

# Carer experience of discharge from hospital

When the person they care for has been admitted for  
elective surgery or via A&E

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## Executive Summary

This report represents the experience of 12 carers living in Barnsley caring for people who were discharged from hospital during the second half of 2021. The person they cared for had been admitted to hospital either for elective surgery or via emergency care. The experience of the carers were very different with some feeling totally involved in the care and in the decision making while others were feeling left out and that their input was not needed or valued. The communication between the hospital and the carer was not always good and there did appear to be better information and involvement where the hospital stay was planned in advance.

All the carers that we spoke to were looking after a family member and the care had evolved over time, in many cases it was a matter of helping with the weekly shop which then progressed to doing the housework and then taking care of the meals and helping with personal care as the illness progressed especially in dementia cases. Because it is family who are supporting they do not see themselves as a “carer” and as such will not seek support or register with their GP as a carer. We need to look at the language we use when trying to identify if someone has caring responsibilities to make it easier for people to recognise themselves and the work they do.

There does seem to be some confusion with claiming carers benefits (Carers Allowance or Attendance Allowance) and registering as a carer to receive non-monetary support. The carers who work in full time employment did not think they would be entitled to any support as they earned too much and would look to other family members for support when things got tough.

There needs to be a better mechanism for people to be identified as a carer, either by themselves or a professional. Once identified they should be given information on the support that is available to them including benefits and assessments. This needs to be followed up by regular check-ins to see if the circumstances have changed and if the level or support needs to be re-assessed.

During the time reflected in this report there was clear challenges in patient flow and in accessing social care during the pandemic. Some carers were able to visit and others were unable due to Covid restrictions. All the carers we spoke to were desperate to be kept informed and supported during the cared for persons stay in hospital, they all referred to it as being a stressful experience.

Where carers reported a poor experience this often related to communication about the discharge process and the frustration in accessing social care. The carers spoke about not being prepared for the discharge and feeling ill equipped to deal with cared for person at home with no support in the first instance, in some cases this resulted in a re-admission within hours of the discharge. This could be improved by involving the carer in the discharge planning and setting clear expectations of when the patient is likely to be discharged and what support they will need at this point. It is important to check with the carer that they are able to provide the level of care that is required and provide signposting of where they are able to go for further support.

During our Focus Group session held in early March 2022 we spoke about the problems identifying unpaid carers as when people are caring for elderly parents, sick partners or young children they do not identify themselves as a carer when asked the question directly. There is some work being undertaken in Barnsley currently to create a Carers Information Pack which will be available in Primary Care settings, so we need to make sure that staff are given guidance in how to phrase the questions we use to identify carers. The Carers Information Pack will be rolled out in Primary Care as it is at this point that we need to try and identify carers and for it to be noted on their own medical records to ensure they are offered vaccinations as an early priority group if needed. The GP will also be aware of any caring responsibilities that could impact on the carers own health and wellbeing.

The Focus Group also discussed giving information packs on support services to carers at the point of discharge and how we can be more pro-active at admission to discover if the person being admitted has support from an unpaid carer and who that maybe.

We also discussed the new Carer Strategy which is going through consultation/approval stage and how this will help the Carers Forum to design a Carers Charter going forward.

## Method and Process

Healthwatch Barnsley were commissioned by NHS England & Improvement to conduct 10 interviews with carers who had recently (within the last 6 months) had experienced the discharge from hospital process, when the person they were caring for had been admitted for elective surgery or via an emergency admittance.

We spoke to services within Barnsley who have contact with carers and explained the project to them and that we were looking for carers who were happy to share their experience with us. We also promoted the project via community newsletters and on our social media accounts. We offered a £20 Amazon voucher to participants as a thank you for their time. We interviewed 12 carers in total, six who were referred to us and six came to us direct.

The interviews were arranged to suit the carer, taking into account their caring responsibilities, Covid restrictions and their preferred method so five interviews took place face to face and five were done over the telephone, the remaining two interviews took place over Zoom. We recorded all interviews with the carer's permission; there was no note taker present at any of the interviews.

Interviews took place between the 17<sup>th</sup> December 2021 and 25<sup>th</sup> January 2022, the longest interview was 82 minutes and the shortest interview was 16 minutes. Two members of Healthwatch staff undertook the interviews.

NHSE/I provided a semi-structured interview guide and some questions and prompts which we had the use of, but many of the interviews flowed naturally and the questions in the guide were answered without having to be asked directly. Before closing each interview, we did ask the carer if there was anything which we had not covered that they would like to include.

## Demographics

Whilst a large percentage of the carer population in Barnsley remain hidden, there are 12,745 carers who are registered with services in the town so it would be impossible for us to match the demographics by the small number of interviews which have taken place.

We tried to speak to a good representation of the caring community and our youngest carer was 16 years old and the oldest was 87 years old. All were White British and we do acknowledge that there will be carers within our BAME communities which make up 3.9% of our population but unfortunately we were unable to secure any interviews within the timeframe of this project.

We spoke to 11 Females and 1 Male, all were heterosexual. Two of the carers have been recently widowed, 7 of them were married and 3 were single. Most of the carers gave their religion as Christian (9) with two having no religion and 1 being an atheist.



Three of the carers had their own health problems including limited mobility, hearing and learning difficulties. Two carers also had the responsibility of caring for someone else. Four of the carers also had a full time job in addition to their caring responsibilities and 2 were still in full time education.

## Focus Group

We invited a number of key stakeholders to attend our focus group including representatives from Barnsley Metropolitan Borough Council Adult & Communities Directorate, Barnsley Clinical Commissioning Group, Barnsley Hospital Foundation Trust and South West Yorkshire Partnership Foundation Trust along with representatives from Barnsley Carers Service, Making Space and Banardos. We received apologies from Crossroads Care Barnsley. Also in attendance were representatives from NHSE/I.

## Key findings.

All of the carers we interviewed were looking after a family member mother, father, daughter or partner and there was a difference in the support they received or were willing to accept. A common theme did seem to be because they were looking after family it was just accepted that, that is what happens. **“Our parents took care of us when we were younger and it is only right that we now care for them.”** There also seemed to be a connection that as the level of care needed increased the relationship changed from Wife/Carer to Carer/Wife this is probably best explained by Dawn who told us

 **“Yes, things were different when he was discharged, when he had been in hospital they had changed his medication and he was back on an even keel. His anger and frustration had disappeared and I became his wife again and we did things together as a couple instead of me doing things for him”** 

Once the illness becomes more pronounced and the care needs increase this seems to be the turning point where people start to acknowledge their role and will start to reach out and look for support. None of the carers we interviewed were asked at the hospital admission stage if they were the main carer, it was just assumed that as a family member or next of kin they had that role or it wasn't acknowledged that the patient needed a carer.

Obviously, communications play a large part of anyone's experience of a hospital admission and the carers we spoke to all mentioned lack of communication, which was most likely impacted by the pandemic. Many had experiences of not being able to visit the person they were caring for as much as they would have liked and had to rely on telephone updates. This seems to have been disjointed and very much a lottery depending on ward the patient had been admitted to



and availability of staff. Some of the carers of older people who did not have access to technology or had been diagnosed with dementia were the most frustrated. When it came to getting information, they felt like they were being given the run around when they tried contacting the hospital, as it would take time to trace which ward they were on. Often they would then be asked to leave their contact number for the nurse who had been looking after patient to call back with an update. When the call back came it was often generic **“they had a comfortable night” “their appetite is good”** etc..

Five of the carers we spoke to kept in contact with the patient via their personal mobile and although they appreciated the contact and were able to see/hear them the carers felt that this was very one sided and they were not able to get updates from a clinical point of view.

Two of the carers told us that they had received excellent communications throughout the persons stay and that they had been kept fully up to date with any treatment or tests that were being undertaken. It is worth noting that one of these was a planned admission and was not to the main hospital in the town but to a specialist unit provided by another Trust.

From our interviews there is a difference regarding communications when the hospital stay is planned. The carers we spoke to when the admission to hospital was planned said they were involved in all aspects of care and treatment and the consultant kept them regularly updated on what was happening and what would happen next including the discharge from hospital and any follow up appointments and aftercare.

Most of the carers told us that the experience of the stay in hospital was good, staff were friendly and attentive.

 **“Even though Barry was unconscious when the nurse came round to do his observations, she still spoke directly to him and showed him respect which I truly valued”** 

Although some reported that they felt the nurses were too busy and at times lacked compassion, one example was in a 6 bed bay of quite poorly elderly ladies the windows were left wide open as a Covid precaution but none of the ladies were offered any extra blankets or help to put on dressing gowns or warmer clothing. As visiting was staggered due to Covid the carer felt they had to rely on other visitors helping out to make sure that the patients basic needs were being met. One carer commented **“I would say they looked after mum, she was not WELL looked after”**



### 3. Personal stories: Christine's story



My mum who has dementia was taken by ambulance after fall at home, she was frightened and confused but no family member was allowed to travel with her. The hospital spoke to me (main carer) and said they would keep her in for 24 hours for observation after the fall. The stay then became extended as the hospital began doing tests for various things that were unrelated to the fall. I asked staff why this was happening, as we (the family) were not being kept informed of what tests were taking place and why, I was told that tests had been requested by the consultant but not given any further information. I felt that this was unnecessary and just prolonged the stay which caused mum further distress as she was away from familiar surroundings. When mum was discharged a few days later there was no explanation given, no new medications or diagnosis.



**Christine, main carer for her mum**

The carers experience of hospital discharge is very varied, some have felt fully involved in the process and have been part of the planning. One carer was told of the plans to discharge her husband back to the care home and was asked to go into the hospital at 10am on the day of discharge so that she could accompany him down to the discharge lounge and stay with him until the ambulance arrived. There were a few delays and they spent most of the day in the discharge lounge waiting for medication and transport. She told us the staff were amazing, they made sure they had food and drink and gave them regular updates on the situation. We then have a carer who received a knock at the door at 7pm one night to find her husband in his wheelchair on the doorstep with two ambulance men. She had not been made aware that he was about to be discharged and was very unprepared for his home coming. She believes he was not fit to be discharge and within hours he was being re-admitted. She was told by the nurse that he had been discharged as he was "back to his baseline" no one has ever explained what his baseline is and how it is measured.

Many of the carers told us that they would have liked to be able to speak to the consultant or doctor in charge of the patient, they feel that this was lacking and most updates were provided in an ad hoc way by nurses who were rushed off their feet. They feel that by having these conversations the process can be improved as it is a two way conversation providing the carer with information on what is happening and providing the professionals with information on the patient that could impact on the way they are treated.

Once the patient had been discharged from hospital the carers experience was again very different, some told us that the hospital stay had improved the situation and things were much better while others felt like they had just been left to get on with things. Again, depending on the severity of the illness seems to be the measure of when family members start seeing their role as an unpaid carer and will take steps to look for support for themselves and the person they are caring for. Some carers sought to find social activities away from the home as a distraction whilst others preferred to have the support of their family. Once a carer

is identified and is made aware of services their experience improves and speaking to others in the same situation has untold benefits.

## Analysis. Focus Group - Evidence review

As we talked through the findings from the interviews it was pretty much what people were expecting. Although some of it did not make comfortable reading there were no real surprises. What we need to look at now is

- how does this experience inform practice?
- What does good look like?
- How can carer experience inform quality of discharge alongside other measures? What can be done to make this happen?
- How can this learning be shared with staff groups?
- What is the best way to raise the profile of unpaid carers?

At the focus group we looked at what common themes we had discovered from the interviews, and shared Dawn's story which talked about her moving into Barnsley with her husband who has an acquired brain injury. Dawn found it difficult moving to a new area and caring for her husband whilst trying to navigate her way through appointments and assessments to find she was left with no help.

There was lots to reflect on and learning to be taken from Dawn's situation. It was also noted that it had been immensely challenging for both ASC and NHS throughout the pandemic but that lessons could be learnt to improve carers experience. Carers service spoke of the need to take into account the pressures within the health services and the pressure to discharge as a result of the pandemic.

Along with communications being a common theme, we also discovered that carers are not being identified at the point of admission and we need to consider the language used to elicit the information about carers and their responsibilities. It was also acknowledged that these conversations need to happen earlier on admittance to hospital, rather than when the patient is being discharged.

It was also acknowledged that Young Carers have a different set of needs, Barnado's currently work with the Young Carers once they are identified but this is a short term offer. The Young Carers who we interviewed said they found it invaluable to be able to speak openly with someone of their age in the same situation. They also told us that they received help from College once they had been identified as a Young Carer and this enabled them to feel more confident in College and they felt they were less pressured.

We also praised the good work going off in the borough with the Better Lives work that is being done and the implementation of the Carers Strategy. There is also work going on regarding Carers identification and Carers passports to be introduced in Primary Care. There is lots of work being done to raise the profile of unpaid Carers and a Carers Guide is being developed with the Carers Forum. South West Yorkshire Foundation Trust already run a successful carers passport

scheme and the intention is to take the learning from this scheme and roll out across Barnsley.

## Analysis. Focus Group - Next steps

There is lots of work currently being undertaken to identify and support the unpaid carers and Local Authority, NHS Trusts and Carer Support Groups are all involved in both local and national programmes. Healthwatch Barnsley will continue to support local Carers and work with services to ensure that they are getting the best offer.

Some of the key takeaways from the focus group were

- Look at the support offer for Carers – creation of carers networking groups within local neighbourhoods. Peer support rather than professional support.
- Signposting to Carers forums
- A Senior Commissioning Manager suggested undertaking a journey map of the process to understand both positive and negative experiences
- Carers Champion roles- opportunities for staff training
- Link up to consider joint initiatives- particularly in relation to the Carers Strategy work



## Reflection.

Healthwatch Barnsley would like to thank NHS England and Improvement for allowing us the opportunity to undertake this piece of work. It has given us a greater insight into the carers sector and enabled us to build relationships with carer support services in the borough.

It has also opened up further work within Adult Social Care which we hope to become involved in during 2022/23 working with Commissioners and service providers.

Through this work we have also made connections within NHSE/I North East and Yorkshire Region where we are able to share the work we have done.

Last but not least we would like to acknowledge the 12 carers who took time out of their busy lives to share their experiences with us.

*"The simple act of caring is heroic" – Edward Albert*



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