healthwatch
Nottingham & Nottinghamshire

Tackling delayed transfers of care from Nottingham University Hospital Report

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Commissioned by

Building Health Partnerships

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Executive Summary

In May 2019 Healthwatch Nottingham and Nottinghamshire (HWWN) were commissioned by the Building Health Partnership Programme to interview family members of people living with dementia in order to understand how the voluntary and community sector can support delayed transfers of care.

As part of this project HWNN interviewed five family members at Nottingham University Hospital and two after their relative had been discharged (sadly we were unable to complete post discharge interviews with family members of three patients as they passed away).

The findings from the interviews showed that none of the family members had received a 'Home First' leaflet or had a planned discharge date. None of the family members were thinking about the needs of their relative or their needs following discharge. Instead they were preoccupied with the present, i.e. whether their relative would be discharged or finding a suitable care home.

Two relatives spoke of and were very grateful for adaptations that had been provided by the Red Cross and a third spoke of advice their relative had received from Age Concern in the past. Three relatives felt reluctant to engage with more services describing how their relative's dementia had made them withdrawn, suspicious of others or unable to engage with others. The only needs that were mentioned were with washing and dressing which relatives had arranged home care to assist with.

Relatives themselves had not considered the support that the VCS could provide them with or whether the VCS could provide support if their relative was taken into nursing care. One person described how more information about what is available would be useful for example attendance allowance and how to apply for it.

These findings illustrate that unless relatives are made aware of what support the VCS can provide it is difficult for them to identify their needs. It was also apparent that these relatives put the patient first and that they themselves may be in need of support or advice from VCS in their role as a carer. Providing more support to people living with dementia and their carers before they become critically ill is an area that the VCS could assist with as long as volunteers are consistent and adequately trained.

Introduction

Healthwatch Nottingham and Nottinghamshire were commissioned by the Building Health Partnership Programme to carry out 6 interviews of family members of people over 75 who are living with dementia. The aim of this project was to understand how the voluntary and community sector (VCS) can support medically fit patients living with dementia (and their carers) to leave hospital and return home. This could include re-enablement, regaining independence, social prescribing and community connectivity service models across the ICS. Three family members (one for each patient) were interviewed twice, once while patients were in hospital and again following discharge from hospital.

The interviews form an extension to a larger study (by HWNN) of people over 75 years of age being discharged from Nottingham University Hospitals (NUH), focusing on the specific needs of a small sample of people living with dementia. Nottinghamshire County Council's Home First Response Service is seen as key to accessing community and voluntary sector support.

Background

The national Building Health Partnerships programme is working with the VCS and Nottingham and Nottinghamshire Integrated Care System (ICS) to help build a better understanding of what it will take to reduce the number of patients who end up staying in hospital when they are medically fit for discharge and when other options would be far better for their health and well-being. The programme's Core Group identified that better use of community resources and less risk-averse discharge planning for people living with dementia could improve independence and reduce costs to health and social care. This is based on national research into people living with dementia admitted to hospital. It is estimated that approximately 25% of beds in hospitals are occupied by people living 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.
https://www.dementiastatistics.org/statistics/hospitals/

Limitations

There were several limitations with this project, principally, the logistics of organising interviews before and after discharge with carers of people living with dementia. In practice three patients died in or after leaving hospital and new participants had to be found which led to delays in completion of the project. Dementia *A state of the nation report on dementia care and support in England* 2013 found people with dementia also stay in hospital for longer, are more likely to be re-admitted and more likely to die than patients admitted for the same reason.
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf

Our approach

HWNN approached a Care of Older People lead at NUH ward B47 at the end of March 2019. This lead person identified patients who fitted the following criteria:

- In-patient of NUH
- Over 75 years old
- Living with Dementia
- Resident in the Greater Nottingham area. i.e. City, Broxtowe, Gedling, Rushcliffe
- Going home
- Has a family member available for 2 interviews

HWNN worked in conjunction with the Building Health Partnership programme to develop a set of questions. These included:

- Have any voluntary organisations such as The Red Cross/Age UK etc. been involved in planning your relative's discharge?
- Do you know of any voluntary organisations that will support your relative getting home?
- Do you know if any voluntary organisations have been asked to make arrangements for the care of your relative once home?

Our findings

Initially it took a number of weeks to meet with the NUH lead, identify people for interview and to gain consent from them to participate in this project. The schedule of interviews is detailed below:

Interviewee	Arrival date in hospital	Date of interview	Discharge date from hospital	Date of second interview
1	17/05/19	23/05/19	24/05/19	28/05/19
2	19/05/19	29/05/19	Deceased	N/A
3	02/04/19	29/05/19	Deceased	N/A
4	03/06/19	10/06/19	Deceased	N/A
5	05/06/19	11/06/19	20/06/19	10/07/19

When it became apparent that the second and third patient were not going to be discharged within the timeframe of this project (one had a temperature and infection another because they were under a DoLS order) HWNN agreed to approach two more patients. Sadly one of these patients died before the second interview took place.

The findings described in this report therefore are based on a first and second interview with two relatives and first interviews in hospital with three others.

All five relatives described not receiving the Home First Discharge letter, they therefore had no questions about it. Relatives of all five patients did not have a

planned discharge date. The reasons given were, *'I haven't been given a date. My sister was phoned by Social Services today to say that the hospital contacted them and told them that she's been getting an iron infusion today and then she'll be fit for discharge. I've just had a conversation with the doctor and they're also talking about wanting to do a scan before she's discharged, so I don't know how long we have to wait for that,'* and *'Dad's had a setback over this weekend, he's had a temperature and an infection'.* This illustrates that planned discharged dates may not be apparent as patients conditions change and that therefore it is inappropriate to involve VCS in the planning of discharge, getting home and managing at home.

It became clear from the interviews that participants were not thinking about their relative's needs or support that could be provided by the VCS while their relative is in hospital. One relative described how they didn't know if their relative would be discharged, *'today was the first day that it was spoke about that he would be discharged'* therefore making it redundant to consider support needs on returning home. Responses from other relatives were as follows, *'We're waiting to hear about a care package', 'my sister and I are now looking for a Care home/Nursing home' , 'I think they are sorting it out to do something – packages'* and, *'the mission has been to find a nursing home with duel aspect. That's the mission at the moment.'* In each of these cases relatives were dealing with short term urgent and immediate priorities. Until urgent concerns are addressed it is unlikely consideration would be given to other needs such as getting to appointments, shopping etc.

Two people described not having thought about contacting the VCS, one because, *'they haven't decided if he has to go into residential care'* and another described how, *'we don't know if there'll be enough funding for both of them to be in a home.'* One relative had, *'got Red Cross nurses in place at home',* a second described not having contacted the Red Cross but were planning to as, *'that's where we are getting our equipment from.'* In this case they had not contacted them themselves but had had assistance from the Parkinson's nurse who was getting equipment through the Red Cross. In both of these cases relatives described being provided, walking aids, a bed, wheel chair and commode. A third relative talked about how, *'I think my Dad's had advice on some things from Age Concern, they gave him numbers for a hairdresser for her, and he has certainly used Age Concern for advice.'*

Relatives described reluctance from family members to engage with others. One said how an, *'Alzheimer's social worker from our local house centre was visiting Mum and Dad'* before being admitted and how they had offered them carers, however the parents had refused help because, *'they didn't want strangers in the house and felt that they could cope themselves together.'* Similar sentiments were echoed by other relatives, *'Mum is very unwilling to engage with other people at the moment. She will only see family and that's been the case for the last two years'* and, *'my Dad doesn't talk now, it's hard to get any conversation out of him, he's been like that a while now with his dementia.'* These experiences

illustrate the challenge that the NHS, social care system and the VCS face in supporting people living with dementia, *'who in later stages may be less able to recognise people'* and, *'if they don't recognise people, they may feel like they are surrounded by strangers and get distressed.'* (Alzheimer's Society website). Bearing this in mind the VCS will need to ensure staff and volunteers are adequately trained in dealing with people living with dementia in order to reduce the stress to them and their relatives/carers. In addition ensuring continuity has been found to help people living with dementia, e.g. continuity of staff, sticking to a daily routine etc. Therefore if the VCS is to support people going home with dementia, then staff, volunteers and funding will need to be long term, consistent and permanent.

Another finding was that relatives of people living with dementia had not thought about the support they might need or could access for themselves from the VCS. *'As long as he's cared for, if he's alright, I'm alright'* and *'I don't have much of a social life, I had to give up a job, which I loved,'* and *'I've been caring for him for years now and I've had no help because I've managed'* and, *'if I can take a career break, I will, if not I'll hand my notice in'* and, *'at the moment Dad keeps saying he wants to die, I could do with somebody maybe like the Alzheimer's Society or carers to say, 'This is par for the course.'* These examples illustrate that carers are not aware of the support the VCS could provide and so may require signposting as well as assistance in contacting organisations for support and advice.

Experiences from two relatives showed that when a patient is going into residential care there is an expectation that, *'the care home will provide everything'*. There was no concept in these instances that the VCS could provide additional support during visits to the care home.

Two people described the care they felt their relative needed was, *'probably with his toiletries, meaning to have a bath and shower and toilets'* and *'help with his washing and dressing in the mornings.'* In both instances they were looking to social services or a care agency to meet these needs. There was no consideration that perhaps these could be met by the VCS.

We talked to one relative who was interviewed after her husband was discharged and had returned home. In this case Red Cross nurses had been pre-arranged to provide short term care. However Social Services put care in place for the day of discharge so Red Cross care was cancelled. This example illustrates the flexibility that the VCS requires as care needs change. The second relative we spoke to after discharge described how her husband had been moved to a rest home. In this case she felt there was no need for any additional support for her husband or herself from the VCS.

In another case a relative described how, *'it's hard to know until we get home and see how he is because from before he came in to where he is now is a real big difference.'* This presents an issue for both the relative and the VCS in determining what a patient's needs may be while they are still ill in hospital.

Lastly one relative described how, *'I think there are times where more information would have been useful. It took me a while to cotton on to all the attendance allowance.'* This is one example where the VCS could have a role in supporting relatives of family members living with dementia.

Conclusions

Relatives do not know until they've got over the initial crisis/emergency stage what their needs are. They also do not know what their home needs are until they have returned home. It is not uncommon for patients on the Dementia ward to stay a long time therefore more time needs to be allocated to data collection in order to interview relatives after the patient has been discharged. There is a high chance that patients living with dementia may die when in hospital or very shortly after returning home so is important that the VCS and volunteers are aware of this and able to appropriate support or signpost carers at this time if required.

Recommendations

- Ensure volunteers are adequately trained in dealing with people living with dementia and that consistent volunteers are provided
- Develop and make available an information leaflet that describes the support the VCS can provide to people living with dementia and their carers
- Provide more support to people living with dementia and their carers before they become critically ill

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