anyone telling them. Whilst they agreed a care home was needed, they did not get a choice of home. *'I didn't even know he was going. I arrived at lunchtime on the ward and all his things were packed…They could have given me a list of available ones for the criteria we needed and then I could have gone there to visit.'* Another patient and family member had waited for an ambulance home for six hours in the discharge lounge.

  Several family members were unclear about whether they had received a discharge letter. Four out of eight family carers confirmed that they had received one; however one person said: *'it doesn't mention the dementia diagnosis at all [but] it was very helpful'*.

- Care and support after discharge. Several family members had found the social workers helpful and reassuring, for example: *'When I was [with] him, the social worker came to talk about him being discharged and to reassure him that he would be not sent home until they've got safe measures in place for him.'* Another person said: *'One [social worker] rang me up, said they were going to set something up for when she came out.'*

  The support available is often homecare and a lack of continuity in staff was found to be a difficulty in caring for people with dementia. One family member who had carers said: *'The first lot of carers were lovely because we had the same ladies each time and we got to know them but this one, it's a different person every time. I'm supposed to have a rota'*. Another family member had cancelled their relative's care when they went into hospital and *'then they couldn't pick any package up. Then we were stuck.'*

- People living with dementia often have difficulty engaging with others, as noted above in relation to homecare. One family member said: *'The thing I'm bothered about now is, because she lives in a flat on her own, she's got no care. She only sees me, and I don't go every day. She just sits in a chair; she doesn't see anybody.'* This person also said they would like respite care whilst on holiday*: 'but mum is still felt to have capacity and refuses to go into temporary care.'*

- Age and health of family members. The study shows that family members caring for people living with dementia are often themselves elderly with their own health problems. All respondents in the study were aged over 60, and 11 out of 15 had a disability. One person had been in hospital with a broken hip. Another family member said they had a very poor memory and: *'Due to my aging, and the body, and the brain, obviously, I haven't got the same faculties like I can imagine I had then.'*

- Several family members sought carer support, such as respite care. One person had some respite care for four hours a week; another sought it for holidays. Family members were often overwhelmed by caring for their relative after discharge. One said: '*I have a tough time to just come home, you know what I mean. It's like having a baby*'. Another person said they were able to cope whilst their relative was mobile and they had good support from the wider family.

- Other services. Access to equipment and supplies, such as a perch chair, commode, shower seat and continence pads was helpful. Two family members were seeking help and advice with continence. One said: *'It would be nice to get just some advice really, somebody to come and talk about it or tell me what the best is, because that's one of the biggest problems is all the washing and drying.'* The other person said that their relative: *'has had continence issues and he was referred to the continence service in September [2019]. He has only just been seen [on 30th December 2019].'* One person also had a psychiatric nurse visit planned.

  Two people mentioned their GP surgery. One said: *'I have had the letter from the hospital to the doctor. That was all I've had as regards dementia. I've heard nothing else from the surgery, nothing from anywhere.'* The second person asked the surgery for a home visit in relation to an infection. A practice nurse visited but the patient was ultimately readmitted to hospital. The relative felt that they had been: '*passed around the system and between clinicians.'*

  Two family members mentioned memory clinics. One said: '*he went to the Memory Clinic and I got quite a long report back from that.'* One other said that the discharge letter recommended:*' she needs to go to a memory clinic… [but] I've not heard anything since'*.

Conclusions

The interviews showed that SFHT are very supportive of people diagnosed with dementia. When people are newly diagnosed with dementia in hospital, relatives wanted to know more about the condition and what would happen next.

The information pack is therefore useful, and has information about local support groups, but did not contain links to the Carers' Hub. Not all relatives received a copy of the pack and some were not sure that it was for them and that it would be something they could refer to over the rest of the patient's life.

It is good that many relatives (at least four out of eight) had met with a Social Worker who was able to put some support in place for when the patient was discharged home, and this was much appreciated. However, once home, relatives often found themselves struggling, *'winging it'*, and a follow up visit would be helpful.

There was a range of types of support relatives accessed once home, but there remain gaps in the care and support provided to people after discharge into the community, and concerns on continuity of care. There is an important role for other health services in supporting people at home, including: continence, GPs' surgeries, memory services and carers' support.

Recommendations

Sherwood Forest Hospitals Trust

- Add information about the Carers' Hub, how to access continence services, memory services and carers' support to the green information pack
- Ensure everyone who needs information receives the pack and understands what it is for
- Provide contact details for the Dementia Nurse Specialist so that people living with dementia and their carers can contact them if they have any questions
- Ensure family members and carers are included in discharge planning

Integrated Care System and Adult Social Care

- Ensure there is follow-up after discharge to ensure people have information and support, to enable them to stay independent where possible
- Improve access to and support from other health services e.g. continence services, GPs' surgeries, memory services and carers' support
- Improve continuity of home care staff

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Appendix Demographics of respondents

Survey respondents only n=15 (Patients and family members)

Age Groups	No.
60-64	1
65-69	4
70-74	1
75-79	5
80-84	2
85+	2
Total	**15**

Gender	No. of patients	No. of family members/friends
Female	1	8
Male	5	1
Total	**6**	**9**

Ethnicity	No.
White	15
Total	**15**

Illness/impairment	No.
Mental health condition	2
Physical impairment	7
Visual impairment	1
Other	5
None stated	4
Total	**19**[2]

Note 1. Includes respondent/s with more than one condition

Disability Count	No.	Percent
Number of respondents	11	73%

Survey respondents only (n=15) – note number of respondents who indicated they had a disability

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